

Dignity in care



The Social Care Institute for Excellence (SCIE) was established by Government in 2001 to improve social care services for adults and children in the United Kingdom.

We achieve this by identifying good practice and helping to embed it in everyday social care provision.

SCIE works to:

- disseminate knowledge-based good practice guidance
- involve service users, carers, practitioners, providers and policy makers in advancing and promoting good practice in social care
- enhance the skills and professionalism of social care workers through our tailored, targeted and user-friendly resources.

Dignity in care

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Introduction

SCIE aims to improve the experience of people who use social care by developing and promoting knowledge about good practice. Using knowledge gathered from diverse sources and a broad range of people and organisations, we develop resources that we share freely, supporting those working in social care and empowering service users.

At the request of the Department of Health, we have produced this practice guide to support its wider Dignity in Care initiative.

What is dignity?

Dignity consists of many overlapping aspects, involving respect, privacy, autonomy and self-worth. The provisional meaning of dignity used for this guide is based on a standard dictionary definition: a state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference.

While 'dignity' may be difficult to define, what is clear is that people know when they have not been treated with dignity and respect. Helping to put that right is the purpose of this guide.

About this practice guide

This guide has been designed for people who want to make a difference and improve standards of dignity in care. It provides information for service users on what they can expect from health and social care services, and a wealth of resources and practical guidance to help service providers and practitioners in developing their practice, with the aim of ensuring that all people who receive health and social care services are treated with dignity and respect.

Whether you only have five minutes to get some quick ideas, or five hours to gain an in-depth understanding, this guide should meet your needs.

The guide begins with an overview of what is known from UK and international research and policy about dignity in health and social care for older people. Further sections, based on subject areas identified by older people and their carers, translate these findings into recommendations for practice (practice points) and give examples (ideas from practice) from people and organisations that have already tackled these issues. There are also links to other useful websites and sources of information.

Who is the guide for?

This guide is aimed at a wide audience. People who use services and their carers will find much useful information on what they can expect from services. The guide will also help frontline workers, practitioners, managers and commissioners to ensure that dignity and respect are integral to the services they provide.

What does 'in care' cover?

This covers all care provided by paid workers in any setting (hospital, residential, nursing, day centres and in people's own homes), including care that is paid for either partially or wholly by the recipient.

The guide applies to England only.

The aim of the guide

Quick and easy access to:

- the meanings and aspects of Dignity in Care and the many related issues
- information and guidance on how to tackle poor standards of service, for practitioners, people who use services and their carers
- key pointers to improving the dignity of older people (practice points)
- examples from all around the country of tangible ways in which dignity can be incorporated into care (ideas from practice)
- the policy context and key research and policy findings, with references
- relevant guidance and standards
- links to further information and useful websites.

What the guide does not cover

Abuse: this guide does not attempt to cover the many complex issues relating to abuse, but a small section gives basic information on how to decide whether abuse is taking place, what to do about it and where to seek further advice.

Background

This guide is part of a wider Department of Health campaign to promote dignity for older people in the health and social care sectors. The issue of dignity features prominently in the new framework for health and social care services. The Department of Health's Green Paper, *Independence, well-being and choice (2005a)* and subsequent White Paper, *Our health, our care, our say (2006)*, are set around seven key outcomes identified by people who use services, one of which is personal dignity and respect. The Commission for Social Care Inspection (CSCI) has incorporated these into their new assessment framework, *A new outcomes framework for performance assessment of adult social care (2006)*. The Department of Health's *National Service Framework for Older People (2001)* also supports a 'culture change so that all older people and their carers are always treated with respect, dignity and fairness', and its *Essence of Care: Patient-focused benchmarking for health care practitioners (2003)* offers a series of benchmarks for practice on privacy and dignity.

Factors that have been held responsible for the absence of dignity in care include bureaucracy, staff shortages, poor management and lack of leadership, absence of appropriate training and induction and difficulties with recruitment and retention leading to overuse of temporary staff. There are also wider societal issues, including ageism, other forms of discrimination and abuse. A great deal of work is needed to tackle negative attitudes towards older people, to bring about a culture change and to ensure that such attitudes have no place in the health and social care sectors. This guide seeks to highlight the small changes that can make a big difference in day-to-day practice.

How you can help

This guide will be helpful but it cannot reflect everything people have learned about ensuring people's dignity. We plan to develop this guide so we would welcome email or written comments on any aspect of this guide, in particular if you have a success story about how you improved people's dignity. The feedback will inform future practice guide updates. We are also keen to collect examples that translate key research findings and practice points into practice. If you'd like to share your views, simply go to www.scie.org.uk and fill in the feedback form for this Guide.

Dignity challenge

Since he took office the Care Services Minister, Ivan Lewis, has been talking to a wide range of people, including providers of care services, organisations who represent people who use services, people who use services themselves and their carers. Through these listening events and an online survey, a lot has been learned about what dignity means to older people. Two things in particular have become very clear. The first is that being treated with dignity really matters to people, but the second is that people are not clear about what they should expect from a service that respects dignity.

The Dignity Challenge lays out the national expectations of what constitutes a service that respects dignity, based on the learning of the last nine months. It focuses on ten different aspects of dignity – the things that matter most to people.

Ivan Lewis is now challenging everyone – those who provide services, those who receive services and those who commission services – to see how services measure up to the Challenge.

What is the Dignity Challenge?

The Dignity Challenge is a clear statement of what people can expect from a service that respects dignity. It is backed up by a series of 'dignity tests' that can be used by providers, commissioners and people who use services to see how their local services are performing.

The Dignity Challenge: High quality care services that respect people's dignity should:

1. have a zero tolerance of all forms of abuse.
2. support people with the same respect you would want for yourself or a member of your family
3. treat each person as an individual by offering a personalised service
4. enable people to maintain the maximum possible level of independence, choice and control
5. listen and support people to express their needs and wants
6. respect people's right to privacy
7. ensure people feel able to complain without fear of retribution
8. engage with family members and carers as care partners
9. assist people to maintain confidence and a positive self-esteem
10. act to alleviate people's loneliness and isolation.

Who are we challenging?

- It is a challenge to service providers to ensure their services respect dignity.
- It is a challenge to commissioners to ensure they commission only services that respect dignity.
- It is a challenge to the public to test how their local services measure up and to tackle rather than tolerate services that don't respect dignity.

How this guide can support you to meet the Dignity Challenge

This guide contains a wealth of information, advice, best practice and other resources to help support organisations to drive up standards of dignity in care. Identified under each Challenge statement is a selection of ideas from practice so you can read about how others have tackled these issues – each section includes more.

1. Have a zero tolerance of all forms of abuse

By this we mean:

Respect for dignity is seen as important by everyone in the organisation, from the leadership downwards. Care and support is provided in a safe environment, free from abuse. It is recognition that abuse can take many forms including physical, psychological, emotional, financial and sexual, and extend to neglect or ageism.

Dignity tests:

- Is valuing people as individuals central to our philosophy of care?
- Do our policies uphold dignity and encourage vigilance to prevent abuse?
- Do we have in place a whistleblowing policy that enables staff to report abuse confidentially?
- Have the requisite Criminal Records Bureau and Protection of Vulnerable Adults List checks been conducted on all staff?

Some ideas from practice:

Addenbrooke's: anticipating concerns before they become complaints

Addenbrooke's undertook an audit to ensure inpatient wards were meeting the requirements set out in the Addenbrooke's Standards of Privacy and Dignity which were developed by the Essence of Care subgroup. An audit pack containing the Addenbrooke's standards, six patient questionnaires and a ward manager's survey were delivered to 35 wards across the trust. Wards were asked to return the completed packs within two weeks. The findings demonstrate where best practice is being achieved against the standards set out, and generated a number of recommendations for the trust to implement.

For further information contact:

Lyn McIntyre, Assistant Chief Nurse. Tel 01223 256221.

Email lyn.mcintyre@addenbrookes.nhs.uk

How West of Cornwall PCT gauged patient satisfaction

The trust conducted a patient satisfaction baseline audit with regard to privacy and dignity within the Minor Injuries Unit based at Cambourne & Redruth Community Hospital. The aim was to demonstrate where best practice was being achieved and to highlight areas where practice could be improved. Subsequently an action plan was developed to address the areas where service improvement had been identified.

For further information contact:

Jane Goldsworthy, Development Manager Communications.

Email jane.goldsworthy@ciospct.cornwall.nhs.uk

Developing a privacy and dignity policy for Guildford and Waverley PCT

The PCT's Essence of Care steering group carried out a privacy and dignity audit on the wards in December 2005, based on the Essence of Care standards. There were some significant findings, as a result of which they:

- increased and improved access to diversity and equality training
- increased confidentiality and Caldicott awareness training for all staff
- added Velcro® fastenings to curtains
- reviewed the procedure on responding to a complaint of inappropriate behaviour towards a colleague or patient, and disseminated the results to all managers.

The group has also developed a draft privacy and dignity policy, stating the requirements and expectations the trust demands from staff.

For further information contact:

Glynis John, Clinical Governance Facilitator. Tel 01483 782102.

Email Glynis.john@nhs.net

Assessing standards: Dorset and Somerset SHA's audit tool

The SHA has developed an audit tool which aims at achieving high standards of patient dignity and putting patient experience high on the agenda. The audit tool is a template covering five key themes:

- patient environment
- privacy, dignity and modesty

- communication with patients
- promoting individual needs
- staff training.

It also contains a score card so progress can be monitored and lapses can be picked up quickly and acted upon, using an action plan template.

For further information contact:

Sharon Waight, NHS South West. Tel 01935 384111.

Email Sharon.waight@southwest.nhs.uk

Dignity and Respect Training Project (John Coupland Hospital, Lincolnshire Teaching Primary Care Trust)

The John Coupland Hospital Older People project team has developed a Dignity and Respect Link Trainers Project in order to establish good practice throughout the hospital. Designated trainers were identified from several departments, each of whom was given special training and materials. These trainers in turn ran sessions for staff within their own departments. All existing and new staff will participate in the training.

For further information contact:

Maria Storti, Interim Operational Lead Intermediate Care, Lincolnshire PCT.

Email maria.storti@lpct.nhs.uk

2. Support people with the same respect you would want for yourself or a member of your family

By this we mean:

People should be cared for in a courteous and considerate manner, ensuring time is taken to get to know people. People receiving services are helped to participate as partners in decision-making about the care and support they receive. People are encouraged and supported to take responsibility for managing their care themselves in conjunction with, when needed, care staff and other information and support services.

Dignity tests:

- Are we polite and courteous even when under pressure?
- Is our culture about caring for people and supporting them rather than being about 'doing tasks'?
- Do our policies and practices emphasise that we should always try to see things from the perspective of the person receiving services?
- Do we ensure people receiving services are not left in pain or feeling isolated or alone?

Some ideas from practice

Five factors of privacy at Southampton

The trust's Essence of Care Group, which carried out an audit to uncover areas of dignity in care that needed further work, identified five factors of privacy and dignity. Guidance was provided for all wards on the 'five factors' and they also developed a charter for patients informing them of the standard of care they should expect.

For further information contact

Julie Dawes, Associate Director of Nursing. Tel 02380 798435.
Email julie.dawes@suht.swest.nhs.uk

'If only the experience could be different'

Luton and Dunstable has taken an innovative approach to the ongoing re-design of their service, which is putting patients and staff right at the centre of the process. A project sponsored and supported by the NHS Institute for Innovation and Improvement is co-produced with thinkpublic (a service design consultancy), anthropological researchers from University College London and, importantly, patients and staff. The objective was not to solve any specific problems but to improve the experience of visiting the clinic. A team comprising patients, carers, healthcare staff, researchers and improvement

leaders identified parts of the clinic process that heightened anxiety rather than reduced it, or contributed to patients' sense of helplessness. With thought, some small things could make a huge difference to the patients - for example, moving weighing scales out of sight of the waiting room: staff hadn't noticed how embarrassing patients found it to be weighed in front of everyone. The layout of the waiting room left patients facing a wall full of official notices or looking directly at others, and the number of different professionals around could be bewildering, so they are now trialling a different approach: instead of the consultants having rooms that patients move in and out of, patients now have rooms and staff move to see them. (Information taken from 'Journey to the interface', a Demos booklet.

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The group has also developed a draft privacy and dignity policy stating the requirements and expectations the trust demands from staff.

For further information contact:

Glynis John, Clinical Governance Facilitator. Tel 01483 782102.

Email Glynis.john@nhs.net

What Do You See? starring Virginia McKenna – a short training film from the Greater London Forum for Older People

The Greater London Forum for Older People released a 10-minute training film, 'What Do You See?' directed by Amanda Waring and starring Virginia McKenna. The film, which promotes seeing older people in a fresh light, is a powerful and evocative story and perfectly illustrates the key message that we must see older people as individuals rather than as part of a category. This is not a free resource (funds raised go to Macmillan Cancer Relief and Help the Aged).

Extra Care scheme for people with dementia (Portland House, St Helens)

Portland House is a small, eight-unit, Extra Care scheme for people with dementia, where staff recognise the value of tenants, their uniqueness and their personal needs. Individuals' views are respected and accepted, providing the rights of other tenants are not infringed.

Staff take time to get to know individual tenants in order to understand their needs and gain knowledge of each person's previous lifestyle, their likes and dislikes. Care and support is agreed with each tenant and provided on that basis. A staff-tenant ratio of 1:4 and a flexible staffing structure make this person-centred approach possible.

Staff take on the role of enablers in order to promote independence in all aspects of daily life and personal care. This in turn preserves dignity and encourages feelings of self worth. Staff support tenants to develop and maintain links with local facilities, and this helps to promote social inclusion.

The combination of the physical environment, philosophy and person-centred practice at Portland House has enabled the eight tenants to maintain their skills, build confidence in their own abilities and has boosted their self-respect. Information taken from the Dignity in Housing LIN Report, 2006.

For further information visit:
<http://icn.csip.org.uk/housing/>

3. Treat each person as an individual by offering a personalised service

By this we mean:

The attitude and behaviour of managers and staff help to preserve the individual's identity and individuality. Services are not standardised but are personalised and tailored to each individual. Staff take time to get to know the person receiving services and agree with them how formally or informally they would prefer to be addressed.

Dignity tests:

- Do our policies and practices promote care and support for the whole person?
- Do our policies and practices respect beliefs and values important to the person receiving services?
- Do our care and support consider individual physical, cultural, spiritual, psychological and social needs and preferences?
- Do our policies and practices challenge discrimination, promote equality, respect individual needs, preferences and choices, and protect human rights?

Some ideas from practice:

Providing advocacy support

An advocate working for East Cheshire Advocacy who supported a client with learning disabilities who was suffering from cancer shows the importance of having someone to act on their behalf when the person is terminally ill. It also demonstrates how services were tailored for an individual with obsessive compulsive disorder when they were receiving emergency care and how instrumental using the Patient Advice and Liaison Service (PALS) can be. The advocate was able to support the person through each stage of treatment, offering advice and helping them to take decisions and also act as an intermediary between clinicians and patient. You can download the full case story from www.scie.org.uk

For further information contact:

Maggie Harwood, Manager, East Cheshire Advocacy, The Moss, 4-6 Congleton Road, Macclesfield SK11 7UE.

Website www.ecadvocacy.co.uk.

Peter's story: how an advocate helped him express his wishes

Peter's story shows how advocacy services were able to help someone with learning disabilities achieve the celebration he wanted.

Peter had recently had his 60th birthday. When asked by members of the self-advocacy group what he had done for his birthday, Peter said that staff where he lived had been busy on the day of his birthday and so he had gone out for a pub lunch with three people he lived with at the weekend. Unfortunately, the pub was not serving food that day so they just got fish and chips to eat at home. When the advocate asked about a party, Peter said he would like one, but that the staff hadn't asked him if he had wanted one. The advocacy group didn't think the staff had supported Peter well for such an important birthday. This was communicated to the service, who acknowledged quickly that they had not treated Peter with dignity and helped him organise the party he wanted, inviting his family and friends, including members of the self-advocacy group.

Peter's story highlights the importance of effective and timely communication and shows how, through joint working between the staff and the advocacy supporter, Peter was able to express his wishes and make them happen.

For further information contact:

David Thompson, Advocacy Partners. Email david.thompson@advocacypartners.org

Champions programme in the Black Country

The aim of this project is to have a champion in all care environments where older people receive care. The champions, who are experienced nurses and allied health professionals, attend an intensive two-day workshop of master classes by expert speakers with a focus on addressing values, attitudes and dignity. Support is provided via resource packs, a dedicated website, mentors, a lead executive for each trust and champion network meetings. The intention is to improve care and support for older people; reduce stays in hospital; build reassurance and confidence in the care provided for older people in hospitals and other care environments; provide a proactive workforce to care effectively for a rising ageing population; and reduce the number of complaints. Independent researchers will evaluate the Champions for Older People project and the next stage is to roll the project out to the primary care trusts and mental health trusts.

Key learning points:

- Ensure that the Essence of Care benchmarks are included in the master classes and that the sessions all relate to dignity, values and attitudes for older people.
- Ensure that key stakeholders are on board from an early stage and that a support network is in place for the champions
- Ensure that long-term sustainability is built in.

For further information contact:

Andrew Hindle, SHA Lead for Older People Services. Tel 0121 695 2562.

Email andrew.hindle@westmidlands.nhs.uk

Person-centred care assessment at Birmingham and Solihull Mental Health Trust

Staff use a [person-centred care \(PCC\) position statement](#), based on the work of the late Tom Kitwood (a leader in the field of dementia care whose goal was to see widespread practice of person-centred care for people with dementia). This covers:

- value people with mental health needs and those who care for them
- treat people as individuals
- acknowledge life experience
- provide a positive social environment.

Senior staff undertake regular 'quality visits'. They walk the wards, scrutinise the patient environment and, if areas for improvement are noted, ensure an action plan is implemented. Staff are supported with regular person-centred training days, focus groups for carers, patients and staff are listened to and complaints are examined closely to see what themes are emerging. As a consequence, the service can produce a range of evidence-based interventions and evaluations of how their constant search for improvement in person-centred care is benefiting patients.

For further information contact:

Linda Playford. Email Linda.Playford@bsmht.nhs.uk

Cooking with Care (Barchester Healthcare)

National care home provider, Barchester Healthcare, has initiated a Cooking with Care campaign, supported by the celebrity chef Paul Rankin, to ensure that mealtimes are enjoyable, dignified and fun. Chefs spend time in the dining room with residents to ensure that food is beautifully presented and to find out about residents' likes and dislikes.

To ensure that chefs are fully trained to support individual needs and tastes, Barchester Healthcare has developed the Barchester Chef Academy to offer training for all levels, from apprentice to Master Chef. The group has also introduced a system of 5 Star Dining to improve dining standards, particularly for patients with swallowing difficulties and those unable to feed themselves. Standards include offering the resident a choice of meal at their table (rather than pre-ordering), presenting food for people on soft diets just as beautifully as other dishes, and providing assistance in cutting up food discreetly.

For further information contact:

Terry Tucker, Director of Learning, Development and Hospitality, Barchester Healthcare. Tel 07718 582139.

Email terry.tucker@barchester.com

Transport with care (Lincolnshire Teaching Primary Care Trust)

The Trust has set up a transport service, to ensure older patients not requiring hospital admission can be driven home after their visit, rather than make an unnecessary overnight stay. This service provides a responsive, needs-led wheelchair access vehicle to drive hospital patients from one care setting to another or to return them home. Working in partnership with the Discharge Rehabilitation Team in Accident and Emergency, the service transports patients safely and settles them home, with provision of a basic grocery pack. The service maintains a social care approach and perspective, putting the individual at the centre.

For further information contact:

Maria Storti, Interim Operational Lead Intermediate Care, Lincolnshire PCT.

Email maria.storti@lpct.nhs.uk

The Hospital Book (Barnet Learning Disabilities Service)

The Hospital Book is a recording system developed by the Barnet learning disability team. Its aim is to help patients communicate their needs to staff who may not be used to working with people who have learning disabilities and communication difficulties. The book holds details of the person's needs and preferences; recording, for example, food likes and dislikes or whether support is needed with personal care. The information can also be summarised on a Health Information Card, which is used as a brief version of the Hospital Book or an addition to it.

For further information contact:

Alison Pointu, Barnet Learning Disabilities Service.

Email alison.pointu@barnet-pct.nhs.uk

Improving the mealtime experience (Methodist Homes for the Aged)

Methodist Homes for the Aged (MHA) have introduced a range of initiatives across their care homes and housing schemes to improve the experience of mealtimes. The initiatives include a catering manual for catering and care staff with a clear set of standards, the introduction of routine nutritional screening, and assessment of residents' eating capabilities by speech and language therapists. In one particular home, staff have looked at ways to ensure residents' rights to privacy during mealtimes. Improvements have included the introduction of pleasant background music and fresh flowers at the dining table.

For further information contact:

George Sampson, Head of Hospitality. Tel 0773 4151988.

Email George.Sampson@mha.org.uk

Red tray system

Many hospitals have adopted this system for identifying patients who require assistance at mealtimes. Food served on a red tray provides an effective signal to staff without compromising the patient's dignity. The system is being monitored and refined, but has been found helpful in promoting individual care and staying alert to changing nutritional requirements. Designating patients who receive a red tray is part of initial and continuing assessment, and a daily updated list of patients due to receive food on red trays can be included in shift handovers and provided for kitchen staff. A red tray is also a simple reminder to staff to check the patient's notes for guidance on any specific help or nutritional needs. In several hospitals the red tray system has been linked with protected mealtimes

Knife and Fork Symbol (United Bristol Healthcare NHS Trust)

Under this system, a knife and fork symbol is placed above patients' beds. This gives staff the same signal as the Red Tray system, indicating which patients need support during mealtimes.

For further information contact:

Toni Williams, Chief Dietician, Food Policy, United Bristol Healthcare NHS Trust. Tel 0117 9283006.

Email toni.williams@ubht.nhs.uk

Enhanced pathways into care (EPiC), Sheffield

The aim of the project was to build a partnership between a Crisis Assessment and Home Treatment team and the Pakistani Muslim Centre. This would enhance access to home treatment for Pakistani service users and reduce over-reliance on inpatient services, and it would enhance the cultural appropriateness of the Crisis Assessment and Home Treatment service.

A community development worker was employed to work with a Pakistani Muslim Centre and, together with a Crisis Assessment and Home Treatment team member, saw service users at home. This constitutes a shared care operational policy, with the development worker actively identifying Pakistani service users. The Pakistani Muslim Centre also developed support services of its own for people with mental health problems.

The outcome was a managed care pathway designed for Pakistani service users, who reported greater satisfaction with services. Inpatient length of stay was reduced for 12.5 per cent of Pakistani patients, and those experiencing relapses sought help earlier.

For further information contact:

Sue Hammond, Team Leader, Project Support Unit, Department of Health.

Email: sue.hammond@dh.gsi.gov.uk

What do you see?

The Greater London Forum for Older People released a 10-minute training film, 'What Do You See?' directed by Amanda Waring and starring Virginia McKenna. The film, which promotes seeing older people in a fresh light, is a powerful and evocative story and perfectly illustrates the key message that we must see older people as individuals rather than as part of a category. This is not a free resource (funds raised go to Macmillan Cancer Relief and Help the Aged).

For further information:

<http://www.amandawaring.com/Text/1126793805537-3301/Charity-Film>

4. Enable people to maintain the maximum possible level of independence, choice and control

By this we mean:

People receiving services are helped to make a positive contribution to daily life and to be involved in decisions about their personal care. Care and support are negotiated and agreed with people receiving services as partners. People receiving services have the maximum possible choice and control over the services they receive.

Dignity tests:

- Do we ensure staff deliver care and support at the pace of the individual?
- Do we avoid making unwarranted assumptions about what people want or what is good for them?
- Do individual risk assessments promote choice in a way that is not risk-averse?
- Do we provide people receiving services the opportunity to influence decisions regarding our policies and practices?

Some ideas from practice:

On the road to independence – Betty's story

Betty was diagnosed with glaucoma just before her 70th birthday and, as the disease progressed, her life slowly changed from one full of hobbies and interests to one of ever more limited involvement in activities. When her husband died she realised how dependent she had become on him. A fortuitous appointment with a consultant ophthalmologist resulted in her being certified severely sight impaired, which then put the wheels of social care and healthcare in motion. A rehabilitation officer was assigned to Betty to enable her to open up a new world of independence. He gave her time to discuss her difficulties and support her. He encouraged her to accept a symbol cane to alert others of her limited vision and then to undertake a course of long cane orientation and mobility training. From one small tentative step forward Betty's confidence grew and she found herself navigating around new as well as familiar places.

For further information visit:

'Changing Lives' - Vision for Adult Social Care and Health
<http://www.staffordshire.gov.uk/health/changinglives/>

Maintaining dignity despite incontinence

The Housing Improvement Learning Network is developing a factsheet on dignity in housing, which includes some examples where dignity issues have been addressed. The following example (from Hanover SmartChoice, a service that helps care providers assist older people and people with disabilities to maintain their independence and remain safely in their own homes) demonstrates how assistive technology can help restore dignity.

Mrs J is a resident of an Extra Care scheme. When carers noticed an increase in her incontinence, the standard approach was for carers to enter her room at night and feel her bed to see if she had soiled herself. This was unsatisfactory for all. The solution was to use an enuresis pad, which issues an alert if Mrs J is incontinent. This allows for carers only to enter her room when an incident occurs, and if she is incontinent she is assisted with her toilet needs and bedclothes are changed straight away. It also enabled carers to examine records of alerts. They could see that a pattern of incontinence developed between 2 and 3 am. Using this information carers can now assist Mrs J to the toilet at 1.30 am and promote Mrs J's continence.

For further information:

Visit the Change Agent Team: Housing website: www.cat.csip.org.uk

Small, effective changes, not changing the world

The Older People's Essence of Care team believe essence of care should be about small, significant improvements that patients have highlighted, not about changing the world, and have found that involving the whole multi-disciplinary team ensures that this service is consistent throughout their locality. Here are some of the developments and improvements they have made, which all disciplines and clinical services must follow:

- induction packs, which include information relating to privacy and dignity, awareness of discrimination (age, culture, sex), confidentiality and record-keeping
- patients to be asked what they prefer to be called on admission/referral, and this to be documented
- patients to be asked for consent to share information on admission
- all areas to provide rooms for private conversations/interviews/phone calls
- patient orientation, including information about quiet areas, privacy and confidentiality
- staff encouraged to challenge others' negative attitudes.

The team is evaluating these improvements and awaiting patient satisfaction results.

For further information contact:
Sheila Kasaven, Modern Matron. Tel 0161 291 6806.
Email Sheila.Kasaven@nhs.net

Palliative care support: Macmillan's and local council working together

Greenwich Macmillan Palliative Care Support Service (funded by Macmillan Cancer Support and Greenwich Teaching PCT) aims to maximise choice for patients at the end of their lives, allowing them to die at home, if that is their wish, in maximum comfort and with maximum dignity. It also offers support to carers. The service operates 24 hours a day every day of the year, with a high level of flexibility to meet the needs and wishes of patients and carers, which can vary from day to day. There are three elements: daytime service, overnight sitting service and pop-in service (providing 15-minute checks through the night). The small, dedicated team of support workers from Greenwich Council are specially trained in health-related care and support for terminally ill patients, such as catheter and stoma care, pressure sore management, minor dressings, medication prompting, blood glucose monitoring, urinalysis, mouth care and peg feed care. They get to know the patient and carer very quickly and work at least 30 hours a week, to provide continuity of care. There has been very positive feedback and a formal evaluation is in progress.

Key learning points:

- Provide support 24 hours a day, seven days a week to ensure maximum flexibility to patients and carers; this is the key to enabling patients to die at home if this is their wish.
- Set up a specialist training programme before the service/new workers start.
- Training should include topics that cross the health/social care divide, such as care of the dying at home and after-death support, clinical communication skills, medicine management, spiritual diversity support, cultural diversity awareness, OT and physiotherapist support, and diet.
- Spend time in local hospice as healthcare assistants and with district nursing staff visiting patients in their homes.
- Use a small team, all working at least 30 hours a week - this makes continuity of care much easier.
- Establish a cross-agency steering group from the start, to enable good links to develop with the PCT continuing care nursing team, community specialist palliative care team, district nursing service and local carers' centre.
- Monitor demand - be ready and able to re-allocate hours between service elements if possible.

- Set up a single point of access to service - provided in this case by the PCT continuing care nursing team.
- Support the support workers - this is a very demanding service. Provide intensive line management support (24/7 if necessary), team meetings and external counselling. A rota of four days on three days off allows workers to recharge their batteries.

For further information contact:

June Williamson, Macmillan Palliative Care Support Service Co-ordinator, Greenwich Homecare. Tel 020 8921 2349.

Email june.williamson@greenwich.gov.uk

Communicating Choice (County Durham and Darlington NHS Foundation Trust)

The Trust has introduced a range of menus in different formats to help patients who cannot communicate what they would like to eat. This includes a multi-cultural pictorial menu to suit Halal, Afro Caribbean and Kosher diets and braille menus. Deaf patients are assisted by the chef, who is a qualified signer.

For further information contact:

Alison McCree, Associate Director of Estates and Facilities. Tel 01325 743022.

Email alison.mccree@cddft.nhs.uk

Making a home: Zoe's story

Zoe is a woman in her late 40s with moderate learning disabilities and enduring mental health problems. Two-and-a-half years ago she lived in a small dwelling in general needs housing stock, with no personal effects to make it feel like home. The approach adopted by staff was to control what Zoe could and could not do, and when. She displayed extremely aggressive and challenging behaviour, including destroying windows and furniture. She was frequently incontinent, apparently using incontinence to defy staff.

Staff did not want to work with Zoe and consequently a high level of agency staffing was used. Frequent incidents occurred, many of which were only reported verbally from one staff member to another. There were no plans in place to guide the staff as to how to manage the challenging behaviour, and recording was poor.

Zoe moved to a two-bedroom semi-detached bungalow managed by a specialist provider. Zoe chose the furnishings and there are more personal effects in evidence. There is now a person-centred plan in place, with policies and procedures to guide staff, accurate recording and staff continuity. Zoe has much greater choice and control over what she does and when she does it.

The improved environment and staff practice has improved Zoe's sense of well-being and independence. As a consequence, she is no longer incontinent and manifests far fewer, and less extreme aggressive and challenging outbursts.

Information taken from the Dignity in Housing LIN Report, 2006:

<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/files/dignityinhousing.pdf>.

For further information visit:

<http://icn.csip.org.uk/housing/>

5. Listen and support people to express their needs and wants

By this we mean:

Provide information in a way that enables a person to reach agreement in care planning and exercise their rights to consent to care and treatment. Openness and participation are encouraged. For those with communication difficulties or cognitive impairment, adequate support and advocacy are supplied.

Dignity tests:

- Do all of us truly listen with an open mind to people receiving services?
- Are people receiving services enabled and supported to express their needs and preferences in a way that makes them feel valued?
- Do all staff demonstrate effective interpersonal skills when communicating with people, particularly those who have specialist needs such as dementia or sensory loss?
- Do we ensure that information is accessible, understandable and culturally appropriate?

Some ideas from practice:

Getting the message across: colourful posters

The trust's Essence of Care Group carried out an audit on dignity in care in the hospital to identify where further work needs to be carried out. This work is part of a two-year project, working with the local primary care trusts. As a result, all wards have been provided with colourful, graphic posters with advice to the staff on how best to communicate with patients. These include reminders on good telephone manners, tips on how to communicate well face to face and factors to bear in mind when speaking or writing to someone who has a communication difficulty, whether through a disability or because of a language barrier.

For further information contact:

Julie Dawes, Associate Director of Nursing, Tel 02380 798435. Email julie.dawes@suht.swest.nhs.uk

Facilitating dignified communication

The trust's Communication Group looks at how the communication needs of patients can be met. Clinical care indicators monitor the fundamentals of care and the patient communication interview, undertaken by the Patients' Panel, highlights any areas of concern or best practice in regard to patients' communication. The group has undertaken extensive work to address the communication needs of individuals, in

particular those with communication difficulties, and is currently building up a supply of equipment within the trust to facilitate more effective and dignified communication. These include RNID crystal loop listeners, wipe-clean A4 boards and speech amplifiers.

For further information contact:

Harriet Stephens, Lead Nurse, Practice Development. Tel 01784 884940.

Email harriet.stephens@asph.nhs.uk

A multi-racial outlook

The trust has a diversity department that advises and supports staff, facilitates training and has Race Champions. Trust staff have access to interpreters for all languages who will come in and see patients and carers and will assist with assessments, consultations and ward rounds. In addition a BME (Black and minority ethnic) team offers support to patients and staff in providing cultural awareness training. There are information leaflets on wards available in a range of languages.

For further information contact:

Linda Playford. Email Linda.Playford@bsmht.nhs.uk

Filming the family: Tracy's story (Isle of Wight Advocacy Trust)

Tracy is 32 and has lived in the same residential home since she was 17. She has no relatives or friends on the Isle of Wight, and is funded by a mainland Authority. Tracy has very high support needs, and her behaviour is challenging. She chooses not to access day care services, and becomes extremely agitated when day care is suggested. Tracy was referred for an advocacy assessment following a review. An experienced advocate spent time with Tracy creating pictures of her likes and dislikes. Tracy was able to communicate that being given regular injections, which were required for medical reasons, distressed her. These injections always followed her visits to the day centre and were, it seemed, related to her refusal to attend. The advocate met with staff, and it was agreed that another form of medication would be adopted; Tracy has since become far less aggressive towards staff.

It was evident that Tracy missed her family and the advocate requested that the care manager research residential homes closer to them on the mainland, two possible homes were found. It was agreed that Tracy may find the long journey stressful and so the advocate travelled with a video camera to film the possible new homes and members of Tracy's family.

The DVD enabled Tracy to be involved in the choice of new home. The DVD worked well as a communication tool and this method can be used again in the future.

Learning points:

- It is important to maintain and support family links
- Where communication is a problem it is important to look below the surface as the reason's for a person's distress may not be as they first seem.
- DVD is a useful resource for communication

For further information contact:

Jan Gavin, Chief Executive, Isle of Wight Advocacy Trust, Quay House, The Quay, Newport, Isle of Wight PO30 2QR. Tel 01983 559299. Mobile 07734 448069.
Website: www.iwadvocacytrust.org/

6. Respect people's right to privacy

By this we mean:

Personal space is available and accessible when needed. Areas of sensitivity which relate to modesty, gender, culture or religion and basic manners are fully respected. People are not made to feel embarrassed when receiving care and support.

Dignity tests:

- Do we have quiet areas or rooms that are available and easily accessible to provide privacy?
- Do staff actively promote individual confidentiality, privacy and protection of modesty?
- Do we avoid assuming that we can intrude without permission into someone's personal space, even if we are the care giver?
- Can people receiving services decide when they want 'quiet time' and when they want to interact?

Some ideas from practice:

Addenbrooke's: anticipating concerns before they become complaints

Addenbrooke's undertook an audit to ensure inpatient wards were meeting the requirements set out in the Addenbrooke's Standards of Privacy and Dignity, which were developed by the Essence of Care subgroup. An audit pack containing the Addenbrooke's standards, six patient questionnaires and a ward manager's survey were delivered to 35 wards across the trust. Wards were asked to return the completed packs within two weeks. The findings demonstrate where best practice is being achieved against the standards set out, and generated a number of recommendations for the trust to implement.

For further information contact:

Lyn McIntyre, Assistant Chief Nurse. Tel 01223 256221.

Email lyn.mcintyre@addenbrookes.nhs.uk

Behind closed doors

The Essence of Care group is currently piloting on wards the Geriatric Society's leaflet entitled 'Behind closed doors, using the toilet in private'. The plan is to roll out the work across the hospital.

For further information contact:

Julie Dawes, Associate Director of Nursing. Tel 02380 798435.

Email: julie.dawes@suht.swest.nhs.uk

Modesty preserved

It was noted that in the general ward areas hospital gowns were open-backed, with ties. Since the gowns were often used as temporary nightwear, mobile patients would frequently wear two gowns (one on backwards, to cover their back). Pyjamas supplied to patients were also often an undignified mismatch. Replacement gowns and pyjamas were agreed with textile services and endorsed by the Patient Experience Council. A bid for funding was presented to the local Patient Environment Action Group and full funding secured from the League of Friends. The change of bedwear overcame a simple matter the Matron's Essence of Care Group had identified, and enabled patients to regain a little more dignity at a vulnerable time.

For further information contact:

Sarah Balchin, Lead Nurse Clinical Developments.

Email sarah.balchin@porthosp.nhs.uk

Do not disturb: simple but effective signs

Sheffield came up with a very simple idea: they use plastic reusable Do Not Disturb signs which have been designed for curtains and doors. They have been found to be effective in reducing interruptions and are now being produced for use throughout the trust.

For further information contact:

sam.debbage@sth.nhs.uk

Paul's story: an Extra Care experience

Paul is a middle-aged man with a physical disability and mental health problems. He has spent most of his adult life living in nursing homes, but just over a year ago moved into a newly built Extra Care scheme. Paul said: 'I suffered a lot of abuse at the nursing homes. I have intelligence which they don't like.'

Paul described how staff in the last nursing home would sweep into his bedroom without knocking and pull the bed covers off exposing his naked body, his physical condition necessitating his sleeping unclothed. Staff would come straight into the bathroom while he was using the toilet to give him his medication, neither knocking nor waiting till he had finished. 'In a nursing home, you're a non-entity because of the power and control that the staff have over you...when you can go to the toilet; when you get up or go to bed; when you have your meals.'

Paul says of the move to Extra Care: 'It is 100% different here. Staff knock before entering. They treat me with respect and dignity. Dignity means being able to go to the loo and close the door; dignity means when you have a bath, not having fun poked at your body.' Paul has no restrictions on him – he can choose when to get up or go to bed. Any concerns that he has raised have received a positive response.

Paul is now a member of the housing association's board. Paul's view is that having a tenancy and his own front door gives him choice and control. 'The tenancy is 101 per cent part of it. Staff can come in – it is a choice that I make. Choice is a precious thing in life.' Paul's sense of well-being and mental health have improved immeasurably. Moving to Extra Care has given him a new lease of life. 'The reason my mental health is helped here is because I'm treated as a human being. I am respected as Paul. People, staff, respect my views and respect me as a person.'

Information taken from the Dignity in Housing LIN Report, 2006:

<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/files/dignityinhousing.pdf>

7. Ensure people feel able to complain without fear of retribution

By this we mean:

People have access to the information and advice they need. Staff support people to raise their concerns and complaints with the appropriate person. Opportunities are available to access an advocate. Concerns and complaints are respected and answered in a timely manner.

Dignity tests:

- Do we have a culture where we all learn from mistakes and are not blamed?
- Are complaints policies and procedures user-friendly and accessible?
- Are complaints dealt with early, and in a way that ensures progress is fully communicated?
- Are people, their relatives and carers reassured that nothing bad will happen to them if they do complain?
- Is there evidence of audit, action and feedback from complaints?

Some ideas from practice:

Easy access to information and help at Caterham Dene

As part of the hospital's clear admissions process, all patients are given an information booklet when they are admitted. This booklet includes a section on how to complain if they are unhappy with the service that is provided to them. Staff are made aware of how to deal with complaints through the PCT complaints policy and associated training. The matron is based on the ward and can easily be accessed by staff for support.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846. Email eileen.clark@eastsurrey-pct.nhs.uk

Electronic feedback for constructive criticism

Through its commitment to quality, PHG views suggestions and complaints as essential for improving customer care. It believes there is a need to acknowledge the value of constructive criticism and complaints. Viewed positively, complaints are a valuable contribution to the development of high quality care. Dealing with complaints is therefore a priority within PHG and it is essential that they are addressed promptly. Key to this approach is early identification and rectification rather than reacting after patients have given their feedback.

PHG uses live electronic measurement of patient satisfaction which starts with quality care rounds conducted by the unit manager:

- Staff ask patients for feedback and, where appropriate, bring portable devices to the bedside.
- The patient reads the questions, and answers by pressing the appropriate buttons, which takes 15 - 20 seconds.
- All responses are automatically downloaded daily to a secure server and information from across the entire hospital/trust/region is collated and analysed.
- Reports are created and automatically emailed daily (or weekly) to the relevant managers, with each report relating to that manager's specific area of responsibility.
- The information contained in the ward/department reports is used as the basis for weekly staff meetings. Members of staff are kept up to date with patients' views and current issues, and are encouraged to suggest ways of improving performance. This encourages participation.

For further information contact:

Mona Van Wyk, Nursing Services, Specialist (Nursing Director), Partnership Health Group. Email: Mona.VanWyk@partnershiphealth.co.uk

8. Engage with family members and carers as care partners

By this we mean:

Relatives and carers experience a welcoming ambience and are able to communicate with staff and managers as contributing partners. Relatives and carers are kept fully informed and receive timely information. Relatives and carers are listened to and encouraged to contribute to the benefit of person receiving services.

Dignity tests:

- Do employers, managers and staff recognise and value the role of relatives and carers, and respond with understanding?
- Are relatives and carers told who is 'in charge' and with whom issues should be raised?
- Do we provide support for carers who want to be closely involved in the care of the individual, and provide them with the necessary information?
- Are we alert to the possibility that relatives' and carers' views are not always the same as those of the person receiving services?

Some ideas from practice:

Burntwood, Lichfield and Tamworth PCT's reassuring checklist

The PCT has developed a simple checklist which is used as part of the admission procedure. This document acts as a prompt to the nurse undertaking the admission to discuss with the patient (or the carer if this is more appropriate) certain aspects that are important to the patient - for example, knowing how to call for assistance, knowing where the toilet is, and being reassured that, if the ward accommodates male and female patients, these facilities are separate. Any relevant issues can then be transferred to the care plan so this is communicated to other staff. Relatives or carers often highlight areas they are concerned about, e.g. a patient prone to falls or not being able to use a call bell. This enables the nurse to explain to them measures that will be put in place and also discuss any risks that maybe relevant. It opens up communication between nurses with patients and carers from day one, and aims to make the patient and carer feel that they are able to approach staff at any time.

For further information contact:

Dawn Llewellyn, Modern Matron. Tel 01827 263819.

Email Dawn.llewellyn@ssh-tr.nhs.uk

Tapping into older people's knowledge and experience

A significant number of development and training courses here routinely involve older people, who share their experiences and say how they would like staff to treat them. Many older people are already experienced presenters but, if any feel anxious, personal presentation skills training can be arranged. The department has also arranged presentation and assertion skills training for groups of older people who volunteer or work in the voluntary sector. The department has also held a number of successful consultation events with older people and developed a useful Older People's Consultation Checklist. This and all development and training activities have been formally evaluated and changed in response to learners' or managers' feedback.

For further information contact:

Jane Simms, Principal Commissioning Officer, Westminster Children and Community Services Department. Tel 020 7641 2079. Email jsimms@westminster.gov.uk

Setting goals in Oldham

The care team are piloting a system of goal and treatment planning which was developed and introduced by one of their occupational therapists (OT), Luke Roberts. The tool is evidence-based and also provides an outcome measure loosely based on the Canadian occupational performance measure (COPM) (Law et al., 2005). On admission the patient and OT together set the goals and the patient receives a folder which contains these goals, to help monitor progress and reinforce a sense of purpose. The team intend to evaluate this method and, if successful, roll it out to other areas of intermediate care in Oldham. It is expected that this method of involving people in their own care will ensure that they feel informed, listened to and treated as an individual. The very functional approach ensures that patients are actively engaged in occupations that will restore their ability to carry out daily activities when they return home.

For further information contact:

Tracy Acton, Clinical Specialist OT. Email t.acton@nhs.net

The Manchester Partnership for Older People Project

MACC is a campaigning organisation that wants to see an inclusive society that supports and increases the health and social well-being of people in Manchester. It facilitates the Manchester Older People's Network and encourages older people to contribute to the planning, development and delivery of local services. The following is just one example of how older people, through the support of MACC, have an active influence.

Partnership for Older People Projects (POPPs) are government grants available for innovative approaches which will support older people to live independently, have a better quality of life and avoid the need for hospital and high intensity care. The Department of Health approved the Manchester bid in 2005. This project will develop:

- a team to provide a single point of access with support, advocacy and navigation for older people, their carers and professionals
- a team to strengthen the capacity of the voluntary sector
- a programme of grants for low-level services.

MACC believes older people should be an intrinsic part of delivering the NSF for Older People and related projects of work, and it involves service users and carers from the beginning of a process. Older people are recruited for their particular skills and experience, and have been involved with the POPP from the beginning - they were instrumental in the recruitment of the staff who now work on it, including the project manager, who is based with MACC.

For further information contact:

Mary Duncan, Development Worker. Tel 0161 834 9823. Email mary@macc.org.uk

Life story books at St Pancras's Evergreen Unit

The Evergreen Unit at St Pancras has developed Life Story books to support and inform the care they give to their patients. Where patients are able to contribute they do, but many have cognitive impairment and difficulty with verbal communication, so relatives are key in providing the information and are actively encouraged to be involved in completion of the books. The Life Story books help staff to engage with patients who have complex needs and are used to inform many aspects of care planning, from personalising bedrooms to meeting personal needs in a way that respects the person's wishes and promotes their dignity. The books, which were developed by the staff on the unit including nursing staff, occupational therapists and the psychologist, are also a guide to providing meaningful occupation. All new staff are taught how to use the books during their induction process. The books are given to the relatives/next of kin when the person dies and these have been welcomed as a 'nice reminder' of the person.

For further information contact:

Colin Owen, Email colin.owen@camdenpct.nhs.uk or Judith Greening, Email Judith.greening@camdenpct.nhs.uk

Success with a DVD diary: Jane's story (Isle of Wight Advocacy Trust)

Jane is a woman of 29 with severe learning disabilities. In October of 2005 her father died unexpectedly and her mother was diagnosed with a terminal illness. Jane was moved into a residential home without the usual preparation, planning and transition.

Jane was withdrawn, frustrated and very anxious and. Having previously suffered mild and infrequent epileptic fits these became frequent and more severe. Staff had little knowledge of epilepsy, and the continuity of care was poor. It was requested that the Advocacy Trust become involved.

The Trust met with Jane's mother, care manager and staff from the home and day care services to discuss how they could work together to support her. It was agreed that staff at Jane's home would receive epilepsy training.

An experienced advocate was allocated to Jane and her mother to make a DVD diary. Consent for the filming was obtained from those involved. The diary is in two parts: 'Me and my mum' and 'Where do I want to live?' Jane is able to use this DVD at her day centre, or at home with the use of a laptop computer. When Jane becomes anxious and distressed, the DVD has an immediate calming effect on her. Within the DVD, Jane's mother talks of Jane's likes and dislikes. This is a useful source of information for care workers now and in the future.

Learning points:

- People with high support needs and communication difficulties benefit from an independent advocacy service.
- Advocates are well placed to challenge services that are not meeting the needs of service users.
- Use of Video/DVD is an effective way of empowering people, and is an excellent training tool.

For further information contact:

Jan Gavin, Chief Executive, Isle of Wight Advocacy Trust, Quay House, The Quay, Newport, Isle of Wight PO30 2QR. Tel 01983 559299. Mobile 07734 448069.
Website www.iwadvocacytrust.org/

9. Assist people to maintain confidence and a positive self-esteem

By this we mean:

The care and support provided encourages individuals to participate as far as they feel able. Care aims to develop the self-confidence of the person receiving services, actively promoting health and well-being. Adequate support is provided in eating and drinking. Staff and people receiving services are encouraged to maintain a respectable personal appearance.

Dignity tests:

- Are personal care and eating environments well designed for their purpose, comfortable and clean?
- Do we maximise individual abilities at all times during eating and personal care and hygiene activities?
- Do we ensure people receiving services wear their own clothes wherever possible rather than gowns etc.?
- While respecting the wishes of the person receiving services as far as possible, are they respectable at all times and are staff tidy and well presented?

Some ideas from practice:

Modesty preserved

It was noted that in the general ward areas hospital gowns were open-backed, with ties. Since the gowns were often used as temporary nightwear, mobile patients would frequently wear two gowns (one on backwards, to cover their back). Pyjamas supplied to patients were also often an undignified mismatch. Replacement gowns and pyjamas were agreed with textile services and endorsed by the Patient Experience Council. A bid for funding was presented to the local Patient Environment Action Group and full funding secured from the League of Friends. The change of bedwear overcame a simple matter the Matron's Essence of Care Group had identified, and enabled patients to regain a little more dignity at a vulnerable time.

For further information contact:

Sarah Balchin, Lead Nurse Clinical Developments.

Email sarah.balchin@porthosp.nhs.uk

Putting therapeutic skills to work

Caterham Dene has a weekly timetable of activities, and all staff have been trained in occupational therapy and physiotherapy skills through an in-house programme developed by the therapists working on the ward. The healthcare assistants, supported by the therapists, are encouraged to take on a range of activities such as recreational therapies - quizzes, craft work and exercise groups, which include chair-based exercises. There is a close working relationship with the nearby local authority residential home, and activity coordinators from there visit to assist with activities.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@eastsurrey-pct.nhs.uk

Drama: fun with a purpose

To alter the image of a 'minding' service, the trust redeveloped their day care service for older people with dementia. They used 'Drama as a powerful clinical tool: fun with a purpose' as a teaching tool for staff, who have since developed activities for people with dementia and expanded community links. The many improvements include

- a very positive environment and workforce to promote a philosophy of independence, individuality and well-being
- actively reaching the person behind the disease, communicating via drama, dolls as therapy, puppetry, music and dance
- improvement in many people's speech, confidence and self-esteem
- using drama techniques/skills and diversion with constructive occupation rather than medication to help positive behaviour changes
- an active promotion of person-focused care.

The service has been evaluated through the use of user/carer questionnaires. It has received letters of appreciation and has won many regional and national awards including The Queen's Nursing Institute/Alzheimer's Society Award for Excellence and Innovation in Dementia Care 2003 and The Dorset and Somerset Modernisation Awards 2004. It has also been presented at many regional and national conferences.

For further information contact:

Lesley Benham, Team Leader. Tel 01305 762508.

Email Lesleybenham@dorset-pct.nhs.uk

Involvement Workshop (Ashfield Community Hospital)

Mental Health Services for Older People at Ashfield Community Hospital ran an involvement workshop in July 2007. The aim was to:

- Raise the profile of mental health services for older people by presenting the service in a positive and pro-active way.
- Bring the wider community closer to the work carried out by the service and demonstrate how it works in partnership with agencies like the Alzheimer's Society to fight for the dignity of older people with mental health issues.

The workshop featured singers and small reminiscence displays, a poet and an organ grinder. People were asked to send in mementoes such as pictures, poems and coins to be mounted on giant jigsaw pieces. These would in turn be hung on the walls leading up to the inpatient wards an installation that would encourage people look back positively and celebrate an exciting and positive future.

For further information contact:

Deborah Thompson, Modern Matron, Nottinghamshire Healthcare NHS Trust.
Email Deborah.thompson@nottshc.nhs.uk

10. Act to alleviate people's loneliness and isolation

By this we mean:

People receiving services are offered enjoyable, stimulating and challenging activities that are compatible with individual interests, needs and abilities. People receiving services are encouraged to maintain contact with the outside community. Staff help people receiving services to feel valued as members of the community.

Dignity tests:

- Do we provide access to varied leisure and social activities that are enjoyable and person-centred?
- Have we reviewed the activities we offer to ensure they are up to date and in line with modern society?
- Do we provide information and support to help individuals engage in activities which help them participate in and contribute to community life?
- Are responsibilities of all staff towards achieving an active and health-promoting culture made clear through policies, procedures and job descriptions?

Some ideas from practice:

Life histories and dementia care mapping

The trust has implemented Life History Work/Diaries, led by person-centred link nurses and taught by a dementia care specialist. This considers what people would like and how they would like to be treated, including invasive treatments and procedures and how to alleviate any distress. They also use Dementia Care Mapping, a validated tool which is able to identify illness/well-being for patients who may not be able to verbalise their thoughts. The trust has also introduced customer care into their induction programme and a specific customer care training day that looks at attitude, and maintaining privacy, dignity and modesty of all client groups.

For further information contact:

Kim Shield, Essence of Care Coordinator. Tel 01332 362221 ext 3783.

Email kim.shield@derbysmhservices.nhs.uk

The Sunshine Project (Help the Aged)

Help the Aged set up the Sunshine Project in order to increase opportunities for those living in care homes to make new friends. Two schemes have been taking place in care

homes in the East of England: a befriending scheme and a computer training scheme. The purpose of both is to increase social contacts, reduce isolation and improve quality of life. Computer training introduced people to information technology and to using email as a means of communicating with family and friends.

An interim evaluation by a research team at Essex University was funded in partnership with the local PCT, which was interested in how the project might lessen the strain on its services. The report was very positive, concluding that:

'Findings [of the evaluation] also reiterate the importance of non-family social interactions, previously documented by studies (McNeil, 1995) which indicate that social relationships and activity per se appear to confer health benefits through psychosocial pathways. Health and social care agencies need to recognise the non-clinical aspects of ageing and work together to maximize well-being in all areas of daily life by whatever means they have at their disposal. This evaluation can be used to build an evidence base to guide ongoing work in this area.'

For a copy of the report, contact:
Dorothy Seymour. Tel 01255 477939.

Putting therapeutic skills to work (Caterham Dene Community Hospital)

Caterham Dene has a weekly timetable of activities, and all staff have been trained in occupational therapy and physiotherapy skills through an in-house programme developed by the therapists working on the ward. The healthcare assistants, supported by the therapists, are encouraged to take on a range of activities such as recreational therapies - quizzes, craft work and exercise groups, which include chair-based exercises. There is a close working relationship with the nearby local authority residential home, and activity coordinators from there visit to assist with activities.

For further information contact:
Eileen Clark, Service Manager. Tel 01737 214846.
Email eileen.clark@east Surrey-pct.nhs.uk

Rural Gloucestershire's In Touch Project

In Touch provides support and advice on services for older people in the county's rural communities. When changes in social services criteria and closures of some day centres led to loss of services, In Touch worked with older people to identify what they would miss and need after services changed. The ideas of the older people were simpler, more cost effective and more acceptable to them than the original services and led to a range of social activities in a sheltered housing complex, informal lunch clubs, and a community minibus providing trips for regular shopping and lunches further afield. Social services staff call on In Touch to make connections between isolated older people and local groups and activities.

For further information:

Gloucestershire Rural Community Council <http://www.grcc.org.uk/>

Local Care Centre Cafe (Plymouth Primary Care Trust/Mental Health Partnership)

The Local Care Centre is a new development in Plymouth that provides a range of health services for the local community. The building's foyer houses a cafe, run by local mental health service users and coordinated by a local carer. The initiative is a joint venture between Plymouth PCT, users, carers and the voluntary sector, set up to enable people with long term mental health problems to gain access to paid employment. Within the first nine months of the scheme, two people found substantive employment.

Reports from service users suggest that the opportunity to work voluntarily in a supported – yet real – work environment has improved their confidence and enabled them to consider work as a real option.

For further information contact:

David Macauley, Plymouth PCT/Mental Health Partnership.

The guide: a summary

This guide has been designed for people who want to make a difference and improve standards of dignity in care. It has been compiled to support the Department of Health's wider Dignity in Care initiative and includes the Dignity Challenge.

The guide provides information for service users on what they can expect from health and social care services, and a wealth of resources and practical guidance to help service providers and practitioners in developing their practice, with the aim of ensuring that all people who receive health and social care services are treated with dignity and respect.

Overview of selected research

This describes evidence from selected research, inspection, policy and practice literature about the idea of dignity and its application in health and social care services for older people. Throughout, the focus is on what older people themselves have said about why dignity is important and – often more easily described – what it is that threatens dignity.

There is one very clear message from these documents: 'dignity in care' obviously has meaning for older people. Recognising and respecting what it means to them in terms of autonomy, privacy, respect, identity and sense of self-worth, and designing practice to support it, contributes to older people's well-being, and – ultimately – to what makes their lives worth living. Dignity is never simple, but always important.

The first part of the report looks at some of the public policy background to dignity in care, and attempts to clarify the range of ways in which the term 'dignity' is understood.

The meanings of dignity

Research with older people, their carers and care workers has identified dignity with four overlapping ideas:

- Respect, shown to you as a human being and as an individual, by others, and demonstrated by courtesy, good communication and taking time
- Privacy, in terms of personal space; modesty and privacy in personal care; and confidentiality of treatment and personal information
- Self-esteem, self-worth, identity and a sense of oneself, promoted by all the elements of dignity, but also by 'all the little things' – a clean and respectable appearance, pleasant environments – and by choice, and being listened to
- Autonomy, including freedom to act and freedom to decide, based on opportunities to participate, and clear, comprehensive information.

Factors which protect, support and promote the dignity of older people in health or social care contexts are grouped under three headings:

- **Resilience** describes the inner strength which, research has found, enables older people to bear difficult situations. A sense of self-worth and meaning was maintained by many, by reference to their families and previous life experiences and achievements, and a focus on everyday pleasures. Resilience could be reinforced or undermined by care workers.
- The **rights** of older people receiving care at home, in hospital or care homes are outlined here. Some analysts see the enforcement of these rights, and increasing awareness of them among service users as the best way to overcome outdated attitudes and systems. Inspection and research have found that the framework of rights is gradually affecting standards of care.
- **Person-centred care** puts the needs and aspirations of the individual service user at the centre of planning. Embedding the principles of person-centred care is still in progress, and evidence is mixed about how successfully this is being done. Barriers to achieving this kind of care in some settings include bureaucracy, tight budgets and restrictive commissioning which, reduce staff time for flexible, personal care.

The overview identifies threats to dignity with fundamental ways in which society is organised:

- **Ageism** – prejudice against people purely on grounds of age – has been challenged by legal and policy changes which have successfully combated overt discrimination against older people – for example, in some areas of the NHS. But ageist attitudes

and practice remain a serious issue, demanding much further effort.

- The effects of ageism are compounded for many older people by other forms of **inequality, disadvantage and discrimination**. These include poverty, social class, gender, ethnicity, physical and learning disabilities and sexual preference.
- The **abuse** of older people has been increasingly recognised as a serious issue in health and social care. Despite legislation to protect vulnerable adults, and detailed guidance for local action, there is evidence that more remains to be done.

The remainder of the overview considers dignity in practice – messages from the literature about dignity in care, in a range of different care settings: at home, in acute hospital, in care homes, in the care of older people with mental health problems, and at the end of life. The fundamental importance of care which respects and supports dignity is the same everywhere, but the implications for practice vary from context to context.

Dignity has proved difficult to define. Researchers have struggled to tackle what is in essence a philosophical idea, and to tie it down with observation, interview and analysis. Everywhere, the literature reflects tensions and questions of balance: between preserving privacy on the one hand, and avoiding silent isolation on the other; between acknowledging autonomy and resilience, while offering close support; between actual frailty and dependence, and the need for usefulness; between setting clear service targets, and leaving room for flexible, personal responses. There are also some gaps in the literature, about the meaning of dignity for some groups of older people, and the specific impact of services on them. But there is one overriding message – that dignity in care matters to older people – and there are consistent themes about what protects or threatens it.

Factors affecting dignity

Ten subject areas relating to dignity were highlighted by older people and their carers in the Department of Health online survey carried out in 2006. The guide takes each of these and covers:

- a brief exploration of the theme
- key points from research and policy
- practice points: what the research highlights, distilled into practical recommendations
- ideas from practice: practical applications from organisations involved in the care of older people, to support and inform those wishing to develop local services
- other resources: links to related websites, sources of information and tools.

Respect

Respect is summarised in terms of courtesy, good communication and taking time. It covers: staff and family attitudes, treating older people as equals and issues relating to death and dying, such as control of suffering and maintaining a respectable appearance. It is clear that people value respectful delivery of services over task-oriented care, and getting to know people for what they are is an essential aspect of person-centred health and social care practice. Ageism and other forms of discrimination constitute a lack of respect, and intergenerational community work has been suggested as one way of tackling ageism.

Communication

Good communication begins with addressing a person as they would wish and speaking to them with respect and without condescension – dignity is threatened by treating adults 'like babies' because of actual or assumed incapacity. Translators, specialised equipment and greater cultural understanding can all help overcome different kinds of communication difficulties. The value of overseas workers in health and social care cannot be underestimated, but it is important that support and training ensure their communication skills are adequate. Good communication is also about providing the right information at the right time, and about building confidence and trust. Older people, especially in residential care, feel more secure by seeing the same faces every day; this presents particular challenges for managers in terms of recruitment, retention and training.

Social inclusion

Age discrimination, sometimes alongside other forms of discrimination, can contribute to the social isolation of older people. The risk is greater for people living alone and the very elderly, and can be increased by bereavement, loss of work or poor health. Such isolation can contribute to the incidence of mental illness, particularly depression. Older people are concerned about lack of social contact with others, lack of meaningful activity and wanting to feel needed. Opportunities to participate, and make a positive contribution to community and society, are integral to dignity. Maintaining contact with family and friends, participating in cultural and community activities and using skills all contribute to social inclusion, and involving older people at all levels of service planning and delivery is an important part of getting it right.

Autonomy

Autonomy is about independence but also control and choice over one's life. Being supported to continue with routine daily tasks such as shopping, walking a dog or going to a social club can be instrumental in maintaining a person's autonomy. Autonomy is particularly at risk where a person needs help with their most basic and private needs, as may happen in hospital or residential care, or when impairment affects their ability to communicate. Advice and support with decision-making, advocacy support and

schemes such as individual budgets are all key to ensuring that older people can exercise autonomy. Proposed amendments to the Mental Capacity Act and involving older people in staff training are positive moves, but a major culture shift is required to support the autonomy of people within the health and social care systems.

Privacy

Aspects of privacy include: modesty and privacy in personal care, confidentiality of treatment and personal information (particularly when using interpreters), and privacy of personal space and belongings, which extends to personal conversations and mail. The Department of Health has given a clear public commitment to eliminating mixed-sex accommodation for hospital inpatients, and many service providers have improved privacy through small but important changes to facilities, systems and staff training. It is important to achieve a balance so that vulnerable people are not either isolated by privacy policies or put at risk, for example through providing privacy for personal and sexual relationships.

Hygiene and personal appearance

A person's appearance is integral to their self-respect and older people need to receive appropriate support to maintain the standards they are used to. Self-respect can be undermined by neglect of patients' appearance and clothing and, even in death, maintaining a respectable appearance is very important to people. Personal preferences should be respected and care taken with details such as respect for laundry. Appearance and hygiene also affect the living environment: a clean and tidy house and a well-kept garden are important aspects of maintaining dignity in daily living – an overgrown garden alone can give out the message that a person is unable to cope. Older people really value support which enables them to live in their own homes, for example, help with cleaning, DIY, gardening, pets, chiropody, transport and befriending.

Mealtimes

Food and mealtimes are a high priority for older people (a top priority for those from black and ethnic minority groups), and mealtimes are the highlight of the day for many people in residential care. Despite a raft of guidance, there are still serious concerns about meals in the health and social care sectors. Nutritional screening should be a key part of care planning: malnutrition affects over 10 per cent of older people, and is costly in economic terms as well as for individual health. Mealtimes should also be seen for their social opportunities: initiatives include local lunch clubs, and many hospitals have introduced 'protected mealtimes'. While socialising should be encouraged, privacy and discreet support is needed to avoid embarrassment or loss of dignity for those who have difficulties with eating.

Complaints

Complaints should be viewed as a means of ensuring that a service is responsive and not as a threat. Service providers should ensure that there is a fair, open and honest culture around complaints and a simple complaints procedure, so that people feel confident in bringing concerns to their attention. In this way problems are picked up at an early stage, poor practice is highlighted and rectified and the lessons learned lead to service improvements. People, especially older people, often find it difficult to complain – through worries of not being understood, or fear of retribution or being seen as a 'trouble maker'. This section includes advice for complainants, and provides contact details of who to complain to in different circumstances and who can help with making a complaint.

Whistleblowing

It takes a great deal of courage for an individual to raise concerns about poor practice or abuse within an organisation. Attitudes are changing, but a lot still needs to be done to ensure that workers feel safe enough to air concerns. For organisations there are clear advantages to supporting whistleblowers, including the safety of staff and service users as well as the organisation's reputation. If whistleblowers are viewed in a positive rather than negative light, then more people will be willing to come forward; the consequence of this will undoubtedly be better protection for vulnerable people. Organisations should implement a whistleblowing policy and staff need to know they will be offered protection if they make a disclosure in good faith – new staff, in particular, are often in a position to be more objective than existing staff members. The section includes do's and don'ts on whistleblowing and who can provide support.

Abuse

Abuse, which encompasses physical and sexual abuse, threats, harassment, exploitation and neglect, is far wider ranging than the remit of this guide, but this short section outlines immediate action that should be taken if abuse is suspected and provides leads to suitable further resources.

Overview of selected research

Introduction

This overview of selected research, inspection, policy and practice documents draws on British and international literature that relates to dignity in health and social care. It is not a comprehensive review, but aims to offer a window on some of the key issues and debates. Throughout, the principal focus is on what older people themselves have said about why dignity is important, and - often more easily described - what threatens dignity.

Section 1 fills in some of the public policy background, and describes a growing awareness of the importance of dignity to the well-being of service users. But what exactly is dignity?

Section 2 considers what dignity means. It outlines some of the many studies which have attempted to define dignity, list its characteristics and refine methods of analysing and evaluating care which supports it. The section ends with a summary of what appears to be the current state of knowledge about the meaning of dignity.

Section 3 outlines what protects dignity. It examines factors identified in the literature which support the dignity of older people in care settings. These include the inner strength and resilience of older people themselves, the range of rights which should protect them and the development of person-centred care, which puts the needs and wishes of the service user at the centre of care planning.

Section 4 considers threats to dignity. These are not just the everyday incidents which dent self-esteem, weaken autonomy and remove privacy. They emerge from fundamental ways in which society is organised, and require fundamental remedies. They include ageism and age discrimination, the range of disadvantages and discriminations that can multiply the effects of ageism, and abuse - the violation of an individual's human or civil rights.

Section 5 moves on to dignity in practice, and considers the messages from the literature about a range of contexts - at home, in hospital, in care homes, in settings which care for older people with mental health problems, and at the end of life. There are issues common to all settings, but also some clear differences which have important implications for practice.

A **brief final section** summarises some of the apparent gaps in the current literature.

There are three conclusions that can be drawn from this selected overview of the literature.

First, there are some themes which occur again and again, many of which coincide with

the findings of the Department of Health's online survey of people's views and experiences of care (DH, 2006).

Secondly, dignity itself has proved very difficult to define. Researchers have struggled to tackle what is in essence a philosophical idea, and to tie it down with observation, interview and analysis. Everywhere, the literature reflects tensions and questions of balance: between preserving privacy on the one hand, and avoiding silent isolation on the other; between acknowledging autonomy and resilience, while offering close support; between actual frailty and dependence, and the need for usefulness; between setting clear service targets, and leaving room for flexible, personal responses.

But, at the same time, there is one very clear message from these documents. 'Dignity in care' obviously has meaning for older care users: this is the third key conclusion. Recognising and respecting what it means in terms of autonomy, privacy, respect, identity and sense of worth, and designing practice to support it, contributes to older people's well-being and – ultimately – to what makes their lives worth living. Dignity is never simple, but always important.

1. Background

'Modernising social services' (DH, 1998) -

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009575 - sets the tone for social services by acknowledging the importance of dignity for all service users. The 'NHS Plan' followed in 2000 by including a chapter on 'Dignity, security and independence in old age' -

<http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/OlderpeoplesNSFstandards/index.htm> - and many subsequent documents developed the theme.

The National Service Framework (NSF) for Older People (DH, 2001), for example, which established a 10-year service development programme, 'was triggered by concerns about widespread infringement of dignity and unfair discrimination in older people's access to care'.

Opportunity Age (DWP, 2005), the government strategy for improving services for older and more vulnerable citizens, also highlights the need to continue the fight against ageism and age discrimination, and defines one of the principles of service provision in terms of older people's entitlement to dignity, respect, freedom from abuse and good quality care.

Health services, in partnership with social services and other agencies, will need to recognise the specific needs of older people in caring for them:

- demonstrating proper respect for the autonomy, dignity and privacy of older people
- treating the person, not just the most acute symptoms, by taking account of the full needs of older people, including the importance of good nutrition ... and enabling the older person to remain as active as possible while in hospital
- making high quality palliative and supportive care available to those older people who need it
- ensuring good clinical practice which recognises the complexities of caring for older people ...

NHS Plan, Ch.15

<http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Olderpeopleservices/OlderpeoplesNSFstandards/index.htm>

Similar themes appear in documents by a range of agencies. They deal with all services for older people (Audit Commission, 2004) housing and housing-related support (HLIN, 2006) –

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4009325 - mental health services (CSIP, 2005), consent to treatment: standards in care homes (DH, 2004a), social exclusion (SEU / ODPM, 2006) and so on.

Voluntary organisations have based campaigns around the idea of dignity in care (Help The Aged and Royal College of Nursing, 2000), and the Wanless Social Care Review (Wanless, 2006) uses the idea of dignity as one factor explaining the relative fairness of different funding systems. Codes of conduct for health and social care practitioners aim to preserve dignity.

In the international field, the World Health Organisation has called for healthcare systems which promote dignity:

‘The standard equation of ideas used by international agencies is well known: Respect for Persons = Autonomy + Confidentiality + Dignity’ (Horton, 2004)

Research has analysed dignity in care – the term itself, what it means to older service users and their carers, and the care professions working with them, and what the implications are for care of all kinds.

2. What 'dignity' means

Despite being widely used and discussed, dignity has seemed a difficult term to pin down. It is often linked with respect from others and with privacy, autonomy and control, with self-respect and a sense of who you are. Threats to dignity have been identified with a very wide range of issues: with how you are addressed; with having to sell your house to pay for long-term care; with the kind of care patients receive at the end of life; or with inadequate help to clean or maintain your home. And the impact of factors linked to disadvantage and discrimination of all kinds further complicate the picture.

The provisional meaning of dignity used for this practice guide is based on a standard dictionary definition:

A state, quality or manner worthy of esteem or respect; and (by extension) self-respect. Dignity in care, therefore, means the kind of care, in any setting, which supports and promotes, and does not undermine, a person's self-respect regardless of any difference.

Or – as one service user put it more briefly:

'Being treated like I was somebody'.

(PRIAE/Help the Aged, 2001).

Aspects of dignity

Building on a long tradition in medical ethics, nursing research has explored and tested the concept of dignity. Analysis of existing literature from the UK, the rest of the EU, the USA and Australia has provided some clear themes. One article in the nursing press (Haddock, 1996) concluded that dignity depended both on the interaction between an internal sense of identity and self-esteem, and the external respect with which a person is treated by others. A nurse is able to maintain and promote dignity by treating patients 'as valid, worthy and important at a time when they are vulnerable'.

A study by Jacelon and colleagues (Jacelon et al., 2004), based on a literature review and focus groups with older people, found that dignity was widely seen as somehow reciprocal: behave with dignity, and you are more likely to be treated with dignity. But it was also an inherent part of being human:

'It doesn't have to be an educated person: just being a human being we have worth. Every person has this basic value, and that value is dignity'

(Focus group member).

Another concept analysis, by Griffin-Heslin (2005) finds all the characteristics of dignity listed above, and adds a set of 'defining attributes' – aspects of a person's situation which tell you that dignity is present:

- respect
- autonomy
- empowerment
- communication

A wide range of other aspects are listed under each attribute, including privacy, choice, self-esteem and taking time with the person.

The Dignity and Older Europeans study

Dignity and Older Europeans (DOE) (Cardiff University, 2001 – 2004) – a three-year international study involving researchers from six countries (Spain, Ireland, Slovakia, Sweden, France and the UK) – was funded by the European Commission. The first phase of the project involved a review of relevant philosophical and professional literature. The research team identified four 'types of dignity' on the basis of this review (see box) and were then tested in a series of studies in each of the countries involving older people, people of all ages, and health and social care professionals.

The four types of dignity identified by the DOE research team:

- merit
- moral status
- personal identity
- the universal worth of human beings
(Menschenwürde)

Nearly 400 older people were involved in focus groups and interviews (Bayer et al., 2005), and there was 'substantial agreement' across the partner countries about the

significance of dignity: 'Dignity was seen as a relevant and highly important concept which, if maintained, enhanced self-esteem, self-worth and well-being'.

Older people across Europe identified three key themes:

- **respect and recognition**, broadly similar to the 'internal' and 'external' aspects described above
- **participation**, linked to views about autonomy and equality, choice and control
- **dignity in care**, including the importance of maintaining independence, being fully informed, and of fighting ageism

'It is in care that human dignity is consolidated... You feel more valued, when someone takes care of you.'

Focus group member, France

Other major issues included staff and family attitudes, and patronising and disrespectful ways of addressing older people; the embarrassment and humiliation caused by exposure and the denial of privacy; and the importance of treating people with dignity when they were dying, and of respecting 'living wills'.

In the discussions and interviews with older people, research team members found that of the four types of dignity identified, the last two – relating to personal identity and universal human worth – were the most often mentioned.

Similar but not identical results were reported by Woolhead and others (Woolhead et al., 2004), following analysis of the UK data alone. The 72 older (aged 65+) British people also confirmed the importance of dignity, although it was easier to describe its absence than its presence. Findings fell into three categories:

Dignity of identity Issues here concerned maintaining self-respect, which could be undermined by disrespectful address or labelling; by neglect of patients' appearances and clothing; by exposure, lack of privacy in personal care, and mixed wards. Dignity was put at risk by suffering, and dying with dignity involved control of suffering, maintenance of a 'respectable' appearance, and not dying alone.

Human rights participants emphasised the intrinsic dignity of all human beings, and the importance of being treated as an equal, regardless of age. Older people want to choose how they live, and how they die (for example, through the use of living wills): 'euthanasia was highlighted as an example of the right to end a life deprived of dignity'.

Autonomy Participants wanted to retain independent control over their lives for as long as possible. Some felt that resisting the inevitable – nursing home care, for example –

was itself undignified. For those who had accepted the necessity of nursing home care, their priorities shifted to maintaining their dignity by being helped to remain clean and tidy.

Other parts of the Dignity and Older Europeans study provide the opportunity to compare the views of older participants with the general public:

More than five hundred people in the six countries, aged between 13 and 59 years, took part in focus groups and discussed their views on old age, and caring for older people. Once again, 'dignity' emerged as an important element in older people's lives, which lack of time and resources could undermine. Many participants had negative views of the health and social care available to older people (Stratton and Tadd, 2005) and with professionals involved in caring:

In interviews and discussion, providers of care came up with definitions of dignity which were broadly similar to those of service users, and agreed that dignity and respect were important for people of all ages. However, the standard of care was not always what it should be. Levels of training, staff and other shortages, and lack of time were all cited as reasons for dignity becoming a low priority. Others believed the 'system' was to blame – an emphasis on performance targets was discouraging staff from providing personalised care.

'There is a great pressure of time getting things done and it is because of what the system values, which is getting off trolleys, getting them sorted out quickly, getting them through quickly and not being delayed – it's a factory'

(Focus group member).

Another participant said: 'It's very easy to focus on problems, rather than people'

(Calnan et al., 2005).

The study produced a number of policy and practice documents, all of which can be found on the Dignity and Older Europeans study website.

Autonomy, privacy and informed consent

Another EU-funded study (Scott et al., 2003a) explored the meanings of patient autonomy, privacy and informed consent in five countries. One part of this looked specifically at the views of older people who were living in long-term care homes in Scotland, and compared them with the views of nursing staff. The study found significant differences of view on the extent to which patients were given enough information on some topics, and on patients' opportunities to take decisions about their care. On privacy, the evidence was mixed. Encouragingly, both nurses and patients

agreed on the importance of privacy, and there was strong agreement about the extent to which privacy was protected in some situations. But in others – for example, in relation to protecting privacy while giving an enema – nurses felt that they successfully protected privacy, but patients disagreed. There was also disagreement about informed consent. In general, nurses reported that they were satisfied that informed consent had been sought and given in appropriate situations. Patients were much less certain that this was the case.

The meanings of dignity: a summary

This section has brought together a range of ideas derived from research and policy documents about how dignity is seen and described by older people, their carers, practitioners and analysts. The validity of the research depends, of course, on the extent to which all potential shades of opinion and cultural difference are represented among the people interviewed. Despite some gaps in the research and identified differences of emphasis depending on ethnicity and extensive research in the EU and the USA has uncovered a number of consistent overlapping themes, as summarised in the box.

The meanings of dignity

Research with older people, their carers and careworkers has identified four overlapping ideas of dignity:

Respect, shown to you as a human being and as an individual, by others, and demonstrated by courtesy, good communication and taking time. (1)

Privacy, in terms of personal space; modesty and privacy in personal care; and confidentiality of treatment and personal information. (2)

Self-esteem, self-worth, identity and a sense of self, promoted by all the elements of dignity, but also by 'all the little things' – a clean and respectable appearance, pleasant environments – and by choice, and being listened to. (3)

Autonomy, including freedom to act and freedom to decide, based on clear, comprehensive information and opportunities to participate. (4)

Footnotes

Birrell et al., 2006, Davies et al., 1997, Woolhead et al., 2004, Woogara, 2005, Calnan et al., 2005, Bayer et al., 2005

Woolhead et al., 2004, Turnock, 2001, Woogara, 2005, Street and Love, 2005, Randers and Mattiasson, 2004, Birrell et al., 2006, Jacelon, 2003, Scott et al., 2003a

Birrell et al., 2006, Furness, 2006, Jacelon, 2003, Afshar et al., 2002, Arino-Blasco et al., 2005, Franklin et al., 2006, Woogara, 2005, Commission for Social Care Inspection, 2006

Davies et al., 1997, Randers and Mattiasson, 2004, Scott et al., 2003a, Hickman, 2004, Clutterbuck and Mahoney, 2003, Bayer et al., 2005 This needs to go back to editor – you don't have footnotes in your house style so this needs to be correctly referenced]

3. What protects dignity?

Resilience

Studies have found that the inner strength and resilience of many older people enables them to bear situations which others might find challenging or disabling. Researchers in Sweden (Franklin et al., 2006) interviewed a group of very elderly people (aged 85+), living in nursing homes and nearing the end of life. Taped conversations based on questions about the residents' past and present lives, and views about their future revealed three consistent themes. The first two related to very negative aspects of their situation: 'unrecognisable' bodies, and dependency or fragility. Both undermined their self-respect and dignity, often as a result of the attitudes of others.

When I lost my hearing, people started to ignore me. They didn't treat me as a human being any more and then when I lost my eyesight, there was nothing left.'

'They never have time for us here, not even to say a word: it's like we are nothing.'

Study participants

But the third theme demonstrated that a sense of self-worth, coherence and meaning was strongly maintained by many of the older people despite the sometimes grim aspects of their daily lives. References to their families and their previous lives, a focus on small pleasures, and finding ways of 'being needed' all helped. Other people – especially family members, but also key staff – reinforced this strength, and enabled them still to enjoy life.

Research with older people who were admitted to acute hospital care in the USA (Jacelon, 2003) also found that they developed strategies for resisting the demoralising effects of their situation. These involved maintaining a 'positive attitude'; managing how they appeared to staff – for example, by deliberately 'not bothering the nurses'; and supporting their sense of worth by consciously reviewing their previous lives and achievements.

These and other studies make the point that resilience can be reinforced or undermined by the practice of health and social care workers; and that the existence of this quality in older patients should not be used as a reason for underestimating the very real threats to their self-esteem and well-being in some care settings.

Rights

Older people receiving care at home, in hospital or care homes have a wide range of rights, and some analysts (Townsend, 2006) see the enforcement of these rights, and

increased insistence on them by service users, as the best way to overcome embedded systems and outdated attitudes. They include the following:

The Human Rights Act 1998, which incorporates the European Convention on Human Rights into English law, protects all citizens from action by public authorities which threatens their fundamental freedoms. These include freedom from 'degrading' treatment, which affects the person's human dignity (Article 3), and from arbitrary detention (Article 5). Article 8 also protects a person's private life, including 'his home and correspondence'. Although 'human dignity' is not explicitly mentioned in the Convention, the High Court has held that it is implicit in almost every one of the Convention's provisions (High Court of Justice, 2003) Independent care providers are not subject to the Act, but when care is purchased from an independent provider on behalf of an older person by a council, it has the duty to guarantee the person's human rights (for example, by monitoring the contract) (High Court of Justice, 2006).

Older people with mental health problems have the usual protections provided under general Mental Health legislation (currently waiting for amendment), and questions of 'capacity' are covered by the Mental Capacity Act 2005. Proposals have been published for strengthening the rights of people in hospitals or registered care homes who suffer from dementia or profound learning disabilities, which the Bournemouth case (DH, 2006)

- http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4136790 – by amendments to the Mental Capacity Act. Under these proposals, whenever hospitals or care homes find that a person who cannot argue for themselves is being effectively detained, or is at risk of it, they must apply for permission for the current treatment programme to continue and demonstrate that it is in the patient's best interests. The agency which controls permissions will arrange for assessors to establish what is in the patient's best interests, taking account of the patient's and their carer's views. Where a patient has no representative to ensure that the recommendations of the best interests assessor are carried out, an independent advocate will be appointed.

Regulations made under the Care Standards Act 2000 protect the privacy and dignity of older people receiving care in their own homes or in care homes, for which there are national minimal standards (DH, 2003) –

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4067778.pdf - and they are protected from abuse by the Protection of Vulnerable Adults Scheme (DH, 2006b).

From October 2007, the Commission for Equality and Human Rights will have the duty to combat age discrimination, made under the Equality Act 2006.

There is evidence that older people – especially the very elderly – may not be aware of these rights (Harding, 2005); advocacy may have an important part to play here (Wright, 2006). Many care staff also remain unaware of them (Woogara, 2005). But inspection and research have also found that the framework of rights is gradually having some impact on standards of care, and next and subsequent generations of older people may

increasingly demand them (Woolhead et al., 2004, Stratton and Tadd, 2005).

Person-centred care

Person-centred care – care which empowers, includes and puts the individual needs and aspirations of the service user at the centre of planning – has been the subject of much policy, research and comment. Person-centred planning was first identified with the reform of care for people with learning and physical disabilities in North America, and has gradually been adopted for other groups of service users. Some of its principles appeared in community care policy in the UK as early as 1989 (Dowling et al., 2006). More recently, it has been linked to debates about choice and quality in the NHS; about direct payments and individual budgets as a means of supporting people with a range of care needs; and about the promotion of dignity, privacy, respect and autonomy throughout the care system.

Putting the commitments about person-centred care made in law and government policy statements into action has involved campaigns to change practice, change attitudes and promote new ways of working. One of these – Essence of Care - http://www.cgsupport.nhs.uk/PDFs/articles/Essence_of_Care_2003.pdf - launched in 2001 and revised two years later (DH, 2003c) – was intended to embed good person-centred practice in the care of NHS patients. It is organised around ten key themes or 'benchmarks'.

The table below shows the factors which were identified as important, in consultation with patients, carers and professionals, when it comes to privacy and dignity. Although designed mainly for use in the NHS, many of the aspects of dignity in care generally discussed in this practice guide feature in the table.

Benchmarks for privacy and dignity

Factor	Benchmark of best practice
Attitudes and behaviour	Patients feel that they matter all the time
Personal world and personal identity	Patients experience care in an environment that actively encompasses individual values, beliefs and personal relationships
Personal boundaries and space	Patients' personal space is actively promoted by all staff
Communicating with staff and patients	Communication between staff and patients takes place in a manner which respects their individuality
Privacy of patient – confidentiality of patient information	Patient information is shared to enable care, with their consent

Privacy, dignity and modesty	Patients' care actively promotes their privacy and dignity, and protects their modesty
Availability of an area for complete privacy	Patients and carers can access an area that safely provides privacy
Privacy = freedom from intrusion	Dignity = being worthy of respect

From *Essence of Care*, 2003

Research into the extent to which the dignity benchmarks were being met in three NHS hospital wards in 2002 (Woogara, 2005) found that they were not met by health professionals, and the 'little things' which would protect the patients' privacy and dignity were often forgotten.

Another article (Birrell et al., 2006) reports on a privacy and dignity project launched at a major NHS hospital – Addenbrooke's – in 2001, led by the palliative care team. Patient and staff views on privacy and dignity were collected by interview and questionnaire, followed by 'specific and prompt' action:

For example, when patients identified that they preferred being wheeled to the toilet rather than using commodes, more wheelchairs were purchased. This enabled staff and patients to see that their views were being acted on, and that the team produced tangible outcomes.

The project led to the development of a local guide, which translated patients' worries about privacy and dignity into practical and detailed instructions for care staff. The guide was expanded and extended throughout the trust; and five years later, the project is still under active review and development. Locally defined Addenbrooke's Standards for privacy and dignity, linked to the *Essence of Care* benchmarks, were agreed in January 2005, and formed the basis for a practice audit later that year. The audit found much good practice, but also specific areas for improvement, which led to a range of recommendations and the development of targeted projects within the hospital (McIntyre and Woodruff, 2006).

Another study (Innes et al, 2006), involving a literature review as well as consultation with discussion and focus groups of service users (including older people), focused on the role of frontline workers in promoting a person-centred approach to community care services. It found a number of barriers in the way of person-centred care including: increasing bureaucracy, tighter budgets and restrictive commissioning leading to limited staff time for flexible, personal care; poor and inconsistent management, and a mixed picture on training. These barriers were made even worse for service users and staff from black and ethnic minority backgrounds by language and cultural factors as well as discrimination

4. And what threatens dignity?

Many of the threats to dignity take place at a small-scale, practical level. These can involve, for example:

- treating adults 'like babies' because of actual or assumed incapacity – giving them mashed food, insisting on early bedtimes, using patronising tones of voice
- apparently small slights such as the imposition of leisure activities that imply a low intellectual level
- care which treats people as objects, or language which labels them as 'conditions' or problems
- poor environments and dirt
- never stopping for a conversation, or taking time to get to know service users as real people
- disregarding grief at bereavement among very old people, who see their circle of friends, relatives and companions shrink.

Older people raised all of these with researchers as factors undermining dignity.

Some of these certainly have their roots in the quality of management, training, supervision and leadership. Remedies have repeatedly been suggested which emphasise these factors. But some commentators (Macdonald, 2001) have seen the need for deeper analysis and more fundamental change. Increasingly, research and policy has begun to focus on the nature of society and on a series of interrelated factors which act as barriers to dignity in care.

Ageism

Ageism is prejudice against people purely on grounds of age – based on what one psychologist (Nelson, 2005) has called 'fear of our future self'. Despite age being the third automatic common category into which we slot strangers (the other two are race and gender), relatively little is known about the origins of ageism. The tendency to view a patient as less than human has been identified with a need to defend oneself against the anxiety which their condition provokes (Menziez, 1977).

None the less, ageism and the age discrimination which follows from it were becoming common features of access to some NHS treatment and social care during the late 1990s. Older people might be refused treatment or care which a younger person could expect because of a number of factors, including:

- tight budgets, leading to locally defined systems of 'rationing' according to age

- embedded routines with discriminatory effects, including ways of defining the benefits of a particular treatment (for example, quality-adjusted life years (Sayers, 2002, King's Fund, 2000))
- ageist attitudes which might, for example, lead care managers to assume that a 'more restricted kind of life' was suitable for anyone over 65.

In the National Standards Framework (NSF) for Older People's (2001), the government announced its determination to 'root out age discrimination'. Formal barriers to NHS treatment based on age were removed; procedures followed by the National Institute for Health and Clinical Excellence (NICE) were amended to ensure that access to treatment should be based on individual need rather than age; and 'older people's champions' were appointed to defend the rights of older people in a range of contexts, including the NHS. A review of progress in 2004 (DH, 2004b) found evidence of changing attitudes and practice. Older people's access to non-urgent care as well as treatment for heart conditions and for cancer has been transformed since 2001, and older people's involvement in activities designed to prevent disease has grown.

More recently, a national report on services for older people (Commission for Healthcare Audit and Inspection, 2006), tested against the NSF standards, also found good progress but some remaining unacceptable weaknesses:

- explicit age discrimination is less common except for mental health services for older people
- poor treatment related to ageist attitudes was reported by some respondents
- some service gaps affect older people disproportionately, e.g. transport and dental care
- the impact of older people's champions is difficult to assess
- a good range of services is less likely in rural areas
- diversity issues are only just being tackled in relation to older people's services.

Despite marked changes for the better in relation to explicit age discrimination, the report notes evidence of ageism among staff across all services. This ranges from patronising and thoughtless treatment from staff to the failure of some mainstream public services [reflecting a] deep-rooted cultural attitude to ageing, where older people are often presented as incapable and dependent ...'

Perhaps most seriously of all, the three inspection commissions found that 'one of the reasons why some people said they would not complain was the fear that this would affect the treatment that they or their relatives received. This fear was highlighted repeatedly in the inspections.'

A bald statement of what ageism is does little to convey the impact that ageist attitudes and practice can have on older people. It contributes to the sense of being treated as 'nothing', as one study participant described it. It undermines resilience, attacks self-esteem, promotes despair, and increases the climate of fear. All of this argues for much further effort.

Inequality, disadvantage and discrimination

The effects of ageism and age discrimination may be multiplied in a range of ways which reflect society's approach to individuals' characteristics and the impact that these have had on their lives. These include social class, gender, relative poverty, ethnicity, physical and learning disabilities and sexual preference. Older people, like all people, may encounter prejudice, discrimination and exclusion because of any of these factors. They may confront old age already suffering from disadvantages which threaten their sense of autonomy and self-esteem. Or they may simply encounter service providers who are unable to understand or fully meet their needs.

The inspection (Commission for Healthcare Audit and Inspection, 2006) also reported that more work is 'required to ensure that older people from black and minority ethnic groups receive services which are culturally sensitive and responsive to their needs'. In 2004, the Joseph Rowntree Foundation's race and equality advisers organised a series of meetings with black older people in Leeds, Bristol and London, as part of JRF's Older People's Programme. The aim was to review with them existing research on black older people, and discuss future work: 'It was an uncomfortable fact, but mainstream services and mainstream society were still seen by the older people in the groups as being both ageist and racist. They said it was impossible to ignore this fact ...' (Butt, 2004).

An initial review of literature by the Joseph Rowntree Foundation had established what research had found about older people from black and minority ethnic groups: their increasing numbers and proportion in the population; their considerable health and social care needs; their relatively low knowledge and use of services; their relative poverty and poor housing; and myths about the extended families who will care for them when necessary. Cultural differences and needs were not met by mainstream services – including basics, such as food – but also religious beliefs and practices, and views on health and well-being. At the same time, older people from black and minority ethnic backgrounds shared the barriers and problems confronting all older people.

One small study (PRIAE/Help the Aged, 2001) which had looked at the experiences of black and minority ethnic older people in hospital focused on their views of dignity. The service users and the managers responded to direct questions about dignity with definitions that were similar to each other, and similar to definitions found in studies already discussed:

- being treated equally and with respect
- being listened to

- self-respect, 'honour' and appropriate care
- privacy, dignity in personal care, and single-sex wards.

But the priorities listed by these service users in terms of barriers to dignity were not identical with those found in studies of the general population:

Food came top of their list – not just food preferences, but also the hospital's difficulties in providing special diets.

Communication was another priority, made acute by the lack of interpreters, and the apparent inability of staff to cope with 'ethnic' accents or forms of speech.

Staff insensitivity and racism came next, especially in relation to religious needs, and coupled with the more common complaint about respectful forms of address. And finally, bureaucracy, staff shortages and poor standards of care were all listed as contributing to the sense that the patients' dignity was at risk.

A study of quality of life and well-being among older women from a wide range of backgrounds, part of the Economic and Social Research Council's Growing Older Programme (Afshar et al., 2002), found that health was the most important issue, with the corollary that 'services need to be ethnically, religiously and linguistically sensitive'. It concludes that 'good policy and practice would build on what women themselves see as significant in enhancing life quality'. The study argues for very detailed analysis of what this means for different groups in the population. This included subgroups of the white population, since 'in multi-cultural settings, disadvantaged white non-migrant women can be excluded from the consultation process if it assumed that white people are homogeneous'.

Abuse

No secrets (DH, 2000), the guidance from the Department of Health about the protection of vulnerable adults from abuse, defined key terms and established multi-agency procedures: Abuse is a violation of an individual's human or civil rights by any other person or persons.

A consensus has emerged identifying the following main different forms of abuse:

- physical abuse ...
 - sexual abuse ...
 - psychological abuse ...
 - financial or material abuse
 - ...
 - neglect and acts of omission ...
 - discriminatory abuse
 - ...
- (*No secrets*, p9)

The guidance was developed in response to the growing sense that abuse of vulnerable adults – including, importantly, older people – was a largely hidden and under-reported but none the less important issue in health and social care. Many of the themes which emerged from the research and stimulated debate about abuse have already been mentioned as threats to dignity in care: labelling and disrespectful, inadequate communication; target- and/or routine-driven care; unequal power relations, ageism, and racism; staff shortages and poor morale (Shore and Santy, 2004).

A Health Select Committee inquiry (House of Commons Health Committee, 2004) three years later commented that the term 'abuse' covers 'an extensive continuum, extending as far as criminal activities'. The DH general definition was widely accepted by the multi-agency teams working locally to combat abuse, indicating that it chimed with what practitioners had found on the ground.

Issues raised by the select committee – the unknown prevalence of elder abuse, the collection of data, and the definition of a performance indicator – were all considered in a study by Action on Elder Abuse (Blake, 2006). This two-year project, funded by DH, has recently reported. The recommendations to the government, based on the study, include:

- establishing a national collection of data on protection of vulnerable adult referrals
- introducing a performance measure based on reduction and elimination of risk
- introducing a statutory framework for the protection of vulnerable adults.

The *No secrets* definition of a 'vulnerable adult' is someone:

who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.

(Paragraph 2.3)

Although the definition of vulnerable people in *No secrets* was felt to be problematic in some respects, it was used for the study. In welcoming the report, the government announced the allocation of additional resources to support further action against abuse.

Meanwhile, the kinds of incidents which had given rise to the guidance in the first place continue to be reported from time to time. In 2005, Skills for Care introduced a compulsory social work training module on abuse and neglect. The joint inspection commissions' review of progress against the NSF for Older People found that, although multi-agency arrangements for safeguarding older people, 'operated successfully in most areas ... there is still room for improvement' (Commission for Healthcare Audit and Inspection, 2006). They identified increased awareness among care staff of how and when abuse and neglect could occur as a critical area for further development.

5. Dignity in practice

Dignity in care and older people's perceptions of it have been treated so far as if they are constant across care settings. Of course, this is not necessarily the case, and this section highlights some of the differences identified by research.

At home

For more than 20 years, the emphasis within care services for older people has been shifting away from institutions towards services provided in the home. Less than 5 per cent of older people end their lives in care homes. Not everyone needs support, of course – in 2002, more than 60 per cent of people aged over 80 in England reported no difficulties with specific activities of daily living. But many are supported in their own homes by the army of informal carers, as well as domiciliary services and home-care workers provided by the state. Very recently, traditional services in the home have been joined by 'personal assistants', paid for by the service user from direct payments, or new individual budget schemes.

As people live longer, and more people remain at home, home-care workers are called on to support people with greater disabilities and more acute needs than they encountered in the past. Increasingly, local authorities purchase care services from the independent and voluntary sectors rather than supplying their own. Another trend has been for local services to be focused on older people with the most severe and complex needs, with limited funds available for small-scale services (Godfrey et al., 2000). All these developments should be seen within the government's vision for adult social care services, which promotes independence, choice and control, and prevention. The proposed outcomes of implementing this vision include protection from abuse and discrimination, involvement in decision-making, access to information, and 'personal dignity' (DH, 2005a).

An extensive review of literature (Godfrey et al., 2000) on the effectiveness and outcomes in home-care services found 'very little emphasis on the service-user and care-giver well-being'. But there was evidence from a range of surveys which showed that the qualities most valued by older people in home-care services were reliability, continuity and the quality of the relationship with the care worker. Women especially valued housework: 'having a clean home was viewed as a key factor in maintaining their sense of dignity and self-respect'.

More recently, a key finding from the Older People's Inquiry (JRF, 2005) set up as part of the JRF Older People's Programme in 2005 was that, 'older people value "that little bit of help" to enable them to retain choice, control and dignity in their lives, but it has become very difficult for them to secure this'. The inquiry developed a range of flexible solutions, in collaboration with older people, to the problem of unmet need, including their 'baker's dozen' of 13 good ideas (JRF, 2005).

A long-term study (Patmore, 2005), designed to establish the kind of home care which

would promote well-being and choice among older people, has investigated the factors which contribute to person-centred care in the home. It found that the most common ungranted wish among older home-care customers was for help to get out of the house, to improve morale and mobility. Where person-centred care of this kind was being provided, it could be time-consuming, but some purchasers, providers or individual care workers were prepared to spend the time. The relationship between individual care worker and customer was very important, but the role of purchasers was critical. A focus on the needs and wishes of the individual depended on purchasers, providers and care staff all believing in 'caring for the whole person'.

Acute hospitals

The big difference between a hospital and the other contexts for care is that most patients can reasonably expect that their stay will be time-limited. Several studies have identified the way in which patients of all ages retain their dignity in hospital through 'necessary submission' to the power of others which leaves their self-esteem intact. One interviewed patient said: 'In terms of dignity, I have been in hospital before and I know what is expected of you. You just accept what is going to happen because you want to get better' (Matiti and Trorey, 2004). In this study, the researchers emphasise the need for care staff to understand and support patients' adjustment to hospital activities. A study of older black women in hospital (PRIAE/Help the Aged, 2001) found the same emphasis on 'getting better', which enabled the women interviewed to suspend their normal approach to dignity, in the interests of quick recovery.

But there is, of course, an important distinction to be made between hospital patients in general, and older patients. Mobility and other key aspects of independent living are known to suffer as result of stays in hospital and other institutions, which can be particularly difficult to reverse for older people. For this reason, studies of older people's experiences of hospital care (Randers and Mattiasson, 2004, Scott et al., 2003b, Jacelon, 2004) often emphasise the importance of maintaining autonomy (in activities and decisions) and independence. One small study (Jacelon, 2004) identified three stages of hospitalisation: 'Although autonomy was important in each stage, it became participants' central focus during their last phase in hospital.' Older patients interviewed in other studies resisted attacks on their autonomy and dignity in hospital by using resilience to manage their situation and maintain their self-esteem (Jacelon, 2003).

A Swedish study of ethical nursing care (Randers and Mattiasson, 2004) identifies 'delegated autonomy', resulting from providing patients with opportunities and information which enables them to delegate some activities and decisions to care staff. In addition, the identification of 'authentic autonomy' – choices consistent with the person's character – depends on full documentation of a patient's previous history, preferences and habits, and also their mental state.

Patients in intensive care (IC) may experience an even greater assault on their dignity, privacy and autonomy. Observation of practice in two IC units (Turnock, 2001) found that the dignity of all patients was maintained in only just over one-third of cases; the remaining patients were not fully screened or covered. Perhaps encouragingly, the

figures in relation to exposure improved for patients aged over 60; and by the age of 70, almost half were not exposed. Effective screening, however, declined sharply with age. Working with focus groups of staff, the researchers developed a set of remedies, and later evaluations found improvements in staff awareness and practice.

Care homes

Care homes are not temporary for residents: they are 'home' to more than 400,000 people in England. As one article on autonomy in long-term care (Hickman, 2004) has pointed out: 'Because the long-term care setting is both a residence and a place in which health care is provided, issues of autonomy take on greater significance and complexity than in hospital settings.'

Most new residents are aged over 80, and are considerably more dependent than in the past. About four in ten residents have some form of dementia (Owen, 2006). In a recent pilot study involving nine local authorities in England, 30 per cent of reported abuse against vulnerable adults took place in residential homes, and older people were the largest group of victims (Blake, 2006).

A small study of 19 care homes, carried out in 2004 (Furness, 2006), uncovered some differences between residents' and managers' perceptions of abuse. Managers' responses reflected the categories of abuse set out in 'No secrets', with the exception of sexual abuse. Of the 19 managers interviewed, 17 knew of abuse happening in either their present or previous post. When asked for examples of unacceptable practice in a hypothetical home, six of the 19 residents interviewed provided them: inadequate staff resources, ill-treatment, rough handling, poor cleanliness, dictatorial staff attitudes and inferior meals. It is impossible to make general statements based on a sample of this size, but the differences in perception, and the proportion of residents who said they would take no action if they came across abuse both argue in favour of listening more carefully and more often to what residents have to say.

The quality of life in care homes has recently been reviewed by a consortium of Help the Aged and the National Care Homes Research and Development Forum, in collaboration with older people and representatives of the care home sector. The main messages resulting from this review have been published in 'My Home Life' (Owen, 2006); a second document, containing evidence and references is forthcoming. They include several messages which are particularly relevant to dignity in care:

- Maintaining a sense of identity is key to retaining self-esteem and a good quality of life. Person-centred care will support it.
- Residents often feel that they want to be useful, and should be encouraged to use the skills and experience that they bring to the home.
- Decision-making should be shared; and assumptions should not be made about who can and cannot give their views.

The thing that would make the biggest difference is if everyone tried to imagine how they might feel when they are my age. They might understand how frustrating it is living in the body of a 93-year-old.

'My home life' makes the point that the care home should be viewed as a community rather than a domestic, family setting. One important context in which community life can be supported is at mealtimes. Meals have also been raised repeatedly in interviews with older people, in institutions of all kinds, as an opportunity to respect or undermine residents' dignity. Issues include:

- respect for cultural, religious and other dietary requirements at mealtimes
- presenting food in an attractive way, even for people who need puréed or chopped food
- supporting eating and drinking where necessary, but without humiliating the eater
- offering food at times and in contexts which are appropriate for adults in their own home.

A recent bulletin on meals in care homes, 'Highlight of the Day?' (Commission for Social Care Inspection, 2006), found that the great majority of care homes in the country met national minimum standards for meals and mealtimes; but nearly 2,000 did not. The bulletin calls for a positive experience at mealtimes; choice and flexibility; appetising food served in pleasant surroundings; and care to avoid hidden malnutrition or dehydration.

We do not expect the elderly to have anything to contribute... We think that the best way to make them feel wanted is to smile nicely, and give them 'en suite' lavatories. But, in reality, the best way to feel wanted is to feel needed.

Care of older people with mental health problems

Research (Commission for Healthcare Audit and Inspection, 2006) suggests that at least 40 per cent of older people attending GP surgeries, 50 per cent of older general hospital inpatients and 60 per cent of older care home residents have mental health problems. Around 15 per cent of older people suffer from depression and 5 per cent of people over 65 have dementia, rising to about 20 per cent among people aged over 80 (CSIP, 2005). It is estimated that 10–15 per cent of the population aged over 65 are suffering from undiagnosed and untreated depression. Despite major government programmes and advances, mental health services for older people remain problematic.

Key messages from the most recent review of progress against the NSF for Older People by the three inspecting commissions included the fact that: 'Most inspected communities were struggling to deliver a full range of integrated, good quality services

to older people with mental health needs' (Commission for Healthcare Audit and Inspection, 2006).

All aspects of dignity in care are of course relevant to older people with mental health problems, but there are additional risks and barriers facing them. In care homes, for example, food and nutrition are important issues for everyone. For a person with dementia or depression who is not given appropriate help with eating and drinking, the problem becomes critical. Abuse of older people has been found in their homes, and in care homes. But the likelihood of abuse, which has been linked to the level of 'confusion' shown by the victim, may be even greater for dementia sufferers than for other older people. Questions of information, involvement in decision-making and giving consent are of concern to all older people. Studies of 'informed consent' in care settings (Turnock, 2001) have found significant disagreement between the views of older people and nursing staff, with patients much less clear than nurses about the extent to which consent had been clearly obtained. For people with cognitive impairments or communication difficulties, problems like these may be especially acute.

The principle of 'geriatric consent' has been developed, particularly in the USA, to describe a package of techniques which enable care staff working with people with dementia to take full account of their individual and personal views and preferences: it involves 'an ongoing and potentially demanding process of actively engaging the patient in any major decisions'. The aim is to take account of the patient's long-standing values and communicate with them 'in a sensitive, respectful, unhurried manner that preserves the dignity of the person' (Coverdale et al., 2006). Similar considerations form the basis of DH's practical guide to seeking consent from older people (DH, 2004), as well the Bournemouth proposals (DH, 2006).

The extent to which people with dementia were being left behind in the development of policy and practice (designed to involve service users in individual and agency decision-making) prompted the Department of Health to fund a three-year project which reported in 2005 (Cantley et al., 2005). The project involved a literature review, a review of good practice, case studies and the development of guidance in collaboration with people with dementia and their carers, as well as voluntary and statutory agencies. Practical advice on how to involve people with dementia begins with first principles: '[involvement] should be founded on the values of personhood, relationship and citizenship, and on the principles of ethical practice'.

A four-step process to implement geriatric consent

- Identify the patient's values and preferences, to the extent that these can be determined
- Assess care plans in terms of physical safety, independence, and the patient's values and preferences
- Protect remaining autonomy by balancing the patient's values and preferences with possible adverse health consequences of implementing a care plan
- Cultivate the professional values of steadiness, self-effacement and self-sacrifice when making decisions under conditions of risk.

(Cantley et al., 2005)

'Raising the standard' (Cobban, 2004), an action research project which took place between 2000 and 2002, looked specifically at how person-centred care was working for people with dementia and their carers. They found an 'under-trained, under-managed and under-valued' workforce, ill-equipped to deal with the demands of an increasingly complex set of needs. Despite improvements to the home care available to people with dementia, resources were still not adequate to meet demand for this key service, nor to achieve a consistently high standard.

Dignity in death

Care at the end of life is of concern to everybody. Yet there is evidence that death remains a taboo subject – something to be swept out of sight (DH, 2004c) Even in palliative care, care staff will go out of their way to disguise the fact of death: 'these practices were defended on the basis that staff were protecting privacy by withholding information about the impending death from other patients' (Street and Love, 2005).

Communication about death and dying is another problem. It's a big problem because all of us are so near to death. By 90 you can't get much nearer without knowing that it's round the corner, and we need to be able to express that if we want to.

A Canadian study (Chochinov et al., 2002a) interviewed 213 adult patients, with a mean age of 62 years, near the end of life in palliative care facilities. Sixteen of them reported loss of dignity – all of them in a hospital setting. These patients tended to be younger than those with an intact sense of dignity, and reported more distress and a stronger desire for death. 'These findings accord with previous reports citing loss of dignity as one of the most common reasons doctors offer when reporting why their patients sought euthanasia or assisted suicide.' Patients identified dignity in a range of ways, but its importance to their sense of self and inherent worth was clear.

The same research team explored in detail the meaning of dignity with 50 patients facing death. Participants described a range of factors which helped to preserve dignity: retaining a sense of individual identity; continuing to function in roles which preceded the illness, as mother or grandparent; hope for the future however short the horizon; maintaining autonomy and control (Chochinov et al., 2002b).

These and other studies have found that threats to dignity include an 'unrecognisable' and unreliable body, and increasing dependency/loss of autonomy. Inner strength, resilience and a sense of self-help to protect against loss of dignity, and despair (Franklin et al., 2006).

As more people live into old age, palliative and end of life care are increasingly important aspects of caring for older citizens. Restoring dignity to death has two related elements. The first concerns end of life nursing practice. This involves supporting contact with valued family and friends while offering privacy when appropriate; and helping to preserve 'a sense of self' by controlling distressing symptoms and maintaining a pleasant environment. The importance of this environment has recently been recognised in the government's investment of £50 million in refurbishing adult hospices (DH, 2006c). The second element relates to the need of older people to have their grief at the deaths of contemporaries and companions openly respected (DH, 2004c).

6. Gaps in the research

This overview describes only a small proportion of the research and policy which is relevant to dignity in care. It is not possible, from this selection, to identify how comprehensively the subject has been studied. But researchers themselves draw attention to weaknesses in their own research and some remaining gaps:

Many of the studies which involve interviewing samples of older care users have commented that people were selected by virtue of their capacity to take part in interviews and or complete questionnaires. By definition, people with dementia, other cognitive impairments or communication difficulties have been excluded, contributing to their relative absence from 'involvement' activity in health and social care.

Men have also frequently been under-represented in these samples.

Literature which relates to aspects and components of dignity in social care exists for some groups of service users – people with learning disabilities, for example. But there is relatively little in relation to older people.

Limited research on the meaning and effects of ageism is reported, and its interaction with other forms of disadvantage and discrimination.

The amount of research about older black and minority ethnic people is greater than in other areas of research on social care, but it still overlooks some key groups and factors.

Other marginalised groups which are represented in the literature rather rarely include gay and lesbian older people.

Respect

'Respect is the objective, unbiased consideration and regard for the rights, values, beliefs and property of all people.' (Wikipedia, 2006)

The Dignity in Older Europeans study (Tadd, 2005) found that: 'Respect for personal identity is the critical aspect of dignity that has to be addressed in health and social care.' A number of issues relating to respect were highlighted in the Department of Health (DH) online survey (DH, 2006d). People expressed concerns that they were not treated as an adult or as an individual, that they were not seen as a whole person but viewed in terms of their illness or disability and that they were not listened to or given time to talk. These findings are supported by further DH evidence in *Now I feel tall* (DH, 2005b) in which NHS patients reported feeling 'isolated, overwhelmed by the experience and treated like a number instead of an individual'.

The research overview highlights a number of issues relating to respect: staff and family attitudes, patronising and disrespectful ways of addressing older people, being treated as an equal and issues relating to death and dying, such as control of suffering and maintaining a respectable appearance. The DH End of Life Care Programme (DH, 2006e) aims to improve the quality of care at the end of life for all patients and enable more patients to live and die in the place of their choice.

The research also associates ageism and other forms of discrimination with the lack of respect for older people and, clearly, there are implications here for wider society. Intergenerational community work has been suggested as one way of tackling ageism.

Respect has been summarised in terms of courtesy, good communication and taking time (Davies et al., 1997, Woolhead et al., 2004, Woogara, 2005, Calnan et al., 2005, Birrell et al., 2006, Bayer et al., 2005). In a Swedish study (Randers and Mattiasson, 2004), the identification of 'authentic autonomy' was found to be dependent on 'full documentation of a patient's previous history, preferences and habits'. Patients in a US study (Jacelon, 2004) found that 'consciously reviewing their previous lives and achievements' was a strategy that helped them to maintain a positive attitude and to 'resist the demoralising effects of their situation'. *My home life* (Owen, 2006) asserts that maintaining a sense of identity is key to retaining self-esteem. For people with dementia, reminiscence activity has been used for many years to reaffirm the identity of individuals based on their own personal history.

A small study into residential care (PG Professional and the English Community Care Association, 2006) found that: 'Residents' primary desire ... is to be cared for with respect and dignity as an individual and to hold onto their independence'. Residents emphasised the importance of staff spending time to chat with them and felt that frequent staff changes made it difficult to build positive relationships; they were concerned that care was task-oriented rather than person-centred. Another study into staff views (Calnan et al., 2005) reiterates this point: 'the "system" (whether an NHS ward or clinic, or a private residential care home) does not value issues such as dignity.

Instead they value what gets done in terms of task-oriented jobs.' The research overview found evidence from a range of surveys which showed that the qualities most valued by older people in home-care services were reliability, continuity and the quality of the relationship with the care worker.

It is clear from the evidence above that people value respectful delivery of services over task-oriented care and, getting to know people for what they are is, therefore, an essential aspect of person-centred health and social care practice.

Key points from research and policy

Being respected as an individual is very important to older people receiving health and social care services.

Older people want a workforce that is patient and takes the time to listen to individuals and does not rush care (DH, 2006d).

Getting to know service users as individuals, people with a history, is key to providing person-centred care (Randers and Mattiasson, 2004, Jacelon, 2004, Owen, 2006, PG Professional and the English Community Care Association, 2006) .

Staff respect for service users and their carers and relatives is enshrined in Standards for Better Health; this also encompasses respect for people's diversity (DH, 2004e).

The Essence of Care benchmarks for privacy and dignity are based on the need for respect for the individual (DH, 2003c). National minimum standards for domiciliary care require that: 'The service should be managed and provided at all times in a way which meets the individual needs of the person receiving care, as specified in their care plan, and respects the rights, privacy and dignity of the individual (DH, 2003b).

National minimum standards for care homes states that: 'The principles on which the home's philosophy of care is based must be ones which ensure the residents are treated with respect, that their dignity is preserved at all times, and that their right to privacy is always observed' (DH, 2003a).

The NHS core standards require that healthcare organisations have systems in place to ensure that 'staff treat patients, their relatives and carers with dignity and respect' (DH, 2004e).

The National Service Framework next steps aims to ensure that, within five years, all older people receiving care services will be treated with respect and dignity (DH, 2006h). The report acknowledges the need for wide-reaching culture change and zero tolerance of negative attitudes towards older people.

Barriers to providing person-centred care have been identified as: increasing bureaucracy, tighter budgets and restrictive commissioning leading to limited time, poor

and inconsistent management and a mixed picture on training (Innes et al., 2006).

Practice points

Ensure that treating older people with respect is fundamental to training and induction for all staff (including domestic and support staff) and followed up by supervision and zero tolerance of negative attitudes towards older people.

Ensure that the service is person-centred and not service- or task-oriented.

Ensure that service users are asked how they would like to be addressed and that staff respect this.

For people with dementia, reminiscence activities may support the maintenance of a person's identity.

Include 'time to talk' in care plans. In residential care this may be time spent with the keyworker to discuss any concerns or plan activities. In home care this can be a vital resource for very isolated people. Voluntary organisations and befriending services may be able to provide some support in this area but the importance of staff taking time to talk cannot be underestimated.

Involve older people in service planning and respect the views of individuals by ensuring their ideas and suggestions are acted upon.

Support intergenerational community activities to tackle preconceived ideas and discrimination against older people.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Champions programme (the former Birmingham and Black Country Strategic Health Authority)

The aim of this project is to have a champion in all care environments where older people receive care. The champions, who are experienced nurses and allied health professionals, attend an intensive two-day workshop of master classes by expert speakers with a focus on addressing values, attitudes and dignity. Support is provided via resource packs, a dedicated website, mentors, a lead executive for each trust and champion network meetings. The intention is to improve care and support for older people; reduce stays in hospital; build reassurance and confidence in the care provided for older people in hospitals and other care environments; provide a proactive workforce to care effectively for a rising ageing population; and reduce the number of complaints.

Independent researchers will evaluate the Champions for Older People project and the next stage is to roll the project out to the primary care trusts and mental health trusts.

Key learning points:

- Ensure that the Essence of Care benchmarks are included in the master classes and that the sessions all relate to dignity, values and attitudes for older people.
- Ensure that key stakeholders are on board from an early stage and that a support network is in place for the champions
- Ensure that long-term sustainability is built in.

For further information contact:

Andrew Hindle, SHA Lead for Older People Services. Tel 0121 695 2562.
Email andrew.hindle@westmidlands.nhs.uk

Anti-ageism training course (Rochdale Metropolitan Borough Council)

In response to 'Rooting Out Age Discrimination' (standard 1 of the NSF for Older People), one nursing home piloted a training course focusing on anti-ageism. An experienced trainer and the 'recruits' – older people and a carer of an older person - developed the programme together. They explored definitions of ageism, issues of an ageist society and their own attitudes and feelings about getting older. They were also asked to think about their own care responses and how they would use this training and awareness to change their own practice. The manager of the home fully supported the initiative and felt the training had had a positive impact.

Key learning points:

- Although a care team may be working together they do not necessarily share the same views – the pilot showed there were many differing views within the team.
- Full support from the home manager is essential.
- Recruit volunteers from as many groups as possible: the project demanded a time commitment and many older people are busy, and while supportive of the project could not commit to the whole process.
- There is a need to pay people the going rate to be involved in such projects, People needed to be encouraged to claim what they were entitled to, but sometimes benefit entitlement and paying tax can be a barrier.
- Clear selection criteria need to attract older people who have particular skills and experience.

For further information contact:

Rowena Vickridge, Joint Strategic Lead, Adults and Older People, Adult Care Services.

Tel 01706 925383. Email rowena.vickridge@rochdale.gov.uk

Learning from patients (Royal Surrey County Hospital, Guildford)

The older people's champion and the manager of the Surrey 50+ Network invited members of the Surrey 50+ Network to meetings on four topic areas: environment, training, communication and telling their story. Members acting as 'mystery shoppers' explored all areas of the hospital and made recommendations for improvement. Eight people also recounted their stories as patients. Problems were identified in the following areas: mealtimes; cleanliness; sensory impairment; patient information; personal dignity; and the environment. A number of solutions were achieved, for example modified training and induction for staff; front hall design was influenced by the group, and signage and notice boards have been made clearer. Members are now also involved in reviewing patient information leaflets. This project marks the beginning of a partnership between older people and hospital staff built on mutual respect and a growing awareness of the complexities of hospital service delivery.

Key learning points:

- Often, minor changes can have a huge impact on patient at minimal cost. Frequently the solution to patients' concerns is about delivering a service differently – not necessarily about spending more money.
- Keep the concerns in the picture but make working on solutions the focus.
- Active user participation requires commitment to make it real engagement.
- Staff were committed in principle but require the support and drive from senior management in order to make progress.

For further information contact:

Mary Foster, Manager, Surrey 50+ Network. Tel 0208 541 8594.

Email: mary.foster@surreycc.gov.uk

Person-centred care (Birmingham and Solihull Mental Health Trust)

Staff use a person-centred care (PCC) position statement, based on the work of the late Tom Kitwood (a leader in the field of dementia care whose goal was to see widespread practice of person-centred care for people with dementia). This covers:

- value people with mental health needs and those who care for them
- treat people as individuals
- acknowledge life experience
- provide a positive social environment.

Senior staff undertake regular 'quality visits'. They walk the wards, scrutinise the patient environment and, if areas for improvement are noted, ensure an action plan is implemented. Staff are supported with regular person-centred training days, focus groups for carers, patients and staff are listened to and complaints are examined closely to see what themes are emerging. As a consequence, the service can produce a range of evidence-based interventions and evaluations of how their constant search for improvement in person-centred care is benefiting patients.

For further information contact:

Linda Playford. Email Linda.Playford@bsmht.nhs.uk

Steps towards greater dignity (Derbyshire Mental Health Trust)

The trust has implemented Life History Work/Diaries, led by person-centred link nurses and taught by a dementia care specialist. This considers what people would like and how they would like to be treated, including invasive treatments and procedures and how to alleviate any distress. They also use Dementia Care Mapping, a validated tool which is able to identify illness/well-being for patients who may not be able to verbalise their thoughts. The trust has also introduced customer care into their induction programme and a specific customer care training day that looks at attitude, and maintaining privacy, dignity and modesty of all client groups

For further information contact:

Kim Shield, Essence of Care Coordinator. Tel 01332 362221 ext 3783.

Email kim.shield@derbysmhservices.nhs.uk

Assessing standards (Dorset and Somerset Strategic Health Authority)

The SHA has developed an audit tool (145kb MS Word file) which aims at achieving high standards of patient dignity and putting patient experience high on the agenda. The audit tool is a template covering five key themes

- patient environment
- privacy, dignity and modesty
- communication with patients
- promoting individual needs
- staff training.

It also contains a score card so progress can be monitored and lapses can be picked up quickly and acted upon, using an action plan template.

For further information contact:

Sharon Waight, NHS South West. Tel 01935 384111.

Email Sharon.waight@southwest.nhs.uk

Palliative care support (Macmillan Cancer Support/Greenwich Teaching Primary Care Trust)

Greenwich Macmillan Palliative Care Support Service (funded by Macmillan Cancer Support and Greenwich Teaching PCT) aims to maximise choice for patients at the end of their lives, allowing them to die at home, if that is their wish, in maximum comfort and with maximum dignity. It also offers support to carers. The service operates 24 hours a day every day of the year, with a high level of flexibility to meet the needs and wishes of patients and carers, which can vary from day to day. There are three elements: daytime service, overnight sitting service and pop-in service (providing 15-minute checks through the night). The small, dedicated team of support workers from Greenwich Council are specially trained in health-related care and support for terminally ill patients, such as catheter and stoma care, pressure sore management, minor dressings, medication prompting, blood glucose monitoring, urinalysis, mouth care and peg feed care. They get to know the patient and carer very quickly and work at least 30 hours a week, to provide continuity of care. There has been very positive feedback and a formal evaluation is in progress.

Key learning points:

- Provide support 24 hours a day, seven days a week to ensure maximum flexibility to patients and carers; this is the key to enabling patients to die at home if this is their wish
- Set up a specialist training programme before the service/new workers start
- Training should include topics that cross the health/social care divide, such as care of the dying at home and after-death support, clinical communication skills, medicine management, spiritual diversity support, cultural diversity awareness, OT and physiotherapist support, and diet
- Spend time in local hospice as healthcare assistants and with district nursing staff visiting patients in their homes
- Use a small team, all working at least 30 hours a week – this makes continuity of care much easier
- Establish a cross-agency steering group from the start, to enable good links to develop with the PCT continuing care nursing team, community specialist palliative care team, district nursing service and local carers' centre
- Monitor demand – be ready and able to re-allocate hours between service elements if possible

- Set up a single point of access to service – provided in this case by the PCT continuing care nursing team
- Support the support workers – this is a very demanding service. Provide intensive line management support (24/7 if necessary), team meetings and external counselling. A rota of four days on three days off allows workers to recharge their batteries

For further information contact:

June Williamson, Macmillan Palliative Care Support Service Co-ordinator, Greenwich Homecare. Tel 020 8921 2349. Email june.williamson@greenwich.gov.uk

Life Story books (St Pancras Hospital, London)

The Evergreen Unit at St Pancras has developed Life Story books to support and inform the care they give to their patients. Where patients are able to contribute they do, but many have cognitive impairment and difficulty with verbal communication, so relatives are key in providing the information and are actively encouraged to be involved in completion of the books. The Life Story books help staff to engage with patients who have complex needs and are used to inform many aspects of care planning, from personalising bedrooms to meeting personal needs in a way that respects the person's wishes and promotes their dignity. The books, which were developed by the staff on the unit including nursing staff, occupational therapists and the psychologist, are also a guide to providing meaningful occupation. All new staff are taught how to use the books during their induction process. The books are given to the relatives/next of kin when the person dies and these have been welcomed as a 'nice reminder' of the person.

For further information contact:

Colin Owen, Email colin.owen@camdenpct.nhs.uk or Judith Greening, Email Judith.greening@camdenpct.nhs.uk

Catching memories (Lincolnshire County Council (LCC))

Heritage Services is training a representative of each of LCC's older people residential care units in reminiscence skills. In addition, Heritage Services are helping the representatives to facilitate reminiscence group meetings, for which they supply articles and memory joggers to encourage members of the group to talk and reminisce.

For further information contact:

Sheila Sibbons, Unit Manager, Adult Social Care. Tel 01522 750889. Email Sheila.sibbons@lincolnshire.gov.uk

'Let's respect' resource box (Department of Health)

Launched in October 2006 as part of the Let's Respect campaign commissioned by the Department of Health, the box contains powerful images and uses case studies to

provide information and practical suggestions on how to better meet the mental health needs of older people, focusing particularly on acute care. There is also a pocket guide published by the 'Nursing Standard'. A number of boxes have been made available for acute hospital trusts, and boxes can be purchased from the social enterprise group, BlueSci. www.bluesci.org.uk

For further information contact:

Deborah Sturdy, Senior Nurse Adviser (older people).

Email Deborah.sturdy@dh.gsi.gov.uk or Nadine Schofield, National Lead for Older People's Mental Health, CSIP. Email nadine.schofield@csip.org.uk

Dignity and Respect Training Project (John Coupland Hospital, Lincolnshire Teaching Primary Care Trust)

The John Coupland Hospital Older People project team has developed a Dignity and Respect Link Trainers Project in order to establish good practice throughout the hospital. Designated trainers were identified from several departments, each of whom was given special training and materials. These trainers in turn ran sessions for staff within their own departments. All existing and new staff will participate in the training.

For further information contact:

Maria Storti, Interim Operational Lead Intermediate Care, Lincolnshire PCT.

Email maria.storti@lpct.nhs.uk

Extra Care scheme for people with dementia (Portland House, St Helens)

Portland House is a small, eight-unit, Extra Care scheme for people with dementia, where staff recognise the value of tenants, their uniqueness and their personal needs. Individuals' views are respected and accepted, providing the rights of other tenants are not infringed.

Staff take time to get to know individual tenants in order to understand their needs and gain knowledge of each person's previous lifestyle, their likes and dislikes. Care and support is agreed with each tenant and provided on that basis. A staff-tenant ratio of 1:4 and a flexible staffing structure make this person-centred approach possible.

Staff take on the role of enablers in order to promote independence in all aspects of daily life and personal care. This in turn preserves dignity and encourages feelings of self worth. Staff support tenants to develop and maintain links with local facilities, and this helps to promote social inclusion.

The combination of the physical environment, philosophy and person-centred practice at Portland House has enabled the eight tenants to maintain their skills, build confidence in their own abilities and has boosted their self-respect. Information taken from the Dignity in Housing LIN Report, 2006

For further information visit:

<http://icn.csip.org.uk/housing/>

Practice ideas from other service user groups

Enhanced pathways into care (EPiC), Sheffield

The aim of the project was to build a partnership between a Crisis Assessment and Home Treatment team and the Pakistani Muslim Centre. This would enhance access to home treatment for Pakistani service users and reduce over-reliance on inpatient services, and it would enhance the cultural appropriateness of the Crisis Assessment and Home Treatment service.

A community development worker was employed to work with a Pakistani Muslim Centre and, together with a Crisis Assessment and Home Treatment team member, saw service users at home. This constitutes a shared care operational policy, with the development worker actively identifying Pakistani service users. The Pakistani Muslim Centre also developed support services of its own for people with mental health problems.

The outcome was a managed care pathway designed for Pakistani service users, who reported greater satisfaction with services. Inpatient length of stay was reduced for 12.5 per cent of Pakistani patients, and those experiencing relapses sought help earlier.

For further information contact:

Sue Hammond, Team Leader, Project Support Unit, Department of Health.

Email: sue.hammond@dh.gsi.gov.uk

Other resources

Now I feel tall (DH, 2005b)

Now I feel tall offers practice examples on 'being talked to and listened to as an equal' and 'being treated with honesty, respect and dignity'

End of life care information and tools are available at:

<http://www.scie.org.uk/publications/practiceguides/practiceguide09/files/nowifeeltall.pdf>

What do you see?

The Greater London Forum for Older People released a 10-minute training film, 'What Do You See?' directed by Amanda Waring and starring Virginia McKenna. The film, which promotes seeing older people in a fresh light, is a powerful and evocative story and perfectly illustrates the key message that we must see older people as individuals

rather than as part of a category. This is not a free resource (funds raised go to Macmillan Cancer Relief and Help the Aged).

Positive Steps

Positive Steps is new, web-based guidance that sets out some of the key mental health issues and cultural needs for different black and minority ethnic (BME) groups, and includes lists of useful contacts and resources. It also describes some of the excellent work done for others to draw on. The Positive Steps online Supporting race equality in mental healthcare guide (www.actiondre.org.uk) was produced with the help of mental health care staff and community workers and offers advice and support for better responding to the needs of BME patients. This web-based guidance sets out some of the key mental health issues and cultural needs for different BME groups.

Communication

In order to maintain control and independence, older people need information about what they are entitled to and what they can expect from services, and they need it at the right time. The Department of Health (DH) online survey (DH, 2006d) indicated that the way in which information is communicated, and the way in which day-to-day communications take place, will have an impact on the maintenance of dignity.

Older people want to be treated with respect and part of this includes the way they are addressed and the way they are spoken to. A number of studies have highlighted concerns about 'staff and family attitudes, and patronising and disrespectful ways of addressing older people' (Bayer et al., 2005).

In a DH survey, culminating in the report *Now I feel tall* (DH, 2005b), good patient experience was seen as synonymous with 'having information to make choices, to feel confident and to feel in control'.

Essence of Care (DH, 2003c) defines communication as: 'a process that involves a meaningful exchange between at least two people to convey facts, needs, opinions, thoughts, feelings or other information through both verbal and non-verbal means, including face to face exchanges and the written word'.

In the DH survey on dignity in care (DH, 2006c) people raised concerns about acceptable levels of English among health and social care staff and a small study into care homes (PG Professional and the English Community Care Association, 2006) found that relatives of residents had concerns about the language barrier between residents and staff caused by the numbers of overseas workers.

Even where staff are fluent in English, strong accents may affect the older person's ability to understand, particularly for people with dementia, communication difficulties or hearing impairments. Difficulties with staff recruitment and retention in health and social care are widespread and the value of overseas workers cannot be underestimated, but it is important to ensure that they receive the appropriate support and training to ensure that their communication skills are adequate.

Good written communication between workers is also vital to providing a consistent service in line with service users' needs and preferences. Again, employers should ensure that workers have adequate literacy skills in English to facilitate good communication.

There may be difficulties where a service user is unable to speak English. Where there are no staff who speak the same language, translation services should be provided. Where the care is provided on a long-term basis, culturally appropriate services should be sought.

Issues of continuity - a key aspect of good communication - have also been highlighted

in relation to staff retention: 'Staff retention is important, residents feel more secure by seeing the same faces every day' (PG Professional and the English Community Care Association, 2006). In a study into the views of health and social care staff on dignity, staff raised some problems associated with the use of agency staff: '... expense, a lack of continuity of care, and a lack of interest in and personal involvement with patients' (Calnan et al., 2005).

Good communication is vital in ensuring person-centred care and this presents particular challenges for managers, in terms of recruitment, retention and training for frontline staff.

Key points from research and policy

Dignity is threatened by 'treating adults "like babies" because of actual or assumed incapacity... using patronising tones of voice'. (Research overview).

Using respectful language and gestures promotes dignity (Tadd, 2005).

Consistent assignment of workers can improve communication and facilitate the building of positive relationships between service users and staff (PG Professional and the English Community Care Association, 2006).

The national minimum standards for domiciliary care require that: 'The skills and experience of care staff are matched to the care needs of each service user and they are able to communicate effectively with the service user using the individual's preferred method of communication' (DH, 2003b).

Essence of Care gives an excellent breakdown of things to consider when communicating with hospital patients (DH, 2003c).

Practice points

- Ensure that service users are asked how they would like to be addressed and that staff respect this.
- Ensure older people are given all the necessary information on the service, in the appropriate format and, wherever possible, in advance.
- When recruiting staff, ensure acceptable levels of both spoken and written English.
- Consider the specific training needs of overseas staff.
- Where service users do not speak English, provide translation services in the short term and seek culturally appropriate services in the long term.

- Care planning should include opportunities for service users to talk with staff regularly.
- Don't make assumptions based on culture, ability or any other factor about what people want; they should always be asked.
- Ensure staff have appropriate training to enable them to communicate with service users with cognitive or communication difficulties.
- Ensure that time for proper handover of information, written or spoken, is scheduled in for staff.
- Involve older people in the production of information resources.
- Facilitate ways of getting the views of service users, such as through residents' meetings.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Getting the message across (Southampton University Hospital NHS Trust)

The trust's Essence of Care Group carried out an audit on dignity in care in the hospital to identify where further work needs to be carried out. This work is part of a two-year project, working with the local primary care trusts. As a result, all wards have been provided with colourful, graphic posters with advice to the staff on how best to communicate with patients. These include reminders on good telephone manners, tips on how to communicate well face to face and factors to bear in mind when speaking or writing to someone who has a communication difficulty, whether through a disability or because of a language barrier.

For further information contact:

Julie Dawes, Associate Director of Nursing, Tel 02380 798435.

Email julie.dawes@suht.swest.nhs.uk

Success through the Single Assessment Process (Leasowes Intermediate Care Centre, Smethwick)

Leasowes is a bespoke 20-bed unit where patients (predominantly older people) can be assessed and rehabilitated. Often, they come in with complex needs and multiple medical conditions that may have culminated in a fall and they may have had difficulty managing at home. Staff believe that the use of the Single Assessment Process enables the whole team to deliver person-centred care. On admission, patients are asked what they want to achieve during their stay. Personal details such as how the

person likes to be addressed, how they wish their privacy to be respected and issues of consent for information sharing with other organisations and partnerships are all an integral part of creating a respectful environment. The staff know that building a strong relationship with colleagues in the community ensures that good quality, person-centred services continues after the client has been discharged.

For further information contact:

Marian Long, Email marian.long@nhs.net or Ruth Clarke. Email ruth.clarke2@nhs.net

Aiding communication (Derbyshire Mental Health Services)

Essence of care activity is undertaken throughout the trust, which involves benchmarking factors of privacy and dignity for each clinical area. This includes how staff converse with patients and carers, what information is given and provides a check that it is in a format they are able to understand. As a result, the service has developed a multi-cultural tool for staff to use and reference against.

For further information contact:

Kim Shield, Essence of Care Coordinator. Tel 01332 362221 ext 3783.
Email kim.shield@derbysmhservices.nhs.uk

A multi-racial outlook (Birmingham and Solihull Mental Health Trust)

The trust has a diversity department that advises and supports staff, facilitates training and has Race Champions. Trust staff have access to interpreters for all languages who will come in and see patients and carers and will assist with assessments, consultations and ward rounds. In addition a BME (Black and minority ethnic) team offers support to patients and staff in providing cultural awareness training. There are information leaflets on wards available in a range of languages.

For further information contact:

Linda Playford. Email Linda.Playford@bsmht.nhs.uk

Facilitating dignified communication (Ashford and St Peter's NHS Trust)

The trust's Communication Group looks at how the communication needs of patients can be met. Clinical care indicators monitor the fundamentals of care and the patient communication interview, undertaken by the Patients' Panel, highlights any areas of concern or best practice in regard to patients' communication. The group has undertaken extensive work to address the communication needs of individuals, in particular those with communication difficulties, and is currently building up a supply of equipment within the trust to facilitate more effective and dignified communication. These include RNID crystal loop listeners, wipe-clean A4 boards and speech amplifiers.

For further information contact:

Harriet Stephens, Lead Nurse, Practice Development. Tel 01784 884940.

Email harriet.stephens@asph.nhs.uk

Practice ideas from other service user groups

Communicating Choice (County Durham and Darlington NHS Foundation Trust)

The Trust has introduced a range of menus in different formats to help patients who cannot communicate what they would like to eat. This includes a multi-cultural pictorial menu to suit Halal, Afro Caribbean and Kosher diets and braille menus. Deaf patients are assisted by the chef, who is a qualified signer.

For further information contact:

Alison McCree, Associate Director of Estates and Facilities. Tel 01325 743022.

Email alison.mccree@cddft.nhs.uk

'If only the experience could be different' (Luton and Dunstable Hospital Head and Neck Cancer Services)

Luton and Dunstable has taken an innovative approach to the ongoing re-design of their service, which is putting patients and staff right at the centre of the process. A project sponsored and supported by the NHS Institute for Innovation and Improvement is co-produced with thinkpublic (a service design consultancy), anthropological researchers from University College London and, importantly, patients and staff. The objective was not to solve any specific problems but to improve the experience of visiting the clinic. A team comprising patients, carers, healthcare staff, researchers and improvement leaders identified parts of the clinic process that heightened anxiety rather than reduced it, or contributed to patients' sense of helplessness. With thought, some small things could make a huge difference to the patients – for example, moving weighing scales out of sight of the waiting room: staff hadn't noticed how embarrassing patients found it to be weighed in front of everyone. The layout of the waiting room left patients facing a wall full of official notices or looking directly at others, and the number of different professionals around could be bewildering, so they are now trialling a different approach: instead of the consultants having rooms that patients move in and out of, patients now have rooms and staff move to see them. (Information taken from 'Journey to the interface', a Demos booklet.

For further information:

The Journey to the Interface: How public service design can connect users to reform

Related document:

Luton and Dunstable head and neck cancer services

The Hospital Book (Barnet Learning Disabilities Service)

The Hospital Book is a recording system developed by the Barnet learning disability team. Its aim is to help patients communicate their needs to staff who may not be used

to working with people who have learning disabilities and communication difficulties. The book holds details of the person's needs and preferences; recording, for example, food likes and dislikes or whether support is needed with personal care. The information can also be summarised on a Health Information Card, which is used as a brief version of the Hospital Book or an addition to it. You can download the Hospital Book from www.scie.org.uk

For further information contact:
Alison Pointu, Barnet Learning Disabilities Service.
Email alison.pointu@barnet-pct.nhs.uk

Social inclusion

Older people have repeatedly identified social inclusion as important to their quality of life and independence. Opportunities to participate, and make a positive contribution to community and society, are integral to autonomy and therefore dignity. In the Department of Health (DH) online survey (DH, 2006d) older people raised a number of issues and concerns including lack of social contact with others, lack of activities and wanting to feel needed and to have a purpose.

In research that formed the basis of 'A sure start to later life' (SEU / ODPM, 2006) older people 'stressed the importance, amongst other things, of good relationships with family and friends, of having a role, feeling useful, and being treated with respect'.

Age discrimination, sometimes alongside other forms of discrimination, can contribute to the social isolation of older people. The risk of social exclusion is greater for people living alone (DH, 2006f) and the very elderly (Barnes, 2006). Some life events, such as bereavement, loss of work or poor health can also increase the risk (Office of the Deputy Prime Minister, 2006).

For people living in residential care, participation in the community outside the home, as well as within it, is an important part of maintaining well-being. 'My home life' (Owen, 2006) argues that: 'feelings of helplessness and powerlessness associated with chronic disability affect motivation levels and are compounded if there is a lack of structure and meaning to the day. These feelings can be alleviated by a motivating and challenging environment with opportunities to socialise and become involved in meaningful activity.' Contact with local community centres, schools and volunteer organisations can support this, as can person-centred activity planning.

The Social Exclusion Unit (Social Exclusion Unit and Office of the Deputy Prime Minister, 2006) defines social exclusion in terms of its causes such as 'unemployment, discrimination, poor skills, low incomes, poor housing, high crime, ill health and family breakdown'. The English Longitudinal Study of Ageing measured social exclusion across the following dimensions:

- social relationships (contact with family and friends)
- cultural activities (such as going to the cinema or theatre)
- civic activities (such as being a member of a local interest group, undertaking volunteering or voting)
- access to basic services (such as health services and shops)
- neighbourhood exclusion (feeling safe in your local area)
- financial products (such as a bank account, or long-term savings)

- material consumption (such as being able to afford household utilities and an annual holiday)
(Barnes, 2006)

The following glossary definition of social exclusion summarises the above points well:

marginalisation from employment, income, social networks such as family, neighbourhood and community, decision-making and from an adequate quality of life (Kerry County Development Board, 2006).

The promotion of social inclusion features prominently in current policy across government departments. The White Paper, 'Our health, our care, our say' (DH, 2006f) acknowledges that social exclusion, isolation and loneliness can contribute to the incidence of mental illness, particularly depression. The report emphasises the need for a universal approach to inclusion from services such as transport, health and housing.

The government is clear that the involvement of members of the community with public bodies is vital to the implementation of its policies. 'Firm foundations' (Home Office, 2004) a report on capacity building, sets out a framework for development. The report defines community capacity building as: activities, resources and support that strengthen the skills, abilities and confidence of people and community groups to take effective action and leading roles in the development of their communities.

The Joseph Rowntree Inquiry (JRF, 2005) identifies: 'a need to engage locally with volunteers and like-minded organisations to tap the potential of local communities and community-development approaches'.

The involvement of older people at all levels of service planning and delivery is an important part of getting it right. In addition, the participation of older people will provide meaningful activity, community participation and a civic role for the individuals involved. The inclusion of people from diverse communities will also bring a range of knowledge and expertise to service planning and delivery. Local authorities need to ensure that support is available to local communities to enable individuals and groups to develop the skills and confidence to facilitate active participation.

Key points from research and policy

- Good relationships with family and friends, having a role, feeling useful, and being treated with respect are all important to older people (Office of the Deputy Prime Minister, 2006).
- Older people who live alone are particularly vulnerable to social isolation and

loneliness (DH, 2006f).

- Social exclusion can increase the chances of mental illness, particularly depression (DH, 2006f).
- In a long-term study of home care, help to get out of the house was the most common unmet need (Patmore, 2005).
- Over all, the elderly are more likely to be socially excluded (Barnes, 2006).
- In applying the national minimum standards for domiciliary care 'regulators will consider... how the organisation collaborates with other services/professionals to maximise independence and ensure the individual's inclusion in the community' (DH, 2003b).
- The national minimum standards for care homes require that: 'The routines of daily living and activities made available are flexible and varied to suit service users' expectations, preferences and capacities' and that 'service users maintain contact with family/friends/representatives and the local community as they wish' (DH, 2003a).
- **Practice points**
 - Promote access to social networks for older people.
 - Address transport issues that act as barriers to community participation.
 - Interlink community projects, community centres and schools to increase levels of intergenerational social contact.
 - Identify and respect the skills of older people, including those gained in previous employment.
 - Ensure people are given ordinary opportunities to participate in the wider community through person-centred care planning.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Manchester Partnership for Older People Project (Manchester Alliance for Community Care (MACC))

MACC is a campaigning organisation that wants to see an inclusive society that supports and increases the health and social well-being of people in Manchester. It facilitates the Manchester Older People's Network and encourages older people to

contribute to the planning, development and delivery of local services. The following is just one example of how older people, through the support of MACC, have an active influence.

Partnership for Older People Projects (POPPs) are government grants available for innovative approaches which will support older people to live independently, have a better quality of life and avoid the need for hospital and high intensity care. The Department of Health approved the Manchester bid in 2005. This project will develop:

- a team to provide a single point of access with support, advocacy and navigation for older people, their carers and professionals
- a team to strengthen the capacity of the voluntary sector
- a programme of grants for low-level services.

MACC believes older people should be an intrinsic part of delivering the NSF for Older People and related projects of work, and it involves service users and carers from the beginning of a process. Older people are recruited for their particular skills and experience, and have been involved with the POPP from the beginning – they were instrumental in the recruitment of the staff who now work on it, including the project manager, who is based with MACC.

For further information contact:

Mary Duncan, Development Worker. Tel 0161 834 9823. Email mary@macc.org.uk

It's good to talk (Community Network)

Some older people may be too frail to leave their home and a telephone conference call can be the only link to the outside world. The national charity Community Network aims to help organisations tackle social isolation through the provision of 'social telephony'. Local authorities and voluntary organisations have worked with Community Network to facilitate regular sessions linking up older people who are unable to get out and about as they wish due to their own frailty, mobility, location or transport issues. These Friendshiplink groups have provided a lifeline for a group of people who might otherwise be unable to have any other social interaction in the course of the week. This example of helping to overcome social exclusion comes from 'A sure start to later life' (SEU / ODPM, 2006)

For further information:

Visit the Community Network website <http://www.community-network.org/>

Over 60s project (Merseyside Fire and Rescue Service)

Merseyside Fire and Rescue has established a schools initiative that plays a key role in bringing older people to the attention of the service, as well as raising awareness of fire

safety among children. A fire fighter leads a session on fire safety, after which children are offered prizes in return for signing up older relatives and neighbours for a home safety check. In 2004/2005, 15,000 checks were made as a result of the project, almost one third of the total target number for Merseyside. This project has a strong intergenerational focus, encouraging children to make contact with older people in the community to improve the safety of their homes. From 'Good practice in services for older people' (Healthcare Commission et al., 2006)

Digging Deep

This scheme was identified in the Joseph Rowntree Foundation's Older People's Inquiry as one of the 'baker's dozen' of promising ideas to be pursued further. It involves older people teaching school children how to grow vegetables in school-based allotments. Volunteer older people tend to stay working with the school, and the scheme provides a valuable way of passing know-how down to a new generation while appreciating the knowledge older people possess.

For further information:

Visit the Older People's Inquiry: 'That little bit of help'
<http://www.jrf.org.uk/bookshop/ebooks/Briefing03.pdf>

The Sunshine Project (Help the Aged)

Help the Aged set up the Sunshine Project in order to increase opportunities for those living in care homes to make new friends. Two schemes have been taking place in care homes in the East of England: a befriending scheme and a computer training scheme. The purpose of both is to increase social contacts, reduce isolation and improve quality of life. Computer training introduced people to information technology and to using email as a means of communicating with family and friends.

An interim evaluation by a research team at Essex University was funded in partnership with the local PCT, which was interested in how the project might lessen the strain on its services. The report was very positive, concluding that:

'Findings [of the evaluation] also reiterate the importance of non-family social interactions, previously documented by studies (McNeil, 1995) which indicate that social relationships and activity per se appear to confer health benefits through psychosocial pathways. Health and social care agencies need to recognise the non-clinical aspects of ageing and work together to maximize well-being in all areas of daily life by whatever means they have at their disposal. This evaluation can be used to build an evidence base to guide ongoing work in this area.'

For a copy of the report, contact:
 Dorothy Seymour. Tel 01255 477939.

Putting therapeutic skills to work (Caterham Dene Community Hospital)

Caterham Dene has a weekly timetable of activities, and all staff have been trained in occupational therapy and physiotherapy skills through an in-house programme developed by the therapists working on the ward. The healthcare assistants, supported by the therapists, are encouraged to take on a range of activities such as recreational therapies – quizzes, craft work and exercise groups, which include chair-based exercises. There is a close working relationship with the nearby local authority residential home, and activity coordinators from there visit to assist with activities.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@east Surrey-pct.nhs.uk

In Touch (Gloucestershire Rural Community Council)

In Touch provides support and advice on services for older people in the county's rural communities. When changes in social services criteria and closures of some day centres led to loss of services, In Touch worked with older people to identify what they would miss and need after services changed. The ideas of the older people were simpler, more cost effective and more acceptable to them than the original services and led to a range of social activities in a sheltered housing complex, informal lunch clubs, and a community minibus providing trips for regular shopping and lunches further afield. Social services staff call on In Touch to make connections between isolated older people and local groups and activities.

For further information:

Visit the Gloucestershire Rural Community Council www.grcc.org.uk/

Drama: fun with a purpose (North Dorset Primary Care NHS Trust, now Dorset PCT)

To alter the image of a 'minding' service, the trust redeveloped their day care service for older people with dementia. They used 'Drama as a powerful clinical tool: fun with a purpose' as a teaching tool for staff, who have since developed activities for people with dementia and expanded community links. The many improvements include:

- a very positive environment and workforce to promote a philosophy of independence, individuality and well-being
- actively reaching the person behind the disease, communicating via drama, dolls as therapy, puppetry, music and dance
- improvement in many people's speech, confidence and self-esteem
- using drama techniques/skills and diversion with constructive occupation rather than

medication to help positive behaviour changes

- an active promotion of person-focused care.

The service has been evaluated through the use of user/carer questionnaires. It has received letters of appreciation and has won many regional and national awards including The Queen's Nursing Institute/Alzheimer's Society Award for Excellence and Innovation in Dementia Care 2003 and The Dorset and Somerset Modernisation Awards 2004. It has also been presented at many regional and national conferences.

For further information contact:

Lesley Benham, Team Leader. Tel 01305 762508.

Email Lesleybenham@dorset-pct.nhs.uk

Help with strategies and projects (Unique Improvements)

Unique Improvements works to involve people in improving services in their communities, helping to make communities stronger and improving people's lives. Unique Improvements places particular emphasis on working with people who face some of the biggest challenges. For older people it provides interactive approaches to:

- older people strategy development
- developing Partnership for Older People's Project (POPPs) bids
- evaluating POPPs
- care home development programmes
- safeguarding adults programmes.

For further information contact:

Safe and Secure in Sheffield Programme with the Home Office and Sheffield Council.

Tel 0151 480 2202 or email linda.henry@uni.gb.com

Involvement Workshop (Ashfield Community Hospital)

Mental Health Services for Older People at Ashfield Community Hospital ran an involvement workshop in July 2007. The aim was to:

- Raise the profile of mental health services for older people by presenting the service in a positive and pro-active way.

- Bring the wider community closer to the work carried out by the service and demonstrate how it works in partnership with agencies like the Alzheimer's Society to fight for the dignity of older people with mental health issues.

The workshop featured singers and small reminiscence displays, a poet and an organ grinder. People were asked to send in mementoes such as pictures, poems and coins to be mounted on giant jigsaw pieces. These would in turn be hung on the walls leading up to the inpatient wards an installation that would encourage people look back positively and celebrate an exciting and positive future.

For further information contact:

Deborah Thompson, Modern Matron, Nottinghamshire Healthcare NHS Trust. Email Deborah.thompson@nottshc.nhs.uk

Practice ideas from other service user groups

Local Care Centre Cafe (Plymouth Primary Care Trust/Mental Health Partnership)

The Local Care Centre is a new development in Plymouth that provides a range of health services for the local community. The building's foyer houses a cafe, run by local mental health service users and coordinated by a local carer. The initiative is a joint venture between Plymouth PCT, users, carers and the voluntary sector, set up to enable people with long term mental health problems to gain access to paid employment. Within the first nine months of the scheme, two people found substantive employment.

Reports from service users suggest that the opportunity to work voluntarily in a supported – yet real – work environment has improved their confidence and enabled them to consider work as a real option.

For further information contact:

David Macauley, Plymouth PCT/Mental Health Partnership.

The Haven Project (North Essex Mental Health Trust)

The Haven Project provides day and crisis services to people with severe personality disorders. Service users play a central role in shaping and running the project; in addition to forming an advisory group, 50 per cent of those on the Haven board of directors have used mental health services.

The success of the service has been impressive. There has been an 85 per cent fall in the admission of Haven Project clients to hospital and the use of A&E services is down by 60 per cent.

Hazel was diagnosed with a personality disorder nine years ago. In 2004 she was referred to the Haven project. Commenting on the help she has received, Hazel said:

'The Haven has given me a future and a life, rather than an existence. I am finally in a position where I can see a happy and useful future. The Haven is the family I never had. It's a place where I feel safe and able to explore my path to recovery.'

For further information contact:

Benedict Knox, Strategic Communications Advisor, Department of Health.

Email ben.knox@dh.gsi.gov.uk

Other resources

Digital Unite specialises in 'socialising IT' - making it relevant to anyone and everyone, but particularly those people who might otherwise get left behind in our increasingly digital world. DU has trainers all over the UK and a rolling trainer recruitment and continuous professional development programme. All DU trainers must be mature, experienced, empathic - this means they are usually also in the older age-groups. DU works a great deal within social housing where clients include residential social landlords, community groups, charities, local authorities and national organisations. The DU brochure outlines how it has helped older people feel more socially included. <http://www.hairnet.org/>

The Alzheimer's Society training pack, Yesterday, Today, Tomorrow, includes a 90-minute video/DVD and 130-page training manual providing eight training sessions. The pack has been designed to help deliver training at a time that is convenient to the home/ward/department. Session four of the pack particularly aims to guide staff working with people with dementia about why activities are important and explores the key principles in using activities. The pack is available from the Alzheimer's Society.

Autonomy

Autonomy is a key factor relating to the dignity of older people and is set within the context of human rights and equality. Dictionary definitions of autonomy include: 'the power of self direction' and 'the ability to make independent choices'. Autonomy is about freedom to act, for example to be independent and mobile, as well as freedom to decide. Control and choice over one's life and involvement - in day-to-day living and the wider community - supports autonomy and self-esteem. For example, being given support to cook a meal will help the person to remain in control and be far more rewarding and meaningful than passively waiting for staff to cook the meal. In terms of involvement in the wider community, being supported to continue with routine daily tasks such as shopping, walking a dog or going to a place of worship, as well as involvement in community activities such as social clubs, can be instrumental in maintaining a person's autonomy.

The issues of choice, control, involvement and self-determination are at the forefront of current government policy. Department of Health (DH) research (DH, 2005b, DH, 2006d) found that health and social care recipients value having information to make choices and decisions for themselves, and that feeling confident and maintaining control is important. The need to know about, and access, advocacy services was also raised. Information, advice, advocacy and support with decision-making, are all key to ensuring that older people can exercise autonomy.

Autonomy is particularly at risk where a person needs support to meet their most basic and private needs (Dignity and Older Europeans Consortium, 2004), during hospital stays (Randers and Mattiasson, 2004, Scott et al., 2003, Jacelon, 2004) and (due to the permanence of placements) in residential care (Hickman, 2004). Autonomy is more easily lost where people have impairments that affect their ability to communicate, including dementia. As one carer points out, this can have a detrimental effect for care workers as well as the cared for:

Careworkers who are bossy, over-controlling, or who scold or argue with people with dementia, are not only compromising the autonomy of the person with dementia, but are actually creating a situation in which resultant frustration, anger or self-loathing can boil over into resistant or aggressive behaviours or actual physical violence. By breaching that sense of autonomy, care workers can actually create a dangerous situation for themselves and others.

(Barbara Pointon, carer and member of Alzheimer's Society)

Direct payments (and in the future individual budgets) can offer increased independence, choice and control to users of social care services. It is important that people have the support they need to cope with the administrative and human resource management aspects of the schemes.

The issues raised here point to the provision of person-centred care, which can be achieved through enabling people to make their own decisions with regard to all aspects of their care. People want care that is driven by the person receiving it and not by bureaucratic systems, targets or staff priorities. A major culture shift is required to support the autonomy of people within the health and social care systems.

Key points from research and policy

- Autonomy is one of the key defining aspects of dignity.
- Withdrawal of respect inhibits autonomy (Dignity and Older Europeans Consortium, 2004).
- Autonomy is important to support the maintenance of skills, particularly in hospital (Randers and Mattiasson, 2004, Scott et al., 2003, Jacelon, 2004).
- There is evidence that the framework of rights within social care is gradually affecting standards (Research overview).
- Some of the reasons identified by staff for not maintaining dignity in care are: levels of training, staff and other shortages, lack of time and emphasis on performance targets (Calnan et al., 2005).
- Participation in day-to-day life is crucial; involvement in meaningful activity is closely linked to autonomy (Owen, 2006).
- The national minimum standards for domiciliary care require that: 'Managers and care and support workers enable service users to make decisions in relation to their own lives, providing information, assistance, and support where needed' (DH, 2003b). This includes ensuring that service users and their carers are informed about local advocacy and self-advocacy schemes.
- The national minimum standards for care homes require the registered manager to 'maximise service users' capacity to exercise personal autonomy and choice' (DH, 2003a).
- An addition to the NHS Essence of Care benchmarking tool (DH, 2006g) focuses on people making healthier choices for themselves through 'empowerment and informed choice'.
- Proposed amendments to the Mental Capacity Act will ensure that people with dementia, who are effectively detained in hospital or residential care, have an assessment of whether the placement is in their best interests.

Advocacy

The three key principles of advocacy are: independence, inclusion and empowerment. Advocacy services form an essential part of the inter-agency framework for the protection of vulnerable adults (DH, 2000).

A recent study by the Older People's Advocacy Alliance (OPAAL) UK defined advocacy as:

A one-to-one partnership between a trained, independent advocate and an older person who needs support in order to secure or exercise their rights, choices and interests. (Wright, 2006)

The study found that:

- older people thought awareness should be raised about advocacy
- advocacy had been used for a number of reasons: protection from abuse; combating discrimination; obtaining and changing services; securing and exercising rights; being involved in decision-making and being heard
- participants identified two sets of successful outcomes – those relating to tangible or material gains (for example, obtaining a service) and those bound up in feelings of greater confidence and self-esteem and of being better equipped to deal with life situations themselves.

Practice points

- Treat older service users as equals who are in control of what happens to them.
- Empower older people by providing jargon-free information about services at the right time and make sure it is accessible to the target group.
- Ensure that people using services are fully involved in any decision that affects their care - this should include both personal decisions on a daily basis (such as what to eat, what to wear and what time to go to bed) and decisions that relate to the service or establishment in a wider sense (such as menu planning or recruiting new staff).
- Don't make assumptions about whether people are able to make decisions or not.
- Respect time for staff to support people with decision-making as much as other practical tasks.
- Ensure that older people have opportunities to participate as fully as possible at all levels of the service, including the day-to-day running of the service.

- Ensure that staff have the necessary skills to include people with cognitive or communication difficulties in decision-making. 'Full documentation of a person's previous history, preferences and habits' will support 'choices consistent with the person's character' (Randers and Mattiasson, 2004).
- Highlight areas where practice undermines the autonomy of older people and develop strategies to redress the balance.
- In partnership with older people, develop advocacy services locally and raise awareness of them.
- Provide support for older people who wish to use direct payments.
- Encourage and support participation in the wider community.
- Involve older people in staff training.

Ideas from practice

Five factors of privacy (Southampton University NHS Trust)

The trust's Essence of Care Group, which carried out an audit to uncover areas of dignity in care that needed further work, identified five factors of privacy and dignity. Guidance was provided for all wards on the 'five factors' and they also developed a charter for patients (24kb MS Word file) informing them of the standard of care they should expect.

For further information contact:

Julie Dawes, Associate Director of Nursing. Tel 02380 798435.

Email julie.dawes@suht.swest.nhs.uk

A reassuring checklist (Burntwood, Lichfield and Tamworth Primary Care Trust)

The PCT has developed a simple checklist which is used as part of the admission procedure. This document acts as a prompt to the nurse undertaking the admission to discuss with the patient (or the carer if this is more appropriate) certain aspects that are important to the patient – for example, knowing how to call for assistance, knowing where the toilet is, and being reassured that, if the ward accommodates male and female patients, these facilities are separate. Any relevant issues can then be transferred to the care plan so this is communicated to other staff. Relatives or carers often highlight areas they are concerned about, e.g. a patient prone to falls or not being able to use a call bell. This enables the nurse to explain to them measures that will be put in place and also discuss any risks that maybe relevant. It opens up communication between nurses with patients and carers from day one, and aims to make the patient and carer feel that they are able to approach staff at any time.

For further information contact:

Dawn Llewellyn, Modern Matron. Tel 01827 263819.

Email Dawn.llewellyn@ssh-tr.nhs.uk

On the road to independence - Betty's story (Staffordshire County Council)

Betty was diagnosed with glaucoma just before her 70th birthday and, as the disease progressed, her life slowly changed from one full of hobbies and interests to one of ever more limited involvement in activities. When her husband died she realised how dependent she had become on him. A fortuitous appointment with a consultant ophthalmologist resulted in her being certified severely sight impaired, which then put the wheels of social care and healthcare in motion. A rehabilitation officer was assigned to Betty to enable her to open up a new world of independence. He gave her time to discuss her difficulties and support her. He encouraged her to accept a symbol cane to alert others of her limited vision and then to undertake a course of long cane orientation and mobility training. From one small tentative step forward Betty's confidence grew and she found herself navigating around new as well as familiar places.

For further information contact:

'Changing Lives' - Vision for Adult Social Care and Health.

<http://www.staffordshire.gov.uk/health/changinglives/>

Tapping into knowledge and experience (Westminster Children and Community Services Department, London)

A significant number of development and training courses here routinely involve older people, who share their experiences and say how they would like staff to treat them. Many older people are already experienced presenters but, if any feel anxious, personal presentation skills training can be arranged. The department has also arranged presentation and assertion skills training for groups of older people who volunteer or work in the voluntary sector. The department has also held a number of successful consultation events with older people and developed a useful Older People's Consultation Checklist. This and all development and training activities have been formally evaluated and changed in response to learners' or managers' feedback.

For further information contact:

Jane Simms, Principal Commissioning Officer, Westminster Children and Community Services Department. Tel 020 7641 2079. Email jsimms@westminster.gov.uk

Escort duty (Bucknall Hospital, Staffordshire)

Older People's Services Assessment and Rehabilitation of Complex Needs have implemented a team to support service users when an escort is needed for patients undergoing medical investigations away from the ward. It was introduced when it was realised that escort duties were depleting staffing levels on the ward, resulting in a lack of continuity of care and a longer length of stay. The team assesses the patient using a

checklist, to ensure they can meet the needs of the patient, knowing that safety, nutrition and dignity are paramount during time away from the ward. Patients say they feel safe and secure having a team member escorting them, and better informed about the expectations - as one lady said: 'The nurse told me exactly what I would have done to me and she stayed with me all the time - I felt less afraid.'

For further information contact:

Lyn Charlton, Modern Matron, Combined Health Care. Tel 01782 273510.

Email Lyn.Charlton@northstaffs.nhs.uk

Setting goals (Oldham Intermediate Care Team)

The care team are piloting a system of goal and treatment planning which was developed and introduced by one of their occupational therapists (OT), Luke Roberts. The tool is evidence-based and also provides an outcome measure loosely based on the Canadian occupational performance measure (COPM) (Law et al., 2005). On admission the patient and OT together set the goals and the patient receives a folder which contains these goals, to help monitor progress and reinforce a sense of purpose. The team intend to evaluate this method and, if successful, roll it out to other areas of intermediate care in Oldham. It is expected that this method of involving people in their own care will ensure that they feel informed, listened to and treated as an individual. The very functional approach ensures that patients are actively engaged in occupations that will restore their ability to carry out daily activities when they return home.

For further information contact:

Tracy Acton, Clinical Specialist OT. Email t.acton@nhs.net

Providing advocacy support (East Cheshire Advocacy)

If you go to SCIE's website

(<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/files/advocacy.pdf>) you can download a paper which describes how an advocate working for East Cheshire Advocacy supported a client with learning disabilities who was suffering from cancer. The example shows the importance of having someone to act on their behalf when the person is terminally ill. It also demonstrates how services were tailored for an individual with obsessive compulsive disorder when they were receiving emergency care and how instrumental using the Patient Advice and Liaison Service (PALS) can be. The advocate was able to support the person through each stage of treatment, offering advice and helping them to take decisions and also act as an intermediary between clinicians and patient.

For further information contact:

Maggie Harwood, Manager, East Cheshire Advocacy, The Moss, 4-6 Congleton Road. Macclesfield SK11 7UE. www.ecadvocacy.co.uk.

Peter's story (Advocacy Partners)

Peter's story shows how advocacy services were able to help someone with learning disabilities achieve the celebration he wanted.

Peter had recently had his 60th birthday. When asked by members of the self-advocacy group what he had done for his birthday, Peter said that staff where he lived had been busy on the day of his birthday and so he had gone out for a pub lunch with three people he lived with at the weekend. Unfortunately, the pub was not serving food that day so they just got fish and chips to eat at home. When the advocate asked about a party, Peter said he would like one, but that the staff hadn't asked him if he had wanted one. The advocacy group didn't think the staff had supported Peter well for such an important birthday. This was communicated to the service, who acknowledged quickly that they had not treated Peter with dignity and helped him organise the party he wanted, inviting his family and friends, including members of the self-advocacy group.

Peter's story highlights the importance of effective and timely communication and shows how, through joint working between the staff and the advocacy supporter, Peter was able to express his wishes and make them happen.

For further information contact:

David Thompson, Advocacy Partners. Email david.thompson@advocacypartners.org

Transport with care (Lincolnshire Teaching Primary Care Trust)

The Trust has set up a transport service, to ensure older patients not requiring hospital admission can be driven home after their visit, rather than make an unnecessary overnight stay. This service provides a responsive, needs-led wheelchair access vehicle to drive hospital patients from one care setting to another or to return them home. Working in partnership with the Discharge Rehabilitation Team in Accident and Emergency, the service transports patients safely and settles them home, with provision of a basic grocery pack. The service maintains a social care approach and perspective, putting the individual at the centre.

For further information contact:

Maria Storti, Interim Operational Lead Intermediate Care, Lincolnshire PCT.
Email maria.storti@lpct.nhs.uk

Practice ideas from other service user groups

Making a home: Zoe's Story

Zoe is a woman in her late 40s with moderate learning disabilities and enduring mental health problems. Two-and-a-half years ago she lived in a small dwelling in general needs housing stock, with no personal effects to make it feel like home. The approach adopted by staff was to control what Zoe could and could not do, and when. She

displayed extremely aggressive and challenging behaviour, including destroying windows and furniture. She was frequently incontinent, apparently using incontinence to defy staff.

Staff did not want to work with Zoe and consequently a high level of agency staffing was used. Frequent incidents occurred, many of which were only reported verbally from one staff member to another. There were no plans in place to guide the staff as to how to manage the challenging behaviour, and recording was poor.

Zoe moved to a two-bedroom semi-detached bungalow managed by a specialist provider. Zoe chose the furnishings and there are more personal effects in evidence.

There is now a person-centred plan in place, with policies and procedures to guide staff, accurate recording and staff continuity. Zoe has much greater choice and control over what she does and when she does it.

The improved environment and staff practice has improved Zoe's sense of well-being and independence. As a consequence, she is no longer incontinent and manifests far fewer, and less extreme aggressive and challenging outbursts. Information taken from the *Dignity in Housing LIN Report, 2006*

For further information visit:
<http://icn.csip.org.uk/housing/>

Other resources

The **Picker Institute's** evaluation of 'experience' rather than satisfaction surveys includes attention to the issue of autonomy.
<http://www.pickereurope.org/page.php?id=21>

Now I feel tall (DH, 2005b) offers practice examples on 'having information to make choices, to feel confident and to feel in control'.
<http://www.scie.org.uk/publications/practiceguides/practiceguide09/files/nowifeeltall.pdf>

Older People's Advocacy Alliance (OPAAL) UK is an organisation which promotes the development of independent advocacy services for older people. OPAAL's development plan for advocacy services to the English regions.
<http://www.opaal.org.uk/default.aspx?page=1470>

Independence, Choice and Risk: a guide to best practice in supported decision making (Ref Department of Health, 2007) offers a range of resources and case studies relevant to anyone involved in helping vulnerable adults to take decisions, make choices, manage risks and support independence. Link
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773

Privacy

Privacy is closely related to respect and features as a prominent issue throughout the related literature. People responding to the Department of Health (DH) online survey (DH, 2006d) raised the importance of being medically examined in a private area, having an acceptable amount of personal space and being dressed in clothes which do not expose your body. An analysis of UK data from the Dignity in Older Europeans study (Woolhead et al., 2004) found that self-respect can be undermined 'by exposure, lack of privacy in personal care, and mixed wards'.

The National Service Framework for Older People (DH, 2001) acknowledges that privacy can be undermined in hospital, and Essence of Care (DH, 2003c) has a series of benchmarks relating to the subject. The national minimum standards (DH, 2003b, DH, 2003a) also devote entire sections to the subject of privacy and dignity. A recent study (Woogara, 2005) found that Essence of Care benchmarks were not being met and that: 'the "little things" which would protect the patients' privacy and dignity were often forgotten'. Aspects of privacy include:

- **Modesty and privacy in personal care** - ensuring that people receive care or treatment in a dignified way that does not embarrass, humiliate or expose them. The desire for single-sex wards has been highlighted in a number of studies (DH, 2006d, Woolhead et al., 2004, PRIAE/Help the Aged, 2001, Cardiff University, 2001 - 2004) and is of particular concern to some minority groups (PRIAE/Help the Aged, 2001).
- **Confidentiality of treatment and personal information** - ensuring that personal files and records and financial information are kept confidential, and only shared with the consent of the person concerned. Discussions about a person's well-being, treatment and any personal information should be carried out where others are unable to hear. Conversations of a very confidential nature, for example about medical diagnosis or toilet arrangements, should be discussed in a private space and not with only a curtain between the individual and others. Privacy of conversation with family and friends should be facilitated through access to a private room or telephone and personal mail should be received unopened. Particular care should be taken to ensure privacy when using interpreters. In small communities the service user and interpreter may know each other or have common friends. This can cause a great deal of anxiety in terms of confidentiality and alternative solutions should be sought. A study of people who use interpreting services (JRF, 2004) found that many people prefer to use family members or to have the same professional interpreter on each occasion so that trust can be built.
- **Privacy of personal space** - staff should gain permission to enter and demonstrate respect for personal belongings and boundaries. It is important to achieve a balance so that vulnerable people are not either isolated by privacy policies or put at risk, for example through providing privacy for personal and sexual relationships. 'My home life' (Owen, 2006) reports that: 'offering couples space for intimacy and privacy and using skilled observation and emotional literacy to understand their needs will help residents feel they have the right to express their sexual identity' (Forte et al., 2006,

Heymanson, 2003, Springfield, 2002). Staff need appropriate training to ensure relationships can be positively, respectfully and safely supported.

Key points from research and policy

- Article 8 of the Human Rights Act (1998) gives the right to respect for private and family life, home and correspondence.
- Some hospital staff need additional training on the issues of dignity, respect and privacy. 'This is particularly true of staff caring for older people with mental health needs' (Commission for Healthcare Audit and Inspection, 2006).
- Older people prefer single-sex facilities (Woolhead et al., 2004, PRIAE/Help the Aged, 2001, Cardiff University, 2001-2004, DH, 2006d).
- The Department of Health has given a clear public commitment to eliminating mixed-sex accommodation for hospital inpatients.
- Essence of Care offers a series of benchmarks to ensure privacy and dignity in hospital (DH, 2003c).
- The national minimum standards refer specifically to privacy and dignity (Standard 8 for domiciliary care and Standard 10 for care homes) (DH, 2003b, DH, 2003a).
- Standards for Better Health sets out core standards which include environments that are supportive of patient privacy and confidentiality (DH, 2004e).

Practice points

- Ensure there is a confidentiality policy in place and that it is adhered to by all staff (including domestic and support staff).
- Make issues of privacy and dignity fundamental to staff induction and training.
- Only those who need information to carry out their work should have access to personal records or financial information.
- Where people have personal and sexual relationships, their privacy should be respected in conjunction with careful assessment of risk to vulnerable people.
- Choose interpreters with the consent of the service user.
- Ensure that all staff gain permission before entering someone's personal space.

- Ensure that access to personal possessions and documents is only via the owner's expressed consent.
- Ensure space is provided for private conversations and telephone calls.
- Ensure service users receive their mail unopened.
- Single-sex bathroom and toilet facilities should be available.
- Provide en suite facilities where possible.
- In residential care, respect people's space by enabling them to individualise their own room.
- If a person requires close monitoring or observation, issues of privacy should be carefully considered.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Maintaining dignity despite incontinence (Housing Improvement Learning Network)

The Housing Improvement Learning Network is developing a factsheet on dignity in housing, which includes some examples where dignity issues have been addressed. The following example (from Hanover SmartChoice, a service that helps care providers assist older people and people with disabilities to maintain their independence and remain safely in their own homes) demonstrates how assistive technology can help restore dignity.

Mrs J is a resident of an Extra Care scheme. When carers noticed an increase in her incontinence, the standard approach was for carers to enter her room at night and feel her bed to see if she had soiled herself. This was unsatisfactory for all. The solution was to use an enuresis pad, which issues an alert if Mrs J is incontinent. This allows for carers only to enter her room when an incident occurs, and if she is incontinent she is assisted with her toilet needs and bedclothes are changed straight away. It also enabled carers to examine records of alerts. They could see that a pattern of incontinence developed between 2 and 3 am. Using this information carers can now assist Mrs J to the toilet at 1.30 am and promote Mrs J's continence.

For further information contact:

Visit the Change Agent Team: Housing website www.cat.csip.org.uk

Modesty preserved (Portsmouth Hospital NHS Trust)

It was noted that in the general ward areas hospital gowns were open-backed, with ties. Since the gowns were often used as temporary nightwear, mobile patients would frequently wear two gowns (one on backwards, to cover their back). Pyjamas supplied to patients were also often an undignified mismatch. Replacement gowns and pyjamas were agreed with textile services and endorsed by the Patient Experience Council. A bid for funding was presented to the local Patient Environment Action Group and full funding secured from the League of Friends. The change of bedwear overcame a simple matter the Matron's Essence of Care Group had identified, and enabled patients to regain a little more dignity at a vulnerable time.

For further information contact:

Sarah Balchin, Lead Nurse Clinical Developments.

Email sarah.balchin@porthosp.nhs.uk

Do not disturb (Sheffield Teaching Hospital NHS Trust)

Sheffield came up with a very simple idea: they use plastic reusable Do Not Disturb signs which have been designed for curtains and doors. They have been found to be effective in reducing interruptions and are now being produced for use throughout the trust.

For further information contact:

sam.debbage@sth.nhs.uk

Developing a privacy and dignity policy (Guildford and Waverley PCT)

The PCT's Essence of Care steering group carried out a privacy and dignity audit on the wards in December 2005, based on the Essence of Care standards.

There were some significant findings, as a result of which they:

- increased and improved access to diversity and equality training
- increased confidentiality and Caldicott awareness training for all staff
- added Velcro® fastenings to curtains
- reviewed the procedure on responding to a complaint of inappropriate behaviour towards a colleague or patient, and disseminated the results to all managers.

The group has also developed a draft privacy and dignity policy, stating the requirements and expectations the trust demands from staff.

For further information contact:

Glynis John, Clinical Governance Facilitator. Tel 01483 782102.

Email Glynis.john@nhs.net

Single-sex bay areas (Caterham Dene Community Hospital)

The hospital ensures that bay areas on the ward are never mixed sex. There is a mix of large and small bay areas, which includes some single accommodation. The majority of patients tend to be female (census data and historical evidence also support this), so the larger bays tend to be allocated to women, although there is flexibility in this arrangement if necessary. All bathroom and toilet facilities are designated as single sex to avoid embarrassment or discomfort for patients.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@east Surrey-pct.nhs.uk

Effective action plan (Doncaster and Bassetlaw Foundation NHS Trust)

The matron in Critical Care put together an action plan which was fed back to the Essence of Care steering group. The action plan included:

- education forums to raise awareness of privacy and dignity; these were locally run departmental sessions attended by nurses, sisters and healthcare assistants.
- posters displayed throughout the directorate with messages, for example, to promote bathtimes without interruption, to keep patients covered at all times and to close bedside curtains tightly.
- 'Do Not Enter signs for the curtains.
- colour-coded clothes pegs to ensure curtains closed properly (these stay in each bed space to comply with infection control). Some areas have used a traffic light system, e.g. red peg = Do Not Enter.

The staff received feedback at departmental meetings and directorate audit meetings. As a result of this work patient privacy and dignity has improved, and staff awareness has been raised - the posters have made staff think about their actions and all staff are empowered to make sure 'Do Not Enter' signs and pegs are used. The multi-disciplinary teams, including doctors, have taken this idea on board and always ask to enter behind curtains if they are drawn.

These actions have proven so effective that the initiative is now trust-wide, and good practice is shared via trust communication newsletters and the Essence of Care steering group.

For further information contact:

Rozz Jones, Sister, ITU, Essence of Care Lead. Tel 01909 502106.

Email rosa.jones@nhs.net

Small, effective changes, not changing the world (Manchester Mental Health and Social Care Trust)

The Older People's Essence of Care team believe essence of care should be about small, significant improvements that patients have highlighted, not about changing the world, and have found that involving the whole multi-disciplinary team ensures that this service is consistent throughout their locality. Here are some of the developments and improvements they have made, which all disciplines and clinical services must follow:

- induction packs, which include information relating to privacy and dignity, awareness of discrimination (age, culture, sex), confidentiality and record-keeping
- patients to be asked what they prefer to be called on admission/referral, and this to be documented
- patients to be asked for consent to share information on admission
- all areas to provide rooms for private conversations/interviews/phone calls
- patient orientation, including information about quiet areas, privacy and confidentiality
- staff encouraged to challenge others' negative attitudes.

The team is evaluating these improvements and awaiting patient satisfaction results.

For further information contact:

Sheila Kasaven, Modern Matron. Tel 0161 291 6806. Email Sheila.Kasaven@nhs.net

Paul's story: an Extra Care experience

Paul is a middle-aged man with a physical disability and mental health problems. He has spent most of his adult life living in nursing homes, but just over a year ago moved into a newly built Extra Care scheme. Paul said: 'I suffered a lot of abuse at the nursing homes. I have intelligence which they don't like.'

Paul described how staff in the last nursing home would sweep into his bedroom without knocking and pull the bed covers off exposing his naked body, his physical condition necessitating his sleeping unclothed. Staff would come straight into the bathroom while he was using the toilet to give him his medication, neither knocking nor waiting till he had finished. 'In a nursing home, you're a non-entity because of the power and control that the staff have over you...when you can go to the toilet; when you get up or go to bed; when you have your meals.'

Paul says of the move to Extra Care: 'It is 100% different here. Staff knock before entering. They treat me with respect and dignity. Dignity means being able to go to the loo and close the door; dignity means when you have a bath, not having fun poked at

your body.' Paul has no restrictions on him – he can choose when to get up or go to bed. Any concerns that he has raised have received a positive response.

Paul is now a member of the housing association's board. Paul's view is that having a tenancy and his own front door gives him choice and control. 'The tenancy is 101 per cent part of it. Staff can come in – it is a choice that I make. Choice is a precious thing in life.' Paul's sense of well-being and mental health have improved immeasurably. Moving to Extra Care has given him a new lease of life. 'The reason my mental health is helped here is because I'm treated as a human being. I am respected as Paul. People, staff, respect my views and respect me as a person.' .Information taken from the Dignity in Housing LIN Report, 2006.

For further information visit:
<http://icn.csip.org.uk/housing/>

Other resources

Confidentiality policies: many organisations have developed policies that spell out how staff deal with aspects of privacy that involve confidentiality. One example is from Southampton City PCT
<http://www.scie.org.uk/publications/practiceguides/practiceguide09/files/confidentialitypolicy.pdf>

The Clinical Governance Support Team Essence of Care Eureka documents describe basic standards of communication, privacy and dignity <http://www.cgsupport.nhs.uk/>

Hygiene and personal appearance

Hygiene and personal appearance were highlighted in the Department of Health (DH) online survey (DH, 2006d) as factors in maintaining dignity for older people. An analysis of UK data (Woolhead et al., 2004) from the Dignity in Older Europeans study (Cardiff University, 2001 - 2004) found that the self-respect of older people could be undermined by neglect of patients' appearance and clothing and that, even in death, maintaining a respectable appearance is very important to people.

A person's appearance is integral to their self-respect and older people need to receive appropriate levels of support to maintain the standards they are used to. Personal preferences should be respected, as well as choice in how support is provided. For example, choosing when and how to carry out personal care tasks, using your own toiletries, choosing what to wear and how to style your hair and having clean, ironed clothes that fit are all ways of maintaining control and identity. Particular care should be taken in residential settings to ensure that personal laundry is treated with respect and not mixed up or damaged.

Appearance and hygiene also affect the living environment: a clean and tidy house and a well-kept garden are important aspects of maintaining dignity in daily living. Poor garden maintenance alone can give out the message that a person is unable to cope. The report 'Now I feel tall' (DH, 2005b) showed that hospital patients valued 'getting good treatment in a comfortable, caring and safe environment'. The Older People's Inquiry, 'That little bit of help' (JRF, 2005), found that: 'older people really valued support which enabled them to live in their own homes - for example, help with cleaning, DIY, gardening, care of pets, chiropody, transport and befriending'.

Aspects of hygiene and personal appearance include:

- Washing, bathing, showering
- Shaving
- Oral hygiene and denture care
- Hair care
- Body and facial hair removal
- Nail care, including chiropody and podiatry
- Toileting and continence needs
- Dressing and undressing
- Laundry

Environmental aspects include:

- Cleanliness of environment
- Tidiness of house and garden
- Control of odours
- Choice of décor (in residential/nursing homes)

Key points from research and policy

- Having a clean and respectable appearance and pleasant environment is key to maintaining the self-esteem of older people.
- Cleanliness in hospitals is one of the top five issues for patients (DH, 2004d).
- Having a clean home is particularly important to older women in terms of maintaining their dignity and self-respect (Godfrey et al., 2000).
- A little bit of help can make a big difference. This includes low-level, flexible services such as help with cleaning, ironing, garden maintenance, foot care and assistance

with caring for pets (JRF, 2005).

- The proper care of laundry is a key issue for many care home residents (PG Professional and the English Community Care Association, 2006).
- 'Hygiene and cleanliness is seen as a key indicator of standards within a [care] home' (PG Professional and the English Community Care Association, 2006).
- The national minimum standards for domiciliary care require that 'personal care and support is provided in a way which maintains and respects the privacy, dignity and lifestyle of the person receiving care at all times' (DH, 2003b).
- The national minimum standards for care homes require that 'the premises are kept clean, hygienic and free from offensive odours throughout' (DH, 2003a).
- The NHS Essence of Care benchmark for personal and oral hygiene focuses on assessment of need, planned care based on negotiation with patients, the care environment and appropriate levels of assistance (DH, 2003c).
- 'Towards cleaner hospitals and lower rates of infection' sets out a number of initiatives to improve hygiene standards in hospitals (DH, 2004d).

Practice points

- Ensure that older people have the support they need to maintain their personal hygiene and appearance, and their living environment, to the standards that they want.
- Ensure that the lifestyle choices of the individual are taken into consideration when providing support with personal care – for example, respect for a person's choice of dress and hairstyle.
- Don't make assumptions about appropriate standards of hygiene for individuals, and cultural factors should be taken into consideration during needs assessment.

Ideas from practice and other resources

Sole Mates (Age Concern)

Sole Mates provide a footcare service, including foot massage, for people over 50 who cannot cut their own nails or tend to their feet safely. It is provided through Age Concern in a number of counties and was among the 'baker's dozen' practical steps praised in the Older People's Inquiry: 'That little bit of help' (JRF, 2005).

Raising the bar on hygiene and cleanliness (Caterham Dene Community Hospital)

Special new blinds and bed curtains have been installed in the inpatient areas. These are coated with anti-bacterial agent, and the bed curtains are dated so that they can be changed every six months (or sooner if there is a patient with an infection nursed in that area). The cost is comparable to traditional curtains and blinds.

As part of the move to improve hygiene, cleaning standards are monitored and regularly reviewed to ensure that the contracted work meets the needs of the hospital. There is a regular schedule, and audits are carried out to ensure that procedures are being followed. Several formal audits will be carried out for very recent improvements and it is planned to hold patient focus groups with the support of the PPI manager.

Key learning points:

- Consult with and involve frontline staff at all stages of any change as they can be your champions in implementation.
- Encourage staff to question and challenge any change – it allows them to understand the rationale behind new developments and move forward with them.
- Talk with other organisations, as most will be prepared to share their experiences and that way it will avoid the time-consuming repetition of mistakes.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@eastsurrey-pct.nhs.uk

Adopting the Behind closed doors leaflet (Southampton University Hospital NHS Trust)

The Essence of Care group is currently piloting on wards the Geriatric Society's leaflet entitled *Behind closed doors, using the toilet in private*. The plan is to roll out the work across the hospital.

For further information contact

Julie Dawes, Associate Director of Nursing. Tel 02380 798435.

Email: julie.dawes@suht.swest.nhs.uk

Other resources

Now I feel tall (DH, 2005b) offers practice examples on 'getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way'.

The Alzheimer's Society training pack, *Yesterday, Today, Tomorrow*, includes a 90-minute video/DVD and 130-page training manual providing eight training sessions. The pack has been designed to help deliver training at a time that is convenient to the home/ward/department. Session five of the pack particularly focuses on supporting personal care. The session aims to guide staff working with people with dementia to respect their right to independence and encourage them to carry out their own personal care tasks. The pack is available from the Alzheimer's Society.

Mealtimes and nutritional care

What's new?

Nutrition and nutritional care have received an increased focus from the Department of Health recently. A wide range of key stakeholders with an interest in Nutrition, Care Homes, Older People, Health and Social Care were invited to discuss nutrition issues at two Ministerial summits in March and July 2007. The stakeholders will work with the Department of Health to produce a Nutrition Action Plan, outlining how the stakeholders will take forward improvements in nutrition and nutritional care. More examples on how to provide care at mealtimes and enhance the enjoyment and experience of mealtimes have been added to the guide to support this work by sharing best practice.

Food, nutrition and mealtimes are a consistent feature in the research and 'have been raised repeatedly... as an opportunity to respect residents' dignity, or undermine it' (Research overview). Meals and mealtimes affect the quality of life for older people and are indeed 'the highlight of the day' for many people in residential care (Commission for Social Care Inspection, 2006). A small study into care homes found that, for residents, food is a definer of the quality of a home (PG Professional and the English Community Care Association, 2006). In the Department of Health (DH) online survey (DH, 2006d) people complained that not enough help is available to those who need assistance with eating. The analysis of British data from the Dignity and Older Europeans study supports this: 'participants said patients were often not fed by nurses and this was often a problem for older people who could not feed themselves'. (Calnan et al, 2003). As the Research overview found, not having appropriate help with eating and drinking can have more serious consequences for people with dementia or depression.

Despite a raft of guidance, and improvements in the quality of hospital food (DH, 2005c), there are still serious concerns about mealtimes in the health and social care sectors. A recent report by the Patient and Public Involvement Forums entitled 'Hospital food, could you stomach it?' (Commission for Patient and Public Involvement in Health, 2006) found that more than a third of hospital patients have left their food, and issues were raised about choice, the temperature and presentation of food and people not receiving the help they need to eat their meals. Age Concern have published a compelling report (Age Concern, 2006) into the scandal of malnourished older people in hospital which strongly argues that it is a change in culture and practice that is required.

Good nutrition and hydration and enjoyable mealtimes can dramatically improve the health and well-being of older people. Mealtimes, therefore, should be considered a priority in terms of importance and dedication of staff time; systems within organisations should support this. Protected mealtimes have been introduced in many hospitals: this means that non-emergency clinical activity stops, the ward is tidied and patients are

made ready for their meals. It gives patients 'space' to eat and enjoy their meals. It also gives housekeepers and nurses time to give assistance to those who need it.

The Commission for Social Care Inspection (CSCI) bulletin *Highlight of the day?* reports that: 'Care homes that meet the national minimum standards for meals and mealtimes are more likely to have: staff that consult with the older people in their care on their needs; managers who met the training needs of their staff; and sufficient staff numbers to support older people in enjoying their meals.' (Commission for Social Care Inspection, 2006).

Malnutrition affects over 10 per cent of older people (British Association for Parenteral and Enteral Nutrition, 2006). Nutritional screening on admission to health and social care services, and improving food intake where necessary, is therefore vital and should be a key part of care planning. This issue also highlights the importance of preventative, low-level support for older people. Health and social care staff in the community have a key role to play in early detection and prevention of malnutrition. It is essential that frontline staff have an awareness of basic nutritional needs, including the symptoms of dehydration and malnutrition, and the importance of meals and mealtimes in care services for older people. Commissioners and home care agencies should ensure that staff are given sufficient time to prepare freshly cooked meals with, or for, the older person and to provide a degree of company through 'time for a chat' - this can improve the mealtime experience and can be a lifeline for people who rarely leave the house and are socially isolated.

Older people in the community are not always able or motivated to cook for themselves, and the death of a partner or spouse can lead to people with no experience of cooking having to start in their later years. Further, the tasks associated with cooking, such as shopping and washing up, can be challenging for some older people. Local lunch clubs may offer the chance to have a good hot meal regularly as well as providing social opportunities.

Some conditions that affect people in later life, such as stroke, Parkinson's and Alzheimer's disease, can seriously affect a person's ability to feed themselves and to swallow. In addition to medical assessment of nutritional needs, consideration should be given to the impact of eating difficulties on the social aspect of mealtimes. A Swedish study (Sidenvall, 1999) noted that older people strive to retain their independence and dignity when eating when they have been affected by debilitating physical or mental conditions, and that such loss of skill can be painful and can cause embarrassment. It is important that support is provided in a discreet, sensitive and respectful manner that does not highlight the person's difficulties.

Key points from research and policy

- Food, nutrition and mealtimes are a high priority for older people and a top priority for older people from black and ethnic minority groups (PRIAE/Help the Aged, 2001).

- Malnutrition affects over 10 per cent of older people. (British Association for Parenteral and Enteral Nutrition, 2006).
- Malnutrition is estimated to cost the UK over £7.3 billion a year. (BBC, 2006).
- Malnourished patients stay in hospital for much longer, are three times as likely to develop complications during surgery, and have a higher mortality rate (Age Concern, 2006, BBC, 2006).
- The needs of people from black and ethnic minority groups, including 'basics such as food' are not always met by mainstream services (PRIAE/Help the Aged, 2001, Afshar et al., 2002).
- Key points in bringing about a culture change in food, nutrition and mealtimes are: good leadership, staff induction and training and adequate staffing levels (Commission for Social Care Inspection, 2006).
- The NHS Standards for Better Health requires healthcare organisations to ensure that patients have a choice of food that is prepared safely and provides a balanced diet; and that 'individual nutritional, personal and clinical dietary requirements are met, including any necessary help with feeding and access to food 24 hours a day' (DH, 2004e).
- National minimum standards for care homes require that 'service users receive a wholesome appealing balanced diet in pleasing surroundings at a time convenient to them.' (DH, 2003a). Nearly 2,000 care homes in England do not meet this standard (Commission for Social Care Inspection, 2006).
- National minimum standards for domiciliary care require that 'personal care and support is provided in a way which maintains and respects the privacy, dignity and lifestyle of the person receiving care at all times'; this includes eating and meals. (DH, 2003b).
- The NHS Essence of Care benchmarks for food and nutrition include attention to nutritional assessment, the environment, presentation of food and appropriate assistance (DH, 2003c).
- In February 2006 the National Institute for Health and Clinical Excellence (NICE) and the National Collaborating Centre for Acute Care launched clinical guidance to help the NHS identify patients who are malnourished or at risk of malnutrition.

Practice points

- Routine nutritional screening should be carried out on admission to hospital or residential care. The dietary needs and preferences of service users, and any assistance needed at mealtimes, should be assessed, recorded and referred to by all frontline staff.

- A speech and language therapist should assess anyone exhibiting swallowing difficulties, to ensure the correct textures of foods and liquids are provided.
- Where necessary, record food and fluid intake daily.
- Food should be made available and accessible between mealtimes.
- Give people time to eat; they should not be rushed.
- Avoid interruptions to mealtimes by other routine tasks, such as administering medication.
- Where necessary, provide assistance discreetly. Use serviettes, not bibs, to protect clothing. Offer finger food to those who have difficulty using cutlery, and provide adapted crockery and cutlery to enable people to feed themselves where appropriate.
- While socialising during mealtimes should be encouraged, offer privacy to those who have difficulties with eating, if they wish, to avoid embarrassment or loss of dignity.
- Managers should ensure that mealtimes are sufficiently staffed to provide assistance to those who need it.
- Don't make assumptions about people's preferences on the basis of their cultural background – people should be asked what their preferences are.
- Staff should receive training to equip them with the skills to communicate with people with dementia and communication difficulties. Visual aids (such as pictorial menus) and non-verbal communication skills may help people to make choices. Gather information on people's needs and preferences from people who know the person well.
- All care staff, including caterers, should have access to quality training to raise awareness of the risk of malnutrition and the importance of providing good nutritional care for all service users.
- Commissioners and providers should ensure that home care staff have sufficient allocated time and the skills to prepare a meal of choice for the service user, including freshly cooked meals.
- Food should be made to look appetising. Where food needs to be puréed, use moulds to keep foods separate and indicate what they are – for instance a fish-shaped mould for fish.
- Carry out regular consultation with service users on menus.

- Wherever possible, involve service users in meal preparation.
- In residential settings, where access to industrial kitchens is denied, provide facilities for people to make drinks and snacks.
- Ensure that fresh water is on offer at all mealtimes and freely available throughout the day.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Red Tray system

Many hospitals have adopted this system for identifying patients who require assistance at mealtimes. Food served on a red tray provides an effective signal to staff without compromising the patient's dignity. The system is being monitored and refined, but has been found helpful in promoting individual care and staying alert to changing nutritional requirements. Designating patients who receive a red tray is part of initial and continuing assessment, and a daily updated list of patients due to receive food on red trays can be included in shift handovers and provided for kitchen staff. A red tray is also a simple reminder to staff to check the patient's notes for guidance on any specific help or nutritional needs. In several hospitals the red tray system has been linked with protected mealtimes.

To put the Red Tray system into practice, Birmingham Heartlands and Solihull NHS Trust have followed the British Association of Parenteral and Enteral Nutrition's guidance and created a Protected Mealtimes Guidelines document that includes Red Tray Guidelines, describing how to operate the system and ensure it is followed by staff. It includes information on the role of meal coordinator and on recording how much food patients have eaten.

Knife and Fork Symbol (United Bristol Healthcare NHS Trust)

Under this system, a knife and fork symbol is placed above patients' beds. This gives staff the same signal as the Red Tray system, indicating which patients need support during mealtimes.

For further information contact:

Toni Williams, Chief Dietician, Food Policy, United Bristol Healthcare NHS Trust.
Tel 0117 9283006. Email toni.williams@ubht.nhs.uk

Eat Well Feel Well (Heatherwood and Wexham Park Hospitals NHS Trust)

The Eat Well Feel Well project promotes a range of nutritional care improvements, including protected mealtimes, a wider range of ethnic menus, nutritional screening, a red tray system, link nurses to monitor quality of care and volunteers to help at

mealtimes. The project also raises awareness through the use of posters, information videos, public awareness sessions and staff training.

For further information contact:

Gay Lewis, Clinical Development Facilitator. Tel 01753 633764.

Email Gay.Lewis@hwph-tr.nhs.uk

Patient Catering Survey (University Hospital of South Manchester NHS Trust)

The Patient Catering Survey was designed to help assess whether service users were satisfied with the standard of food and support during mealtimes. In addition to the survey, nutritional awareness training was made mandatory for all new staff, and a newsletter, Essence of Care News was produced outlining the work and improvements made. The changes were carried out as part of Department of Health Essence of Care benchmarking on Food and Nutrition

For further information contact:

Sheila Wilkinson, Improving the Patient Experience Project Manager.

Tel 0161 2912761. Email Sheila.wilkinson@smuht.nwest.nhs.uk

Improving the mealtime experience (Methodist Homes for the Aged)

Methodist Homes for the Aged (MHA) have introduced a range of initiatives across their care homes and housing schemes to improve the experience of mealtimes. The initiatives include a catering manual for catering and care staff with a clear set of standards, the introduction of routine nutritional screening, and assessment of residents' eating capabilities by speech and language therapists. In one particular home, staff have looked at ways to ensure residents' rights to privacy during mealtimes. Improvements have included the introduction of pleasant background music and fresh flowers at the dining table.

For further information contact:

George Sampson, Head of Hospitality. Tel 0773 4151988.

Email George.Sampson@mha.org.uk

Best Practice Guidelines (Harrogate Neighbours Housing Association)

The Harrogate Neighbours Housing Association have produced their own Best Practice Guidelines for catering in residential homes and sheltered housing. It includes a philosophy statement on catering and a skills assessment of catering staff.

Food and Nutrition Benchmark (St Michael's Community Hospital, Aylsham)

The Food and Nutrition Benchmark at St Michael's Community Hospital was put in place as part the Essence of Care toolkit. The ward housekeeper, together with a healthcare assistant, spoke to patients about mealtime practices and asked for ideas as

to how they could be improved. Following patients' suggestions, mealtimes were protected and made more of an event, with new cutlery and tablecloths improving the dining environment. Since the changes were made, patients have reported enjoying mealtimes more. Regular audits ensure the practices are still effective. Information taken from Essence of Care Eureka! Protecting Patients' Mealtimes at St Michael's Community Hospital.

For further information see:

Essence of Care Eureka! Protecting Patients' Mealtimes at St Michael's Community Hospital

Volunteers and Mealtimes project (United Bristol Healthcare NHS Trust)

The Trust has introduced a range of initiatives to improve nutrition and dignity at mealtimes, including the Volunteers and Mealtimes project, established on one ward to provide more assistance to elderly patients. The project set out to recruit volunteers to make mealtimes on the ward a more social occasion. Following its success, more mealtime volunteers were recruited, each one attending a multi-professional half-day programme of training. The Hospital is considering extending the idea to other wards.

For further information contact:

Jayne Weare, Occupational Therapy Manager. Email Jayne.Weare@ubht.nhs.uk

Cooking with Care (Barchester Healthcare)

National care home provider, Barchester Healthcare, has initiated a Cooking with Care campaign, supported by the celebrity chef Paul Rankin, to ensure that mealtimes are enjoyable, dignified and fun. Chefs spend time in the dining room with residents to ensure that food is beautifully presented and to find out about residents' likes and dislikes.

To ensure that chefs are fully trained to support individual needs and tastes, Barchester Healthcare has developed the Barchester Chef Academy to offer training for all levels, from apprentice to Master Chef. The group has also introduced a system of 5 Star Dining to improve dining standards, particularly for patients with swallowing difficulties and those unable to feed themselves. Standards include offering the resident a choice of meal at their table (rather than pre-ordering), presenting food for people on soft diets just as beautifully as other dishes, and providing assistance in cutting up food discreetly.

For further information contact:

Terry Tucker, Director of Learning, Development and Hospitality, Barchester Healthcare. Tel 07718 582139. Email terry.tucker@barchester.com

Nutritional Awareness Week (Southampton University Hospitals NHS Trust)

This helped raise the understanding of how important it is for patients to receive good nutritional food. Guidance was also given to all wards on nutritional supplements. The work was carried out through the Essence of Care Group.

For further information contact:

Julie Dawes, Associate Director of Nursing. Tel 02380 798435.

Email julie.dawes@suht.swest.nhs.uk

Related documents:

- A guide to nutritional supplements and their uses
<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/files/nutritional1.pdf>
- Newsbite: August 2006
<http://www.scie.org.uk/publications/practiceguides/practiceguide09/ideas/files/nutritional2.pdf>

Malnutrition Universal Screening Tool (Caterham Dene Community Hospital)

All patients at Caterham Dene are nutritionally screened on admission as part of the assessment process, using the Malnutrition Universal Screening Tool (MUST) tool. This screening immediately identifies any difficulties a patient may have so that appropriate support can be arranged through the dietitian. All meals are supervised by the nursing staff, and the hospital is due to implement protected mealtimes to ensure that mealtimes are uninterrupted and that those with specific needs are easily identified.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@east Surrey-pct.nhs.uk

Nutrition support pack (Surrey and Borders Partnership NHS Trust)

The support pack was developed by the practice development nurse, who worked with a number of professionals, including dietitians, speech and language therapists and medical staff. The guide includes information on:

- promoting good dietary intake (including special needs and gastrointestinal diseases)
- nutritional requirements of older people and those from ethnic minorities
- MUST (Malnutrition Universal Screening Tool) and flow charts
- DETERMINE ABCDEF Tool for assessing nutritional risk in the community
- audit - monitoring and recording of food waste

- care plan for patients who will not eat
- constipation and incontinence in older people
- Diabetes mellitus, including pathways
- bone health.

The nutrition support pack was originally developed for use in one of the trust's localities working with older people and mental health services. The intention is to expand its use across the trust after evaluation.

For further information contact:

Jill Ruhomutally, Practice Development Nurse. Email Jill.Ruhomutally@sabp.nhs.uk

Practice ideas from other service user groups

Involving residents (Dorset County Council)

Adults with learning disabilities in residential care are now involved in developing their own care plan as part of Dorset County Council's dignity in care at mealtimes. Residents are nutritionally screened on admission and at monthly intervals, and are surveyed regularly about meals and mealtimes so that menus can be adapted accordingly.

For further information contact:

Sue Hawkins, Catering Services, Adult and Community Services.

Email s.hawkins@dorsetcc.gov.uk

Other resources

The Hospital Caterers Association have suggested a framework for a protected mealtime policy. Many hospital trusts have used this as a template to develop their own local policies. It can be found at:

Improving the health choices for older people: implementing patient-focused mealtime practice through addressing the culture within a hospital unit:

The Alzheimer's Society training pack, Yesterday, Today, Tomorrow, includes a 90-minute video/DVD and 130-page training manual providing eight training sessions. The pack has been designed to help deliver training at a time that is convenient to the home/ward/department. Session five of the pack particularly focuses on personal care, including eating and drinking. The session aims to develop participants' understanding of appropriate choices of food and drink. The pack is available from the Alzheimer's Society.)

The Alzheimer's Society also provides nutrition training events, called Food for Thought.

The Commission for Social Care Inspection's bulletin 'Highlight of the day?' is 'designed to assist care home managers and staff to improve the delivery of meals to older people, and in particular to improve their experiences of mealtimes in care homes'.

Hungry to be heard (Age Concern, 2006) gives seven steps to end malnutrition in hospital.

The National Association of Care Catering offers guidance and a checklist for care caterers and has produced a series of guidance manuals. Key publications are:

- Menu Planning and Special Diets in Care Homes (2006/7)
- National Minimum Care Standards for Care Catering (Care Homes for Older People, 2005)
- A Recommended Standard for Community Meals (2005)

These can be purchased in hard copy, CD ROM or PDF format from NACC:
www.thenacc.co.uk/

Skills for Care have produced a Knowledge set for nutrition and well-being. It sets out the competencies expected of care workers in terms of the preparation and presentation of food, understanding the importance of food and drink, and helping people to eat.

The Food Standards Agency have produced nutrient and food based guidance for care homes: Food served to older people in residential care; FSA Nutrient and Food Based Guidelines for UK Institutions and Menus for Care Homes. The advice for care homes includes guidance on appropriate nutrient intakes, healthy eating, allergy and food hygiene tips. There is also an example menu plan to help caterers for care homes follow the guidance, with a technical report showing how the menus follow Food Standards Agency advice.

Water UK has published Water for Healthy Ageing: Hydration Best Practice Toolkit for Care Homes to help care managers, caterers and other service providers to develop best practice on keeping older people well hydrated.

Delivering Nutritional Care through Food and Beverage Services produced by the British Dietetic Association and endorsed by the Hospital Caterers Association provides useful information on the nutritional content of food in a hospital setting.

The Caroline Walker Trust has issued two reports containing nutritional guidance specifically for older people. The first, entitled Eating well for older people (CWT, 2004;

available for sale at www.cwt.org.uk), offers practical guidance on catering for older people in care homes, nursing homes, at lunch clubs or community meals. The second, *Eating well for older people with dementia* (Voices, 1998) gives specific advice on how dementia affects the ability to eat and the role that good nutrition can play in patient care.

Eating for Health in Care Homes – A practical nutrition handbook (Royal Institute of Public Health) is designed for owners, managers, chefs and other care home staff responsible for the nutritional health of older people. Call 0207 2918353 to purchase a copy, or order from www.riph.org.uk

The British Association for Parenteral and Enteral Nutrition (BAPEN) provides a wealth of information on how to screen people for nutritional health in the form of the Malnutrition Universal Screening Tool, or MUST.

Complaints

Many people find it difficult to complain for a number of reasons. It may be difficult for them to find their way around the system, for example because English is not their first language, or because they have a cognitive impairment. Some people are reluctant to complain because they worry that their service may be withdrawn. They may fear being seen as a 'trouble maker' and being treated differently as a result of their complaint; this concern was raised repeatedly in Healthcare Commission inspections (Healthcare Commission et al., 2006). Being able to complain without fear of retribution was also raised in the Department of Health (DH) online survey (DH, 2006d), alongside a need for clear and simple complaints procedures. It may be particularly difficult to make a complaint about someone providing a face-to-face service on a daily basis - for example a home-care worker or residential staff - particularly if the complaint only applies to one aspect of their otherwise good work.

It is important to ensure that there is a fair, open and honest culture around complaints so that:

- people feel confident in bringing concerns to the attention of service providers
- staff and managers view complaints as a means of ensuring that the service is responsive, and not as a threat
- problems are picked up at an early stage and lessons are learned which lead to service improvements
- poor practice is highlighted and rectified
- vulnerable people, or those who find it difficult to make their views heard, are protected and have access to adequate support.

If people feel comfortable in raising concerns with frontline staff - and staff act promptly to address the issues raised - then escalation to the official complaints procedure is less likely and resources used on complaints can be kept to a minimum. Service user forums, particularly in residential settings, may help people to feel more comfortable in raising concerns. Such forums can also offer non-bureaucratic opportunities for service users to influence change. Acting promptly can help to reassure people that their complaints will be listened to and that it is not necessary to enter into a bureaucratic process to get a good response. As one practitioner put it: 'If you complain that your breakfast is cold, you don't want to go through the complaints procedure - you want a hot lunch!'

As part of the drive to ensure dignity in care the Department of Health has issued new regulations on complaints procedures for adult social services. The new procedures emphasise the significance of providing an accessible, customer-focused service that encourages people to speak out about their experiences - both good and bad - and to

challenge poor practice when they come across it. In addition, timescales for resolution at all stages of the process have been shortened and the independent review panels now have a more precise and focused brief to ensure less variation between local authorities and a more consistent response to complainants against measurable frameworks. The new procedures, Learning from Complaints, came into force on 1 September 2006.

There is also guidance for NHS complaints managers: 'Supporting staff, improving services - guidance to support the implementation of the NHS (complaints) amended regulations 2006'.

There is a commitment in the White Paper, *Our health, our care our say* (DH, 2006f), to introduce a single complaints process covering both health and social care in the near future.

Standard 16 of the national minimum standards for care homes (DH, 2003a) requires that 'there is a simple, clear and accessible complaints procedure which includes the stages and timescales for the process, and that complaints are dealt with promptly and effectively'.

How to complain

It is sometimes difficult to know who to complain to and this will depend on the type of service in question and the regulatory body concerned. For example, you may want to complain about a council activity, such as an assessment, or a service commissioned by the council such as residential care. Each organisation should have in place a complaints procedure. You should be able to get an information leaflet on this from the organisation concerned. The information leaflet should be available in different languages on request.

Abuse

If you have concerns that a vulnerable person is being abused you should report it immediately in order to protect that person.

Points to remember

- Where possible, approach the service first to see if the problem can be resolved at an early stage. If this is not an option (for example, because the complaint is about the manager or because the service user fears reprisals) it may be more appropriate to approach the commissioning or regulatory body instead.
- If the problem cannot be resolved informally, ask for a copy of the organisation's complaints procedure.

- Keep a record of any phone calls, letters or conversations with staff regarding your complaint.
- If you are not satisfied with the outcome of the complaint you can refer it to an external body or ombudsman. The complaints procedure should give you information on who to contact if you are not satisfied.

Good practice by service providers in dealing with complaints

- Try to resolve complaints at the earliest stage.
- Offer advocacy or support to the complainant where required.
- Ensure the complainant is kept informed of progress.
- Give a clear report of the outcome and information on what to do if the complainant is not satisfied.
- Ensure staff are properly briefed on the complaints procedure.
- Ensure people from seldom heard groups (e.g. people with dementia or people from minority groups) receive appropriate support to complain.

Help with complaining

The charity, Counsel and Care, have produced a factsheet that offers a comprehensive guide to complaining about health and social services.

Complaining about community care and NHS services in England

The Department of Health offers guidance on how to complain about:

- the NHS
<http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Complaintspolicy/NHScomplaintsprocedure/index.htm>
- local social services
http://www.dh.gov.uk/en/PolicyAndGuidance/OrganisationPolicy/ComplaintsPolicy/SocialServicesComplaintsProcedure/DH_4080889

Find your local council at Direct Gov:

http://www.dh.gov.uk/en/PolicyAndGuidance/OrganisationPolicy/ComplaintsPolicy/SocialServicesComplaintsProcedure/DH_4080889

If you find the process complicated or daunting you may be able to access local

advocacy services <http://www.advocacyfinder.net/findadv/directory.html>

Some charities may be able to help:

Help the Aged have a free advice line: SeniorLine 0808 800 6565

Age Concern information line: 0800 009966

The Independent Complaints Advocacy Services (ICAS) 'supports patients and their carers wishing to pursue a complaint about their NHS treatment or care'.

All health trusts have a Patient Advice and Liaison Service (PALS), which can help explain complaints procedures.

Regulatory bodies

Each organisation is monitored by a regulatory body. The list below outlines which authorities should be contacted. (Note: Day services are unregulated).

The **Commission for Social Care Inspection** (CSCI) regulates:

- Care homes (residential care homes providing personal care including the provision of intermediate care and short breaks)
- Nursing homes
- Domiciliary care agencies/home care services
- Nurse agencies
- Adult placement schemes
- Local authority social services departments

The **Healthcare Commission** (HCC) regulates:

- All NHS trusts and primary care trusts, which are responsible for: hospitals, GP practices, community teams, intermediate care services in hospital
- Hospices, private clinics and private hospitals (these are licensed by the HCC)

The **Housing Inspectorate** (part of the Audit Commission) regulates social housing. Complaints are handled by the Housing Ombudsman Service or, for housing association complaints, The Housing Corporation.

The Counsel and Care factsheet gives some guidance on which organisation should be

contacted under what circumstances.

The **Commission for Social Care Inspection (CSCI)** is responsible for the regulation and inspection of care homes and services, and the inspection and performance ratings for local councils, See the CSCI's guide to how to complain about services

The **Local Government Ombudsman** investigates complaints about how councils have carried out their business. This is a free and impartial service. The Ombudsman will usually only take up a complaint if the local authority's complaints procedure has failed to resolve the matter. However, the Ombudsman can make exceptions to this policy, for example if the situation needs to be resolved urgently.

The **Audit Commission** 'is an independent body responsible for ensuring that public money is spent economically, efficiently and effectively, to achieve high-quality local services for the public'. Its remit covers a number of local public services, including social services and housing.

The **Healthcare Commission** is responsible for complaints about the NHS and independent health services that have not been successfully resolved at a local level.

The **Health Service Ombudsman** investigates 'complaints about unfair or improper actions or poor service by UK government departments and their agencies, and the NHS in England'.

Professional bodies

Many professionals, including doctors, nurses and social workers, are required to register with a professional body. These organisations aim to protect the public by setting and maintaining standards within the professions, by publishing codes of conduct, registering individuals and monitoring continuous professional development. Serious misconduct by an individual can be reported to these bodies.

- The **General Medical Council** - register all doctors
- The **Nursing and Midwifery Council** - register nurses and midwives
- The **General Social Care Council** - registers social workers
- The **General Dental Council** - registers dentists, dental nurses, dental technicians and orthodontic therapists
- The **Royal Pharmaceutical Society of Great Britain** - registers pharmacists and their premises
- The **Committee on Standards in Public Life** monitors the standards of people working in public office, including councils

Performance indicators

Star ratings for local authorities aim to indicate how well an authority is performing, they are published by the Commission for Social Care Inspection.

CSCI have plans to publish star ratings for individual care homes and services. Currently you can find information about a service by reading their inspection report:

Performance indicators for NHS services are set by the Healthcare Commission.

Patient Opinion is a website that allows patients to feed back and share information on their hospital experiences.

Judicial review

If you think that a public body has made an unlawful decision you may want to challenge that in the courts. The route for such challenges is judicial review. You can find more information about judicial review at the Public Law Project, which 'aims to improve access to public law remedies for those whose access is restricted by poverty, discrimination or other similar barriers'.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Easy access to information and help (Caterham Dene Community Hospital)

As part of the hospital's clear admissions process, all patients are given an information booklet when they are admitted. This booklet includes a section on how to complain if they are unhappy with the service that is provided to them. Staff are made aware of how to deal with complaints through the PCT complaints policy and associated training. The matron is based on the ward and can easily be accessed by staff for support.

For further information contact:

Eileen Clark, Service Manager. Tel 01737 214846.

Email eileen.clark@east Surrey-pct.nhs.uk

Electronic feedback for constructive criticism (Partnership Health Group (PHG))

Through its commitment to quality, PHG views suggestions and complaints as essential for improving customer care. It believes there is a need to acknowledge the value of constructive criticism and complaints. Viewed positively, complaints are a valuable contribution to the development of high quality care. Dealing with complaints is therefore a priority within PHG and it is essential that they are addressed promptly. Key to this approach is early identification and rectification rather than reacting after patients have

given their feedback.

PHG uses live electronic measurement of patient satisfaction which starts with quality care rounds conducted by the unit manager.

Staff ask patients for feedback and, where appropriate, bring portable devices to the bedside.

The patient reads the questions, and answers by pressing the appropriate buttons, which takes 15-20 seconds.

All responses are automatically downloaded daily to a secure server and information from across the entire hospital/trust/region is collated and analysed.

Reports are created and automatically emailed daily (or weekly) to the relevant managers, with each report relating to that manager's specific area of responsibility.

The information contained in the ward/department reports is used as the basis for weekly staff meetings. Members of staff are kept up to date with patients' views and current issues, and are encouraged to suggest ways of improving performance. This encourages participation.

For further information contact:

Mona Van Wyk, Nursing Services, Specialist (Nursing Director), Partnership Health Group. Email: Mona.VanWyk@partnershiphealth.co.uk

Related document:

Patient satisfaction feedback in partnership health group

Linking Essence of Care into reviewing complaints (Derbyshire Mental Health Trust)

The Essence of Care lead attends all meetings about complaints and matches these complaints to the Essence of Care standards, so appropriate action can be taken. This is fed to the trust board, matrons and to ward teams.

For further information contact:

Kim Shield, Essence of Care Coordinator. Tel 01332 362221 ext 3783.
Email kim.shield@derbysmhservices.nhs.uk

Anticipating concerns before they become complaints (Addenbrooke's Hospital, Cambridge University Hospitals Foundation NHS Trust)

Addenbrooke's undertook an audit to ensure inpatient wards were meeting the requirements set out in the Addenbrooke's Standards of Privacy and Dignity which were developed by the Essence of Care subgroup. An audit pack containing the

Addenbrooke's standards, six patient questionnaires and a ward manager's survey were delivered to 35 wards across the trust. Wards were asked to return the completed packs within two weeks. The findings demonstrate where best practice is being achieved against the standards set out, and generated a number of recommendations for the trust to implement.

For further information contact:

Nicola Woodruff, Clinical Governance & Audit Coordinator – Nursing & AHPs.
Tel 01223 217871. Email nicola.woodruff@addenbrookes.nhs.uk

Gauging patient satisfaction (The West of Cornwall PCT)

The trust conducted a patient satisfaction baseline audit with regard to privacy and dignity within the Minor Injuries Unit based at Cambourne & Redruth Community Hospital. The aim was to demonstrate where best practice was being achieved and to highlight areas where practice could be improved. Subsequently an action plan was developed to address the areas where service improvement had been identified.

For further information contact:

Jane Goldsworthy, Development Manager Communications.
Email jane.goldsworthy@ciospct.cornwall.nhs.uk

Improving first impressions (Stockport NHS Foundation Trust)

In 2004, Stockport NHS Foundation Trust established an initiative to improve the dignity and respect towards its patients via a campaign which centred on a patient's first impressions of the hospital.

First Impressions took the top three issues raised by patients in the national patient satisfaction survey – patient correspondence, staff attitudes and the environment, and set about improving them.

Patient correspondence:

The letters we send are often the first point of contact for the patient with the trust and should provide information in a reassuring, timely and accurate manner.

The First Impressions work lead to the development of a consistent approach to patient correspondence, implementing standards for letters which reinforced the trust's image as a professional and caring organisation and inspired patient confidence in the services provided. It led to further work in improving the general information sent out to patients prior to coming into hospital, and the same information in video format on Patientline.

Staff attitudes:

Widespread focus groups with staff lead to a list of seven behaviours we would expect all staff to demonstrate. These have become known in the trust as the Dignity and

Respect standards and staff have received training in how to meet them and how to train colleagues. They are:

- A tidy and professional image
- Personal introductions
- Listening and informing
- Taking responsibility for patients and customers
- Valuing staff and being a role model
- Telephone standards
- Treating patients according to their needs and beliefs

Large posters depicting these standards are placed around the trust with a telephone number inviting the public to let us know how we are doing.

The environment:

This workstream concentrated on the public areas of the hospital, improving the appearance of the corridors, public toilets, waiting areas, entrances and outside areas. The trust has now built on this by using Patient Advice and Liaison Service volunteers to ask patients for their views on their experience of the hospital. The issues raised, together with key issues from complaints and the national patient satisfaction survey, form the basis of a ward indicator framework which allows the Board of Directors to keep updated and assured of quality on a regular basis. In this way we aim to develop 'Ward to Board' reporting.

For further information contact:

Judith Morris, Deputy Director of Nursing, Stockport NHS Foundation Trust,
Tel. 0161 419 4049.

Whistleblowing

'Society desperately needs principled and courageous people, and it needs them to be successful in exposing problems and exploring solutions.' (Martin, 1999)

It takes a great deal of courage for an individual to raise concerns about poor practice or abuse within an organisation. Where organisational culture tolerates bad practice an individual challenging this can become the focus of attention (Dadswell, 2000). They may be labelled with negative words and seen as the wrongdoer. Members within the organisation may see the whistleblower as a traitor (Greene, 2004). Fear of legal action and compensation claims can deter organisations from acknowledging and dealing with whistleblowers' disclosures.

As Martin (Martin, 1999) points out: 'the organisation has all the advantages. It has far more money, unlimited time and usually little individual responsibility. It can stall, resist giving information, hire expensive lawyers and mount attacks.' But there are many cases where people have chosen not to blow the whistle - with disastrous results. For example, witnesses in the Bristol heart scandal said they had been afraid to come forward even though they knew there was something wrong (BBC, 1999). Investigations into cases of abuse invariably lead to calls for the implementation of whistleblowing policies. It is vital that whistleblowers are supported and protected and that enabling whistleblowers to come forward is seen as an aspect of excellence within organisations.

Attitudes towards whistleblowers are changing (Benn, 2000), but a lot still needs to be done to ensure that workers feel safe enough to air concerns. For organisations there are clear advantages to supporting whistleblowers - these can include safeguarding the safety of staff and the people using the service as well as the organisation's reputation (Holihead, 2000). Failure to implement appropriate policies will lead to lack of public confidence.

New members of staff are often in a position to be more objective than existing staff members, who may have become accustomed to certain practices over a period of time (Dadswell, 2000). It is therefore important to ensure that new employees are supported to feed back on what they observe and that whistleblowing is covered during induction.

If whistleblowers are protected and viewed in a positive rather than negative light, then more people will be willing to disclose concerns about poor practice. The consequence of this will undoubtedly be better protection for vulnerable people.

Since July 1999 whistleblowers have been protected by the Public Interest Disclosure Act 1998. The Act protects public, private and voluntary sector workers from victimisation in employment following a disclosure which fits into any of the following categories:

- a criminal offence
- the breach of a legal obligation
- a miscarriage of justice
- a danger to the health and safety of any individual
- damage to the environment
- deliberate covering up of information tending to show any of the above (Health and Safety Executive, 2006).

Further information is available on the Health & Safety Executive's whistleblowing website <http://www.hse.gov.uk/workers/whistleblowing.htm>

Where there is no threat of immediate danger, whistleblowers should protect themselves by ensuring they prepare carefully to make a disclosure. It may help to gather evidence (for example, record dates, times and the names of any witnesses), seek support and take external advice, possibly from a voluntary advice service or union.

Public Concern at Work (PCaW) is an independent organisation that offers support to whistleblowers. It was established in 1993 'in response to a number of disasters and public scandals. Almost every official enquiry revealed that staff had been aware of the dangers but had not felt able to raise the matter internally or to pursue it if the concern was not taken seriously' (Van Den Hende, 2001).

The organisation supports both individuals and employers by:

- offering free advice and assistance to individuals who are concerned about apparent danger or malpractice in the workplace
- providing professional advice, training and consultancy services for employers and organisations
- influencing public policy through research and campaigning activities.

Key research and policy findings

- A number of high-profile scandals have highlighted the reluctance of individuals to disclose concerns about poor practice or abuse within the workplace (Van Den Hende, 2001).
- Investigations into cases of abuse invariably lead to calls for the implementation of whistleblowing policies.

- Organisations that support whistleblowers will protect staff and people who use services, safeguarding the reputation of the organisation and increasing public confidence (Holihead, 2000).
- The Public Interest Disclosure Act 1998 protects whistleblowers from victimisation.
- Public Concern at Work supports whistleblowers and promotes good practice in employment (Van Den Hende, 2001).
- Most health and social care professionals are required to register with a professional body and adhere to a code of conduct. These bodies should be able to offer advice to whistleblowers as well as register complaints against their members.

Practice points

- Staff need to be made aware that they should report concerns and that they will be offered protection if they make a disclosure in good faith.
- Organisations should implement a whistleblowing policy.
- The whistleblowing policy should give special consideration to staff who are in their probationary period.
- Whistleblowing awareness should be included in induction.
- Staff should be given information on external means of support (such as PCaW).
- Potential whistleblowers should prepare by gathering evidence, seeking support and taking external advice.

Whistleblowing do's and don'ts

Do:

- keep calm
- think about the risks and outcomes before you act
- remember you are a witness, not a complainant
- phone PCaW for Advice on 020 7404 6609

Don't:

- forget there may be an innocent or good explanation
- become a private detective
- use a whistleblowing procedure to pursue a personal grievance
- expect thanks

(Van Den Hende, 2001)

Ideas from practice

Whistleblowing (Hyndburn short break service)

At Hyndburn short break service for people with learning disabilities ensures staff feel confident enough to blow the whistle on bad practice by:

- providing support to blow the whistle during supervision
- ensuring the manager is approachable and responsive
- issuing all staff with a whistle blowing card
- displaying numbers of Welfare Counselling.

For further information contact:

Rebecca Toman, Short Breaks Manager, 98 / 100 Gloucester Avenue, Accrington, BB5 4BG. Tel: 01254 395060

Other resources

Public Concern at Work Suite 306 16 Baldwin Gardens London EC1N 7RJ Tel: 020 7404 6609 Email: email@pcaw.co.uk Website: www.pcaw.co.uk/

Whistleblowing for a healthy practice gives guidance for GPs:

<http://www.nhsemployers.org/practice/whistleblowing.cfm>

Health and Safety Executive: whistleblowing on health and safety issues:
<http://www.hse.gov.uk/workers/whistleblowing.htm>

You can download an example of a whistleblowing policy from Bolton Metropolitan
Borough Council from
<http://www.scie.org.uk/publications/practiceguides/practiceguide09/files/bmbc.pdf>

Abuse

This section does not attempt to cover the subject of abuse, which encompasses complex and wide-reaching issues that cannot be covered within the remit of this resource. The information below outlines immediate action that should be taken if abuse is suspected and directs you to suitable further resources.

What constitutes abuse?

Abuse is not easily defined and can have complexities stemming from the relationships of individuals involved. 'No secrets' (DH, 2000) - <http://www.thamesvalley.police.uk/reduction/victimsofcrime/adult-protection/pdf/nosecrets.pdf> - offers the following aid to identifying abuse:

- physical abuse, including hitting, slapping, pushing, kicking, misuse of medication, restraint, or inappropriate sanctions
- sexual abuse, including rape and sexual assault or sexual acts to which the vulnerable adult has not consented, or could not consent or was pressured into consenting
- psychological abuse, including emotional abuse, threats of harm or abandonment, deprivation of contact, humiliation, blaming, controlling, intimidation, coercion, harassment, verbal abuse, isolation or withdrawal from services or supportive networks
- financial or material abuse, including theft, fraud, exploitation, pressure in connection with wills, property or inheritance or financial transactions, or the misuse or misappropriation of property, possessions or benefits
- neglect and acts of omission, including ignoring medical or physical care needs, failure to provide access to appropriate health, social care or educational services, the withholding of the necessities of life, such as medication, adequate nutrition and heating
- discriminatory abuse, including racist, sexist, that based on a person's disability, and other forms of harassment, slurs or similar treatment.

SCIE has produced practice guidance on making referrals to the Protection of Vulnerable Adults (POVA) list, which is a national register of people who are considered a risk to vulnerable people. The guidance gives more detailed information on the 'warning signs' of abuse.

<http://www.scie.org.uk/publications/practiceguides/practiceguide07/deciding/deciding4.asp>

What to do?

- If there is risk of harm to one or more people, or if you think a crime has been committed, call the police and the local authority adult protection coordinator.
- If you are in doubt about whether a situation amounts to abuse or whether it should be treated as a complaint, ask the advice of the local authority adult protection coordinator.
- If there is no risk of immediate harm, consider informing one or more of the organisations below, depending on the circumstances:
- For care homes (including nursing homes), domiciliary care services or adult placement schemes, raise your concerns with the service, with the funding authority or the Commission for Social Care Inspection.
- For NHS services, raise your concerns with the service or with the primary care trust (PCT) providing the service.
- Each area has multi-agency adult protection procedures which they must follow once suspected abuse has been reported.

Other resources

Action on Elder Abuse (AEA) provide guidance on how to report suspected abuse. AEA also run a helpline which provides confidential support and advice for people who have been abused or know someone who may be suffering abuse. Available weekdays 9am - 5pm on freephone 0808 808 8141.

Counsel and Care have a factsheet, Older people at risk of abuse
http://www.counselandcare.org.uk/assets/library/documents/20_Abuse_Older_People_at_Risk.pdf

No secrets - This is the Department of Health guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse: <http://www.thamesvalley.police.uk/reduction/victimsofcrime/adult-protection/pdf/nosecrets.pdf>

Dignity in care within mental health

Introduction

The Dignity in Care Campaign, launched in November 2006, aims to eliminate tolerance of services that don't respect dignity. The initial focus for the campaign has been on older people, because they were identified as the group most at risk of not experiencing dignity when in contact with health and social care services.

The campaign is now being rolled out further and will look at issues relevant to dignity in mental health services. Ultimately, the campaign will be extended to all health and social care services.

What constitutes a dignified service does of course differ in some ways depending on the client group. Much of the information in this practice guide will be relevant to any client group. However, there are some specific areas of mental health services in which dignity may be more of an issue.

Recent evidence and feedback from stakeholders highlighted key areas where maintaining dignity is at risk:

- tackling stigma
- older people's mental health
- acute inpatient care.

Subject to further consultation with key stakeholders and mental health users it is intended to extend the dignity in care campaign to focus these key areas.

This section of the guide looks at mental health and dignity in care. It provides a range of resources and links to some specific practice examples which may be helpful to people working in mental health services.

Ideas from practice

Practice examples are self-reported and have not been evaluated.

Enhanced pathways into care (EPiC), Sheffield

The aim of the project was to build a partnership between a Crisis Assessment and Home Treatment team and the Pakistani Muslim Centre. This would enhance access to home treatment for Pakistani service users and reduce over-reliance on inpatient

services, and it would enhance the cultural appropriateness of the Crisis Assessment and Home Treatment service.

A community development worker was employed to work with a Pakistani Muslim Centre and, together with a Crisis Assessment and Home Treatment team member, saw service users at home. This constitutes a shared care operational policy, with the development worker actively identifying Pakistani service users. The Pakistani Muslim Centre also developed support services of its own for people with mental health problems.

The outcome was a managed care pathway designed for Pakistani service users, who reported greater satisfaction with services. Inpatient length of stay was reduced for 12.5 per cent of Pakistani patients, and those experiencing relapses sought help earlier.

For further information contact:

Sue Hammond, Team Leader, Project Support Unit, Department of Health.

Email: sue.hammond@dh.gsi.gov.uk

Improving the mealtime experience (Methodist Homes for the Aged)

Methodist Homes for the Aged (MHA) have introduced a range of initiatives across their care homes and housing schemes to improve the experience of mealtimes. The initiatives include a catering manual for catering and care staff with a clear set of standards, the introduction of routine nutritional screening, and assessment of residents' eating capabilities by speech and language therapists. In one particular home, staff have looked at ways to ensure residents' rights to privacy during mealtimes. Improvements have included the introduction of pleasant background music and fresh flowers at the dining table.

For further information contact

George Sampson, Head of Hospitality. Tel 0773 4151988.

Email George.Sampson@mha.org.uk

Life Story books (St Pancras Hospital, London)

The Evergreen Unit at St Pancras has developed Life Story books to support and inform the care they give to their patients. Where patients are able to contribute they do, but many have cognitive impairment and difficulty with verbal communication, so relatives are key in providing the information and are actively encouraged to be involved in completion of the books. The Life Story books help staff to engage with patients who have complex needs and are used to inform many aspects of care planning, from personalising bedrooms to meeting personal needs in a way that respects the person's wishes and promotes their dignity. The books, which were developed by the staff on the unit including nursing staff, occupational therapists and the psychologist, are also a guide to providing meaningful occupation. All new staff are taught how to use the books during their induction process. The books are given to the relatives/next of kin when the person dies and these have been welcomed as a 'nice reminder' of the person.

For further information contact:

Colin Owen, Email colin.owen@camdenpct.nhs.uk or Judith Greening,
Email Judith.greening@camdenpct.nhs.uk

Local Care Centre Cafe (Plymouth Primary Care Trust/Mental Health Partnership)

The Local Care Centre is a new development in Plymouth that provides a range of health services for the local community. The building's foyer houses a cafe, run by local mental health service users and coordinated by a local carer. The initiative is a joint venture between Plymouth PCT, users, carers and the voluntary sector, set up to enable people with long term mental health problems to gain access to paid employment. Within the first nine months of the scheme, two people found substantive employment.

Reports from service users suggest that the opportunity to work voluntarily in a supported – yet real – work environment has improved their confidence and enabled them to consider work as a real option.

For further information contact:

David Macauley, Plymouth PCT/Mental Health Partnership.

Palliative care support (Macmillan Cancer Support/Greenwich Teaching Primary Care Trust)

Greenwich Macmillan Palliative Care Support Service (funded by Macmillan Cancer Support and Greenwich Teaching PCT) aims to maximise choice for patients at the end of their lives, allowing them to die at home, if that is their wish, in maximum comfort and with maximum dignity. It also offers support to carers. The service operates 24 hours a day every day of the year, with a high level of flexibility to meet the needs and wishes of patients and carers, which can vary from day to day. There are three elements: daytime service, overnight sitting service and pop-in service (providing 15-minute checks through the night). The small, dedicated team of support workers from Greenwich Council are specially trained in health-related care and support for terminally ill patients, such as catheter and stoma care, pressure sore management, minor dressings, medication prompting, blood glucose monitoring, urinalysis, mouth care and peg feed care. They get to know the patient and carer very quickly and work at least 30 hours a week, to provide continuity of care. There has been very positive feedback and a formal evaluation is in progress.

Key learning points:

- Provide support 24 hours a day, seven days a week to ensure maximum flexibility to patients and carers; this is the key to enabling patients to die at home if this is their wish.
- Set up a specialist training programme before the service/new workers start.

- Training should include topics that cross the health/social care divide, such as care of the dying at home and after-death support, clinical communication skills, medicine management, spiritual diversity support, cultural diversity awareness, OT and physiotherapist support, and diet.
- Spend time in local hospice as healthcare assistants and with district nursing staff visiting patients in their homes.
- Use a small team, all working at least 30 hours a week - this makes continuity of care much easier.
- Establish a cross-agency steering group from the start, to enable good links to develop with the PCT continuing care nursing team, community specialist palliative care team, district nursing service and local carers' centre.
- Monitor demand - be ready and able to re-allocate hours between service elements if possible.
- Set up a single point of access to service - provided in this case by the PCT continuing care nursing team.
- Support the support workers - this is a very demanding service. Provide intensive line management support (24/7 if necessary), team meetings and external counselling. A rota of four days on three days off allows workers to recharge their batteries.

For further information contact

June Williamson, Macmillan Palliative Care Support Service Co-ordinator, Greenwich Homecare. Tel 020 8921 2349. Email june.williamson@greenwich.gov.uk

Success through the Single Assessment Process (Leasowes Intermediate Care Centre, Smethwick)

Leasowes is a bespoke 20-bed unit where patients (predominantly older people) can be assessed and rehabilitated. Often, they come in with complex needs and multiple medical conditions that may have culminated in a fall and they may have had difficulty managing at home. Staff believe that the use of the Single Assessment Process enables the whole team to deliver person-centred care. On admission, patients are asked what they want to achieve during their stay. Personal details such as how the person likes to be addressed, how they wish their privacy to be respected and issues of consent for information sharing with other organisations and partnerships are all an integral part of creating a respectful environment. The staff know that building a strong relationship with colleagues in the community ensures that good quality, person-centred services continues after the client has been discharged.

For further information contact:

Marian Long, Email marian.long@nhs.net or Ruth Clarke, Email ruth.clarke2@nhs.net

Other resources

Legislation relevant to offering dignified services within Mental Health:

The Mental Capacity Act will help underpin similar values to those upheld in the Dignity in Care Campaign. The Mental Capacity Act 2005 aims to empower people who lack capacity to make decisions, put them at the heart of the decision-making process, and provide clear safeguards for them and their families. It establishes important principles for professionals who work with this client group. The Act offers better protection because for the first time it tells everyone what the law expects. It makes it clear **who** can take decisions in **which** situations and **how** they should go about this. It aims to protect vulnerable people, carers and professionals.

Independent Mental Capacity Advocacy Service from April 2007:

This document provides guidance on the new Independent Mental Capacity Advocacy service, in England, and the new criminal offence in England and Wales that are introduced by the Mental Capacity Act from April 2007 and the planned implementation of the whole Act by October 2007.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_066049

For more information about legislation and how it relates to Dignity in Care, please look out for our forthcoming Guide to Dignity in Care Legislation which will be placed on SCIE's website shortly www.scie.org.uk

The National Institute for Mental Health in England (NIMHE) www.nimhe.org.uk

NIMHE (part of the Care Services Improvement Partnership) works with the NHS, social care and beyond, helping all those involved in mental health to implement positive change.

Currently, NIMHE are addressing some key priorities in Mental Health, including:

- a comprehensive programme to deliver race equality in mental health services
- a national programme on social inclusion
- new programmes to give people more choice in the services they can receive, and to give people greater access to psychological therapies
- work on primary care including commissioning
- workforce
- a new programme to support services to measure outcomes as part of their routine practice.

Promoting dignity within the law

Introduction

This is a brief introduction to the legislation which supports the rights of people, adults in the main, to dignity and respect when using health and social care services. It describes the workings of the Human Rights Act 1998 and some key legal provisions in the areas of discrimination, mental capacity, sexual offences, information legislation and health and safety. It also suggests ways in which apparent conflicts between the legal responsibilities placed upon practitioners and commissioners and the human rights of service users may be resolved. The requirements of the legislation promoting dignity in care may seem intimidating but it is important to recognise that many of the principles now enshrined in law embrace current best practice.

Who is it for?

It is aimed at practitioners and commissioners within health and social care in England and Wales, but will also be relevant to people using services and their carers. It should be helpful to anyone who wishes to understand the way legislation protects service users' rights, in particular, their rights to be treated with dignity and their right to autonomy – that is, their right to have their wishes respected.

This guide is at an introductory level, but provides suggestions for further reading and websites for more specific information.

Note: As a result of devolution there is increasing divergence in the regulation of social care and therefore practitioners should consult local guidance for detailed information.

Dignity in Care

To view the full version of SCIE's Dignity in Care practice guide please go to www.scie.org.uk/publications/practiceguides

Sources of law

This gives a very brief introduction to the basic workings of the English legal system. It explains the sources of law and the functions of the courts, as starting points for understanding the relationship between human rights legislation (guarding the rights and freedoms of individuals that have been agreed as fundamentally important in maintaining a fair society) and the care and treatment of adults using care services.

The rule of law

The rule of law, in simple terms, means that neither an individual nor the state is above the law. The rule of law is a crucial element of democracy. People cannot take action in connection with another person if the law prevents them from doing so. For example, organisations such as local councils cannot take action unless the law gives them the authority to do so. This applies even where the action is for the person's own good.

The role of the courts

Courts are both bound by and uphold the rule of law. Their function is twofold. They must decide what principles of common law and/or equity are relevant to the issues in front of them. They also have a crucial role to play in the interpretation of the will of Parliament as expressed in statute law.

Common law and equity

Common law is most simply explained as law that is established by the courts and developed from precedents (judicial decisions in earlier comparable cases). It is judge-made law. It is distinct from statute law, which is legislation passed by Parliament.

Equity describes the principles of fairness developed by the courts to mitigate or reduce the harsh impact of certain common law rules. For example, common law remedies are limited to damages (financial compensation), whereas equitable remedies can extend to specific performance (insistence that a party performs its obligations) and injunctions (orders preventing certain behaviour such as harassment).

Statute law

Statute law is law that has been passed by Parliament. As society has become more complex the role of common law has diminished and an ever-increasing number of statutes – Acts of Parliament – have been passed, dealing with more and more areas of behaviour within society.

Statutes start life as Bills. These may be sponsored by government ministers or be private members' Bills, and are debated and voted for in Parliament. They go on the statute book as an Act of Parliament when they receive the Royal Assent. Note: an Act does not necessarily come into force when it receives Royal Assent. Different Acts have different implementation schedules, which are either contained in the statute itself or announced later (the Mental Capacity Act 2005, for example, was not implemented until 2007, and then in two parts).

Delegated (secondary) legislation

No matter how long Parliament sits, it would not be able to pass sufficient legislation in the detail that the running of a sophisticated democracy requires. As its name implies, delegated legislation gives the power to some person or body to pass legislation, and many Acts of Parliament (which are primary legislation) contain a provision which gives ministers and other executive bodies, such as the Welsh Assembly Government, power to produce detailed regulations which are not debated by Parliament but have statutory force.

Delegated legislation, also known as secondary legislation, or statutory instruments, has the same effect as if it had been passed by Parliament through its normal process. However, the courts may overrule a decision based on secondary legislation, but not primary legislation.

Guidance

Guidance provides advice and assistance on the procedures for putting into action provisions of statute. It may be statutory or non-statutory. Statutory guidance – that is, guidance authorised by statute – is more authoritative than non-statutory guidance. The Code of Practice under the Mental Capacity Act 2005 is an example of statutory guidance. Non-statutory guidance might be, for example, in the form of local authority circulars.

As a general rule, all guidance should be followed unless there are powerful and justifiable reasons not to do so. In the field of social care and health services, guidance issued by the relevant Secretary of State or government department can be taken to be the clearest expression of the government's intention, although it remains the function of the court to decide what the legislation actually means should a particular guidance be questioned.

Good practice

Good practice is quite distinct from delegated legislation or guidance. It can be very helpful, and can provide principles for making decisions. It is not, however, statute law, and much of what does amount to good practice is not issued in the form of either regulations or statutory guidance. Therefore, good practice must always give way to the requirements of statute, regulations and guidance, if the requirements conflict.

Statutory interpretation

When courts have had to decide what a statute says, there develops a series of so called 'rules' that guide the courts. Their effect is to set out the approach that should be adopted by the courts. There are three main rules: first, the 'literal rule', which says that the words in a statute are taken to have their literal meaning unless such an interpretation produces a nonsensical result. In that case the 'golden rule' applies, which says that if the literal meaning produces an absurd result then it should be looked at in the overall context of the statute. If these two rules do not help then the 'mischief rule' is applied. This rule states that meaning is interpreted in the light of the problem or 'mischief' that the statute was passed to deal with.

Declaration of incompatibility

The Human Rights Act 1998 has an impact on statutory interpretation, in that courts must strive to interpret legislation in a way which is compatible with the European Convention on Human Rights and the intention of Parliament. When it is not possible to interpret the legislation in this way, the courts may strike down delegated legislation but not primary legislation, although they may make a declaration of incompatibility.

A declaration of incompatibility is the means by which courts inform Parliament that primary legislation may be in breach of the UK's obligations under the Convention. This should prompt Parliament to act, although it is not obliged to change the law.

Public law and private law

Public law cases are cases that involve the actions of public bodies, such as local authorities. Private law cases are concerned with actions between private individuals. The actions of public bodies, because they involve them intervening with the way individuals live their lives, are required to conform to certain standards. Those standards are achieved through the operation of the law. The particular area of the law that performs this function is administrative law.

Administrative law

The state is very powerful and well resourced in comparison with an individual. Administrative law attempts to ensure that justice is done between the state and the individual by embracing particular principles that operate to restrain arbitrary or wrong decision-making by the state. These principles are openness (often described as transparency in cases), fairness, rationality (including giving reasons for decisions), impartiality (which means that decision-makers should be independent), accountability, the control of discretion, consistency, participation, efficiency, equity, and equal treatment. Public bodies must also take account of service users' legitimate expectations (which means strong indications that the user can rely on public provision). These principles can be collectively described as the requirements necessary for fairness, and are often referred to as the requirements of 'natural justice'. Sometimes these principles conflict, and then the decision-maker must weigh up the various principles and make the best decision he or she can in the circumstances.

A home for life

When the local health authority decided to close the residential home in which she lived, Mrs Coughlin applied for a judicial review of the decision since, she had been promised the residence would provide her with a home for life. The court ruled that the closure decision was unfair, particularly in the light of the promise made to Mrs Coughlin, and could not be justified by an overriding public interest. [R. v North & East Devon Health Authority ex parte Coughlin (2001) QB 213]

Further information

For more information on the operation of the law see 'e-Learning: law and social work.

Brief summary of key legislation

The Human Rights Act 1998 (HRA)

The HRA came into force on 2 October 2000. It enables individuals in the United Kingdom to enforce – in British courts – 16 of the fundamental rights and freedoms contained in the European Convention on Human Rights (ECHR). This makes Parliament and public bodies more accountable to UK citizens through the courts. The fundamental rights include rights which impact directly on service provision in the health and social care sector, such as the right to life, the right not to be subjected to inhuman or degrading treatment, and the right to family life.

The HRA builds on the mechanisms in the ECHR which recognise that a balance has to be reached between rights and responsibilities. Not all rights are absolute and frequently practitioners are required to balance competing rights.

Further information

The Act can be found on the web at www.opsi.gov.uk/ACTS/acts1998/19980042.htm
Click here for explanations of articles of the Act particularly relevant to health and social care workers, with practical examples [Section 5 of this doc]

Click here for more on the balance of rights and responsibilities, with examples relating to health and social care [Convention rights in Section 4 of this doc]

The Ministry of Justice provides an excellent user-friendly guide to the Human Rights Act: see www.justice.gov.uk/docs/hr-handbook-intro.pdf and further details are on the Ministry of Justice website www.justice.gov.uk/guidance/humanrights.htm

Anti-discrimination legislation

Anti-discrimination legislation (sometimes known as equalities legislation) is designed to eliminate unjustifiable discrimination on legally specific grounds. It is constantly evolving, as society recognises new areas of inequality, and over the last 30 years a number of laws have been passed in response to changing public perceptions and the development of human rights law. The scope of the legislation is set out below.

(‘Regulations’ rather than ‘Acts’ denote that they were passed as secondary (delegated) legislation.)

Statute	Scope
Sex Discrimination Act 1975	<ul style="list-style-type: none"> prohibits discrimination on the basis of sex or marital status applies equally to discrimination against men and women also prohibits discrimination against a person on the basis of gender reassignment
Race Relations Act 1976	<ul style="list-style-type: none"> prohibits discrimination on the basis of race, colour, nationality (including citizenship) national or ethnic origin

Disability Discrimination Acts 1995 and 2005	<ul style="list-style-type: none"> prohibits discrimination against a disabled person – i.e. someone who has a disability as defined in Section 1 and Schedule 1 of the DDA from December 2006 all public bodies have a duty to promote a duty disability equality
The Race Relations (Amendment) Act 2000	<ul style="list-style-type: none"> places a duty on public bodies in carrying out their functions to have due regard to the need to eliminate unlawful discrimination and to promote equality of opportunity and good relations between persons of different racial groups.
Employment Equality (Sexual Orientation) Regulations 2003	<ul style="list-style-type: none"> prohibits discrimination on grounds of sexual orientation the definition covers lesbians and gay men, heterosexuals and bisexuals can include discrimination based on perception of a person's sexual orientation or association with individuals of a particular sexual orientation
Employment Equality (Religion or Belief) Regulations 2003	<ul style="list-style-type: none"> prohibits discrimination on the grounds of religion or belief no definition of religion or belief although the explanatory note to the regulations states that 'courts and tribunals may consider a number of factors when deciding what is a 'religion or belief' (e.g. collective worship, clear belief system, profound belief affecting way of life or view of the world).
The Employment Equality (Age) Regulations 2006	<ul style="list-style-type: none"> prohibits discrimination on grounds of age it is irrelevant whether the discrimination is because you are young or old

Anti-discrimination and public bodies

Originally, protection against unjustifiable discrimination was provided to individual victims. More recently, public bodies (for instance, central or local government, state schools, health trusts and emergency services) have been given strategic duties to eliminate unlawful discrimination. The Race Relations (Amendment) Act 2000, for example, extends the original 1976 Act by placing a duty on public bodies to promote racial equality as well as eliminate discrimination. The Equality Act 2006 amended the Sex Discrimination Act 1975 in a similar way. Public bodies must publish race, disability and gender equality schemes, which are their action plans for implementing their statutory duties.

Anti-discrimination in care

Anti-discriminatory practice is fundamental to the ethical basis of care provision, and equalities legislation is critical to the protection of service users' dignity. It imposes particular responsibilities on public bodies and service providers to avoid stereotyping and to respect service users' diverse needs and cultural diversity. Providers of health and social care also have equivalent responsibilities to their employees.

The legislation is designed to promote the dignity of citizens by ensuring that they are treated with respect. Together, these laws and regulations help to:

- prevent direct discrimination on the legally prohibited grounds
- prevent indirect discrimination unless it can be justified.

Direct discrimination occurs when someone is treated less favourably than someone else in similar circumstances on the grounds of their gender/marital status/race/disability/age and the treatment was detrimental.

Indirect discrimination occurs when a condition or requirement is applied equally to everyone but in practice the proportion of one race or gender who can comply is considerably smaller than other groups and an employee is unable to comply because of their race or gender and the employer cannot show the condition or requirement is objectively justifiable.

Further information

For more details see the website of the Equality and Human Rights Commission (EHRC) [[link:www.equalityhumanrights.com](http://www.equalityhumanrights.com)]. This is a non-departmental public body (accountable for its public funds, but independent of government) which oversees equality and human rights law and practice. It has taken over the functions of the Equal Opportunities Commission, the Commission for Racial Equality and the Disability Rights Commission, as well as oversight of the workings of the Human Rights Act 1998.

Mental health and mental capacity legislation

Mental Capacity Act 2005 (MCA)

The MCA provides a statutory framework to protect and empower adults who may lack capacity (ability) to make all or some decisions about their lives. It also governs the way decisions can be made for an individual who lacks capacity to make specific decisions at specific times.

Section 1 of the MCA sets out five principles to support decision-making either by or on behalf of a person who may lack capacity. In brief:

- There is a presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.
- Individuals should be supported to make their own decisions.
- People have the right to make unwise decisions and making an unwise decision does not mean they lack capacity to make that decision.
- If someone lacks capacity then an act done or a decision made for them under the Act must be done in their best interests.
- Anything done for or on behalf of a person who lacks capacity should be the less restrictive option.

These principles promote the human rights of people who may lack capacity because they enshrine respect for individual autonomy and make it clear that we should always

presume that a person has the capacity to make decisions unless it is established otherwise.

The government has published a Code of Practice to the Act, which provides guidance and information on how the Act will work on a day-to-day basis for anyone who works with or cares for people who lack capacity to make decisions, including family, friends and unpaid carers. Certain categories of people are legally required to 'have regard to' relevant guidance in the Code of Practice. That means they must be aware of the Code of Practice when acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves, and they should be able to explain how they have had regard to the Code when acting or making decisions. Those categories include people acting in a professional capacity for, or in relation to, a person who lacks capacity and people being paid for 'acts' for or in relation to a person who lacks capacity. These categories include a variety of healthcare staff, social care staff (social workers, care managers, support workers) and others who may occasionally be involved in caring for people who lack capacity, such as ambulance crew, housing workers or police officers. They will often include care assistants in a care home and home-care workers.

Further information

The legal definition of a person who lacks capacity is set out in section 2 of the Mental Capacity Act 2005 and elaborated on in chapter 4 of the Code of Practice. The Code of Practice is available from the Ministry of Justice website <http://www.justice.gov.uk/guidance/mca-code-of-practice.htm>

For more details see the DH core training sets on the Mental Capacity Act www.dh.gov.uk/publicationsmentalcapacityact2005

Mental Health Act 2007 (MHA)

The Mental Health Act 2007 amended the MCA to respond to what has been known as the 'Bournewood gap' (see box). This refers to the lack of a procedure to challenge the deprivation of liberty of a person resident in a hospital or care home who lacks capacity to consent to that deprivation.

Mr L and Bournewood Hospital

Mr L, a 49-year-old man with learning difficulties and autism, was detained under common law powers as an informal patient in Bournewood Hospital for a period during 1997, on the grounds that he required treatment for a mental disorder. He did not have capacity to consent to or to refuse admission and treatment. In 2004 the European Court of Human Rights held that Mr L's detention under common law was incompatible with Article 5 of the Human Rights Act (which is concerned with the right to liberty), because it was arbitrary and lacked appropriate safeguards. The European Court ruled that judicial review – which was the only way that Mr L had been able to challenge his detention at Bournewood – did not provide the kind of rigorous challenge that was required by human rights provision. [HL v United Kingdom (2004) ECHR]

The result of the Bournemouth case meant that compliance with the European Convention on Human Rights required the process of detention in such circumstances to be formalised. It needed to be clear, for instance, who could propose deprivation of liberty for people like Mr L and for what purpose. There needed to be procedures for review of the detention and formal mechanisms – such as an appeal – by which detention could be challenged.

The Mental Health Act 2007 introduced the 'Deprivation of Liberty' or 'Bournemouth' safeguards. These protect against illegitimate deprivation of liberty for people who do not have the capacity to consent to arrangements made for their care that would deprive them of liberty. Deprivation of liberty is to be avoided wherever possible and is only authorised if it is identified by independent assessment as a necessary and proportionate course of action to protect the person from harm. The MCA principles of supporting a person to make a decision when possible, and acting at all times in the person's best interests and in the least restrictive manner, apply to all decision-making in operating these safeguards.

The Mental Health Act also enhances the human rights of people who have a mental disorder. It requires the Code of Practice that is to be published in connection with the Mental Health Act 2007 to include a statement of the principles informing decisions made under the Act, which addresses the following matters:

- respect for patients' past and present wishes and feelings
- respect for diversity generally including, in particular, diversity of religion, culture and sexual orientation
- minimisation of restrictions on liberty
- involvement of patients or service users in planning, developing and delivering care and treatment appropriate to them
- avoidance of unlawful discrimination
- consideration of the effectiveness of treatment
- account taken of the views of carers and other interested parties
- respect for patients' well-being and safety
- account taken of public safety.

Further information

The Code of Practice for the Deprivation of Liberty Safeguards and training materials to support the implementation of this part of the Act are being developed at the time of writing this guide. Details of these will be put on the Department of Health and SCIE websites.

For the practical implications of the Deprivation of Liberty (Bournemouth) safeguards, see [link to Section 5, Art 5 of this doc]

Legislation protecting vulnerable people from abuse

One important part of the drive to promote respect for and dignity of people using services is the recognition of their particular vulnerability to abuse. Part of the Dignity in Care initiative is zero tolerance of abuse. The need to safeguard service users from some of the risks they face has led to a range of statutory developments.

The Sexual Offences Act 2003 (SOA)

This Act modernised the law on sexual offences. In the past there had been difficulties in bringing prosecutions against individuals who committed sexual offences against people with mental disorders. Under the Act, any sexual activity between a care worker and a person with a mental disorder is prohibited while that relationship of care continues. A 'relationship of care' exists where one person has a mental disorder and another person provides or may provide face-to-face care, where that care arises from the mental disorder. It applies to people working both on a paid and an unpaid basis and includes doctors, nurses, care workers in homes, workers providing services in clinics or hospital, volunteers and so on.

The offences in the Act relating to care workers apply whether or not the victim appears to consent, and whether or not they have the legal capacity to consent. Examples include the intentional sexual touching by a care worker of a service user who does not have the capacity to consent to that touching and a care worker causing or persuading someone with a mental disorder to engage in any sexual activity. Note that intentionality is important here. If a care worker follows the normal procedures for bathing and toileting this would be strong evidence that the behaviour was not intended to be sexual. In addition, the Act is not intended to interfere with the right of people with a mental disorder who have the capacity to consent to engage in sexual activity.

The SOA also attempts to make the prosecution of rape easier by clarifying the meaning of consent. Section 74 of the Act provides that someone consents to a sexual act if and only if he or she agrees by choice and has the freedom and capacity to make that choice.

Further information

More information on the SOA is available in a series of leaflets published by the Home Office which can be found at www.homeoffice.gov.uk/documents/adults-safe-fr-sex-harm-leaflet

Safeguarding Vulnerable Groups Act 2006 (SVG)

This Act sets out a new scheme which aims to help avoid harm, or risk of harm, to children and vulnerable adults by preventing people who are deemed unsuitable to work with children and vulnerable adults from gaining access to them through their work. The scheme will be introduced from autumn 2008 and replaces the Protection of Vulnerable Adults (POVA) List set up under the Care Standards Act 2000. It will

- provide employers with a more effective and streamlined vetting service for potential employees
- bar unsuitable individuals from working, or seeking to work, with children and vulnerable adults at the earliest opportunity.

The potential for enhancing the dignity of people using services is that the new Act will allow for more effective checking of staff, including workers in healthcare settings who are not covered under the POVA List. People receiving direct payments or individual budgets will also be able to access the scheme to make checks.

Further information

For further information and training on the new Act see ([link to Home Office's Safeguarding Vulnerable Groups Act site](#)).

Information legislation

Information legislation is overseen by the Information Commissioner's Office, an independent official body whose role is to promote access to official information and to protect personal information. All public and private organisations are legally obliged to protect any personal information they hold. Public bodies are also obliged to provide public access to official information. Specific obligations are set out in two important statutes.

The Data Protection Act 1998 (DPA)

Information held by public bodies is governed by the requirements of the Data Protection Act 1998 which requires data controllers who process personal information to comply with a range of data protection principles. In essence, this Act supports the importance of sharing information with people using services. There are very few exceptions to this. Enhancing the dignity of people using services demands that practitioners pay attention to confidentiality. There are some limits on confidentiality and these apply where there is a risk of harm to other people.

Data controllers are people, including organisations, who decide how and why personal data are processed. 'Personal data' refers to information relating to an identified or identifiable living individual which is processed automatically (including information processed on a computer) or recorded manually as part of a filing system or part of an accessible record. This will include records such as social services files. Processing covers anything done in relation to such data, including collecting them, holding them, disclosing them and destroying them. The eight data protection principles are key to understanding the Act:

Data protection principles	Comment
Fairly and lawfully processed	Lawfully refers to the requirements found in the common law of confidentiality, administrative law (the processing must not be 'ultra vires', i.e., outside the authority of the organisation or contrary to statutory provisions) and with the provision of Article 8 of the European Convention on Human Rights.
Processed for limited purposes	Information is held for a purpose. You should be clear what that purpose is and the information should only be used for that purpose.
Adequate, relevant, and not excessive	Only necessary information should be held.

Accurate	You have a responsibility to ensure that the information is accurate and you should have systems in place for checking the accuracy, for instance confirming details with your service user.
Not kept longer than necessary	Once the reason for holding the information is past then the information should be destroyed. There should be a system in place for checking regularly the continuing relevance of information held.
Processed in accordance with the data subject's rights	These are set out in Schedules 2 & 3 of the Act
Secure	Non-authorized people should not be able to get access to the information. You should be clear who has authority to access information and who does not.
Not transferred to other countries without adequate protection	Information should not automatically be sent to other countries when the service user moves abroad. The new country may not have similar standards of protection of information.

Further information

For general information on the Data Protection Act (1998) see <http://www.justice.gov.uk/whatwedo/datasharingandprotection.htm> which sets out principles which safeguard confidential information for citizens.

For Department of Health guidance on data protection, see [web link to Data Protection (Subject Access Modification) (Social Work) Order 2000]

The Freedom of Information Act 2000 (FoIA)

This provides statutory rights for members of the public requesting information. Under the Act any member of the public is able to apply for access to information (unless that information is covered by exemptions) held by a wide range of public bodies, including local authorities and hospitals. The FoIA imposes a duty on public bodies to adopt schemes for the publication of information which must be approved by the Information Commissioner.

Information legislation protects the human rights of service users by:

- ensuring that information held about someone is held only with a person's consent and is held securely
- ensuring that personal information is only shared on a 'need to know' basis
- enabling service users in certain circumstances to have access to the information that is held about them.

Further information

Further advice on handling personal information can be found on the Information Commissioner's website (link: www.ico.gov.uk)

Dignity in Care's relationship to human rights and equalities legislation

The government's Dignity in Care initiative highlights that 'High quality health and social care services should be delivered in a person-centred way that respects the dignity of the individual receiving them'. One crucial element of achieving dignity is for providers to understand the significance of human rights legislation.

The legal framework of human rights and anti-discrimination law requires that health and social care workers, alongside other providers of public services, respect the dignity of people using services. As the Department of Health points out in 'Human Rights in Healthcare – A Framework for Local Action 2007' [link to www.bih.org/downloads/Health_framework.pdf], a human rights ethos is an important way to improve services:

Quite simply we cannot hope to improve people's health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people's lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.

Human rights principles are very closely related to other principles of good professional practice that have underpinned public service provision for a long time. Human rights and health and social care practice share an ethical basis of concern with the autonomy, privacy and dignity of people using services. So, even before the vocabulary of human rights was developed, good practice in the delivery of social and healthcare recognised needs for privacy and dignity, and also recognised the tensions between these requirements and the need sometimes to protect people in vulnerable situations from harm.

However, the introduction of the Human Rights Act provided a real opportunity to look at traditional practices in social care and health services. It puts the focus on the person using services and so is different from a paternalistic culture where assumptions are made by professionals about what is best for the people in their care. Instead it gives us a way by which individuals or their advocates can articulate demands on services. A judge, His Honour Justice Munby, emphasised the importance of human dignity in a case that concerned health and safety regulations. He said:

The recognition and protection of human dignity is one of the core values – in truth, the core value – of our society and, indeed, of all societies which are part of the European family of nations and which have embraced the principles of the Convention...The other important concept embraced in the 'physical and psychological integrity' protected by Article 8 [of the Convention] is the right of the disabled to participate in the life of the community...This is matched by the positive obligation of the State to take appropriate measures designed to ensure to the greatest extent feasible that a disabled person is not 'so circumscribed and so

isolated as to be deprived of the possibility of developing his personality'. [R (on the application of A and B) v East Sussex County Council 2003]

Challenges to providers of care

One special feature of human rights requirements is that they may be enforced, or made to work, through legal action by people using services or their representatives. However, human rights cannot work solely through individual enforcement. The government takes responsibility for the enforcement of standards through guidance, inspection and regulation. In addition, organisations and individuals that deliver care and treatment need to understand human rights principles, accept challenges to the traditional way of doing things and adapt their practices in response. It is not only organisational policies or paperwork which must respond to positive participation in service delivery; everyday practices such as providing support with personal hygiene, eating and the discussion of confidential information with other people may be challenged by people using services and their advocates and will require responses from frontline workers.

This does not mean that every assertion of human rights must be complied with. Health and social care workers have a number of other legal responsibilities imposed on them, for instance through health and safety laws, through 'common law' duties of care, through legal requirements that personal information should be treated as confidential and processed in accordance with the principles of the Data Protection Act 1998 (see [add link to DPA above]) or through their contracts of employment, which may at times or in some circumstances appear to conflict with the necessity to respect human rights.

Particular dilemmas may face staff when there is a conflict between their legal responsibility to protect someone and that person's human right to self-expression, for example, of their sexuality. Moreover, people work in organisations that impose a whole range of demands and targets on them and it can be hard to see the relevance of human rights to these targets, never mind their central importance. What is often required is a careful consideration of the human rights issues involved, which need to be weighed against the other duties imposed on provision. Depending on the nature of the right asserted the right should only be infringed if it is legitimate, necessary and proportionate to do so. The different types of rights understood by the Human Rights Act are explained in Section 4 [add link to section 4]

Whistle-blowing

Dignity also requires providers of care to challenge practices in their own workplaces, to make it clear when service users' rights are being infringed. In extreme circumstances workers may have to contact external agencies such as local authorities or regulators to advise on possible malpractice. While this is essential for the protection of service users and organisations it can be a very risky step for individuals to take.

Some protection is given to employees who disclose malpractice, commonly described as whistle-blowing, by the Public Interest Disclosure Act 1998. This Act gives protection to those acting in good faith and with reasonable suspicion that malpractice has, is, or may be, occurring and who disclose this to a manager or an employer. It protects

employees from victimisation and dismissal. The Act is designed to ensure that organisations respond by addressing the message rather than the messenger and resist the temptation to cover up serious malpractice.

Families and friends may also find it difficult to raise concerns, and of course, people who are dependent on services may be very reluctant for fear of making things worse. Helplines (see below) may be useful sources of advice and support for anyone concerned.

Further information

Further information and support in connection with whistle-blowing are provided by the charity Public Concern at Work (www.pcaw.co.uk). See also [link to Whistleblowers section of DiC site]

National helplines include: Action on Elder Abuse (tel 0808 808 8141); Respond Helpline (0808 808 0700) and Voice (0845 122 8695). Others are run locally and details of them will be available from the local council.

The legal mechanisms for enforcing human rights

Generally, when someone has been the victim of a potential breach by a public body of their rights under the European Convention on Human Rights, the appropriate legal action will be judicial review of the public body's action by the High Court. Such cases usually have to be taken within one year of the action that is the subject of the complaint. When the court considers the human rights issue raised it will review the law to see if the public body had any choice about the action it took. It will try to interpret the legislative basis of the public body's action to see if it can be interpreted in a way which is compatible with Convention rights. If the legislation can be interpreted compatibly and the public body is found to have acted in breach then the court can remedy that breach using its usual powers.

The Human Rights Act also gives the courts a power to grant damages for breach of Convention rights. However, the courts are reluctant to do this and where they have made an award, the levels of damages have been quite small.

The greater political significance of the Human Rights Act lies in the actions the courts can take if the legislation cannot be interpreted compatibly. The courts' powers depend on the type of legislation that forms the basis of the public body's action. If the legislation was secondary legislation then the court may quash or disapply that legislation. However, if the breach arises out of primary legislation – an Act of Parliament – then the court cannot quash the legislation. This is because the Human Rights Act maintains the supremacy of Parliament, which must be recognised by the courts. Instead, what the courts can do is to make a declaration of incompatibility. Such a declaration will not make that Act invalid and the public body involved will not be acting unlawfully in applying the legislation. However, any declaration of incompatibility makes it clear to the government that there is a problem with the legislation and provides support for the victim in taking his or her challenge to the European Court of Human Rights in Strasbourg. This court hears cases brought against those states who

are parties to the European Convention, and acts as a final decision-maker on allegations of non-compliance.

The burden of proof

One early example of a declaration of incompatibility arose in the case of Mr H. Under the Mental Health Act 1983 the burden of proof rested on the patient to show that he no longer suffered from a mental disorder that warranted his detention. The Act did not require a tribunal to discharge a patient who could not be shown to be suffering from a mental disorder warranting detention, and the courts found the lack of such a requirement amounted to unlawful detention and infringed a person's right to liberty. The court therefore declared sections 72 and 73 of the Mental Health Act 1983 incompatible with Article 5 of the Human Rights Act, which protects the right of liberty. The government acted quickly and reversed the burden of proof. [R. (on the application of H) v Mental Health Review Tribunal (2001)]

There is another mechanism built into the Human Rights Act, which is designed to ensure that all new legislation takes the European Convention into account. A minister who is introducing a Bill into Parliament has to make a statement as to whether or not the Bill is compatible with Convention rights and to highlight those provisions of the Bill which are relevant. All Bills are scrutinised by the Joint Parliamentary Committee on Human Rights. This is a committee of both Houses of Parliament which has considerable expertise in human rights law and is able to make proposals as to how a Bill can be made more compatible with Convention rights. It also carries out inquiries into problematic areas such as human rights and terrorism, and human rights and vulnerable people.

The legal mechanisms for enforcing equalities law

Discrimination arising out of employment is dealt with by employment tribunals. The time limit for starting the case is normally three months from the date of the last discriminatory act.

If the discrimination takes place outside the employment field (for instance in connection with the provision of care services), the case is brought in the county court. Proceedings have to be started within six months of the last act complained of, or eight months in the case of discrimination in education. The court can order damages to be paid, including compensation for distress to feelings, and an injunction requiring the discriminator to do or stop doing certain acts.

Service users (and employees) who wish to complain about discrimination can contact the Equality and Human Rights Commission (link to: www.equalityhumanrights.com) for advice and support.

Adhering to human rights law

This section

- provides a brief history of the Human Rights Act
- explains the features and terms of the Act relevant to dignity in care
- explores some of the potential and limitations of the Act
- provides examples of grey areas of interpretation relevant to health and social care.

The origins of the HRA

The primary purposes of the HRA are

- to enable the rights set out in the European Convention on Human Rights 1950 (ECHR) to be enforced through the UK courts
- to provide a check on the activities of Parliament and public bodies.

The Act is set out in <http://www.opsi.gov.uk/ACTS/acts1998/19980042.htm>

The most significant force behind the ECHR was the Second World War and its aftermath. The ECHR was designed to prevent a repeat of the rise of fascism and totalitarianism and to restrict the oppression of individual rights in the name of the state and in the name of the majority. As Lord Justice Sedley put it in a lecture to the Legal Action Group:

The Convention is a child of its time – the post-war years when the states of western Europe tried to set their faces both against the devastation of the recent past and against any new form of totalitarianism. So the Convention says many important things about due process, personal integrity and free speech and ideas; but nothing directly about the most elementary of all human needs, a right to enough food and shelter to keep body and soul together.' [Lord Justice Sedley, 'Legal Action', December 2003, p.19]

British lawyers were actively involved in the drafting of the ECHR; the UK signed it in 1951 and the ECHR became binding upon its signatories in 1953. However, the UK for many years refused to incorporate the Convention into its domestic law. This meant that, prior to the implementation of the Human Rights Act in 2000, enforcement of the Convention's provisions was through the European Court of Human Rights in Strasbourg and not through the British courts.

Since 2000 many people have relied on the Act to assert their individual rights under the Convention. Perhaps more importantly, public services have reviewed their provision to ensure that they comply with the legislation. However, a rights-based culture is not achieved only by individuals saying what their rights should be or asserting their rights or by organisational policy and practice documents. It requires people who are in the front line of service delivery to understand the requirements of the law.

This is a much more subtle demand than simply giving people their rights when they demand them; it requires an understanding of the law and the balancing acts that are inevitable in society. Nonetheless, if frontline workers understand that there is a legal duty on them to avoid some of the routine indignities imposed on people using services, then the circumstances of many people's lives will be improved. The case of Mrs Bernard (see box) illustrates the potential of human rights.

Respect for family life

Mrs Bernard, a severely disabled woman, lived with her family in inappropriate local authority accommodation. Despite the social services department having assessed her needs and recommended special adaptations so that, for instance, Mrs Bernard could access the bathroom, the High Court found that the local authority had failed to respond to the family's needs. The court said that the local authority had positive obligations to enable the family to live as normal a life as possible and to secure Mrs Bernard's physical integrity and human dignity. The lack of action by the local authority was a breach of Mrs Bernard's right to respect for family life, under Article 8 of the Convention. [R. (Bernard) v Enfield LBC (2002) EWHC 2282]

Explanation of some technical terms

Before describing the nature of rights enshrined in the Convention, it is necessary to explain some of the technicalities about the ways in which they operate and summarise some important aspects of the Convention that frontline practitioners may find helpful when trying to make sense of this complicated area.

Public bodies

While the courts have to consider the Convention rights in all cases, even if they do not involve a public body, a person can only bring a case under the Act if the act or decision in question is one made by a public body.

A public body is best understood as a body carrying out a governmental or public function, although the exact remit of public body is still being worked out by the courts. Examples of organisations which are definitely public bodies include local authorities such as councils, central government departments, NHS trusts, and state-run schools, hospitals and prisons. It also extends to private companies that exercise public functions, such as companies that run private prisons. There are, however, grey areas. Some bodies have mixed public and private functions – for the purposes of the Human Rights Act they are described as 'hybrid' authorities. The question of which bodies are 'hybrid' has turned out to be complex. Many housing associations, for instance, carry out functions which courts may decide are public functions. However, other functions would clearly be private functions.

It is difficult to provide clear guidelines on whether a housing association is or is not a public body. In one important case (*Donaghue v Poplar Housing and Regeneration* [2002] EWHC 2559), the court decided that because the housing association concerned had a particularly close relationship with and was performing very similar functions to a

local authority, then it was a public body. However, in another case heard the same year (*Heather v Leonard Cheshire Foundation* [2002] 2 All ER 936) the Leonard Cheshire Foundation, a charity providing residential care for disabled people, was held by the court not to be a public body.

A decision in this area made by the House of Lords in June 2007 highlighted the scope and limits of the Human Rights Act. It concerned the private provision of care in a care home to a woman who was publicly funded (see box).

Public or private?

A woman with Alzheimer's disease, aged 84 years, was threatened with eviction from the private care home where she was living, because of what was said to be the bad behaviour of her family when they visited her. Medical opinion was that the woman, known as YL to protect her privacy, would be put at considerable risk if she were moved. Lawyers for YL argued that it was a breach of her human rights under Article 8 of the Convention (which covers respect for an individual's home) if she were evicted. They argued in the House of Lords that the private care home was exercising the functions of a public body because the local authority had funded YL's placement there after assessing that she was in need of care because of her condition. The private care home argued that it was not carrying out public functions but was a private body, and it said that the funding source of any individual service user is irrelevant. [*YL v Birmingham City Council* [2007] UKHL 27]

The House of Lords, on a majority decision, found in favour of the care home. It decided that the provision of care services by a private body did not engage the provisions of the Human Rights Act, even in circumstances where a public body was paying the fees of the service user.

Where a service is provided by a private organisation, even though the provision is publicly funded, individual victims of bad treatment cannot claim the protection of the European Convention. They are limited to private law remedies such as breach of contract or proving wrongdoing.

There are three points to note here.

- Local authority care workers and support workers or nurses in the NHS and other employees of public bodies are bound by the provisions of the Act.
- The law may change. The decision in the case of YL was not unanimous: there is the possibility of a different decision in the European Court of Human Rights, and the Joint Parliamentary Committee on Human Rights has recommended changing the HRA to specifically cover publicly funded residents of private residential care homes.
- Finally, even if an organisation is not a public body, it is very useful for staff to be aware of the implications of the HRA. The Convention provides a sound framework for ensuring that service users' dignity is preserved.

Living instrument

This is an important feature of the Convention. The Convention is a living instrument, which is designed to be interpreted in the light of current social and cultural conditions. It is not 'frozen' in the 1950s when it was first drafted. So the fact that a challenge under the Convention has failed in the past does not mean that it will not succeed in the future.

The idea of rights as things that evolve as we become more aware of the impact of certain practices is particularly relevant to how people are treated in social care and health settings. For instance, what were once often seen as normal institutional practices in some care homes, such as putting residents to bed or providing meals at times that suited staff rather than residents, are now generally and rightly seen as unacceptable.

Margin of appreciation

This is a technical term that has lost some clarity in its translation from French. What it means is that the European Court of Human Rights will allow domestic courts (e.g. in the UK) some space to make decisions which reflect their national domestic concerns, rather than impose its interpretation on the way the rights laid out in the Convention should operate. This is particularly relevant when the domestic courts have to weigh up competing priorities, for instance the individual liberty of the service user and the reduction of risk to workers providing the service. Of course, the margin of appreciation can only go so far; the European Court of Human Rights does ensure some consistency in the interpretation of the Convention.

Victims

Only 'victims' can take action under the Act. What this means is that only people who have been directly affected by an act or omission of a public body can take action using the Act. This means that a patient pressure group, for instance, could not take action to enforce patients' human rights. It could, however, be involved in any action taken by a person directly affected, providing support, expertise, evidence and so on.

Victims do not have to be UK citizens.

Rights under the Convention

The rights in the HRA are taken straight from the European Convention on Human Rights. Rights are formulated in different ways under the Convention, and are categorised as absolute, limited or qualified.

Absolute rights

Some rights are so fundamental that they are absolute. These rights include the right to protection from torture, inhuman or degrading treatment, and the prohibition on slavery. What this means is that if a practice – for instance toileting in full public view with no recognition of the need for privacy – is found to be inhuman and degrading, it cannot be justified because of necessity or public interest.

Limited rights

Other rights are limited, but can be breached only in the explicit and finite circumstances set out in the ECHR. In other words, the Convention itself provides exceptions to the general right.

One example is Article 5: the right to liberty and security. Exceptions include the power of the state to arrest and detain people suspected or convicted of crimes and the detention of people with 'unsound' mind. Article 5 also states: 'Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.' This has enabled people admitted to hospital under compulsion or 'sectioned' under mental health legislation to challenge the operation of mental health review tribunals for not being speedy enough and for failing to ensure that patients are discharged quickly if the criteria for detention are not met.

Qualified rights

Certain rights are qualified, which means that interference with them (i.e. action which limits someone's freedom under a qualified right) is permissible only if:

- there is a clear legal justification for the interference
- the action is necessary to achieve a legitimate aim – legitimate aims are set out in each article of the Convention
- the action is necessary in a democratic society; in other words, there must be both a pressing social need and the action taken must be proportionate to and no greater than the problem it seeks to resolve.

Examples of qualified rights are the right to respect for private and family life (Article 8) and the right to freedom of expression (Article 10). The wording of Article 8 illustrates what is meant by a qualified right.

Paragraph 1 of Article 8 sets out the right:

Everyone has the right to respect for his private and family life, his home and his correspondence.

(When 'he' is written in a law it includes 'she'.)

Paragraph 2 sets out the limits:

There shall be no interference by a public body with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals or for the protection of the rights and freedoms of others.

So, in certain carefully defined circumstances Article 8 rights can be interfered with.

This Article is particularly important in connection with the provision of personal care services and with the handling of confidential information. The limits on Article 8 that are particularly relevant for care workers are where an action that would interfere with someone's Article 8 rights is necessary for the protection of health or morals or for the

protection of the rights and freedoms of others. This does not mean that the right can be overruled in all circumstances, for example, where the practitioner considers that the health of the service user is at risk. It is also necessary that the acts which make up the interference with a person's human rights are proportionate to the aim of the interference. The examples below explain what this means.

Proportionality is a particularly important requirement. Interference with rights is not justified if the means used to justify the aim are disproportionate. For instance, a care worker may be concerned that a service user is at risk from traffic if she or he goes out alone. It would be disproportionate to the risk to lock the person in their room to ensure they were not injured in traffic. Medical treatment without consent poses particular problems. It cannot be imposed on someone except in very limited and statutorily defined circumstances that are supervised by the courts.

A more straightforward example is that the state can interfere with a person's right to a family life if a child will suffer significant harm by remaining with the family, but not because the child will have a better standard of living if taken away from the family.

The qualifications on Article 8 mean that an individual's freedoms must always be balanced against public safety – and remember that the state has a responsibility which is set out in Article 2, the right to life, to protect the safety of its citizens. So, as long as the interference with the person's private life is legitimate and proportionate, the rights of individuals can be breached.

Relevant articles in the Convention of the Human Rights Act

All the articles of the Convention covered in the HRA may relate to people who use services and their carers in certain circumstances, and practitioners should be aware of them. Those highlighted here are of particular relevance: click on them for further explanation, practice points and practice examples.

Article 2	establishes a right to life
Article 3	is the right not to be subjected to torture, inhuman or degrading treatment
Article 5	provides a right to liberty and security
Article 6	ensures the right to a fair trial and to innocence until proved guilty
Article 8	provides the right to respect for private and family life, for home and for correspondence
Article 10	provides the right to freedom of expression
Article 14	prohibits discrimination in the 'enjoyment' of Convention rights

Further information

For further discussion of these articles see the Ministry of Justice study guide www.dca.gov.uk/peoples-rights/human-rights/pdf/act-studyguide.pdf

The full text of the Convention rights included within the Human Rights Act, can be found in <http://www.opsi.gov.uk/ACTS/acts1998/19980042.htm>

Five training packs for frontline workers are available at [www.dh.gov.uk/publicationsMental Capacity Act 2005](http://www.dh.gov.uk/publicationsMentalCapacityAct2005)

There is very useful guidance to the Act in SCIE's e-learning tools: [link to <http://www.scie.org.uk/publications/elearning/law/index.asp>]

Article 2: a right to life

Individuals have the right to have their life protected by law. There are only certain very limited circumstances where it is acceptable for the state to take away someone's life, and in certain circumstances the state has positive duties to protect life. One example is where someone is a prosecution witness whose life is under threat (see box).

Witness for the prosecution

Mr Van Colle, who was to have been a witness against a former employee charged with theft, was shot dead by the accused before the trial. Van Colle had received threats against his life, and the Court of Appeal ruled that the state had breached Article 2 in failing to take the measures within the scope of their powers that, judged reasonably, might have been expected to protect their witness's life. The court made it clear that, where it was established that the state authorities knew or ought to have known of the existence of a real and immediate risk to the life of an individual as a result of the criminal acts of a third party, the state had a positive obligation under Article 2 to take preventive, operational measures to protect that individual. [Van Colle v Chief Constable for Hertfordshire (2007)]

The positive obligations on public bodies to protect life mean that failure to take necessary precautions may be a breach of Article 2. Cases where breaches of Article 2 have been claimed include destitute asylum seekers who could not access healthcare or subsistence and prisoners forced to share cells with violent cellmates who may place their life in jeopardy.

Examples of potential breaches of particular relevance to organisations in the field of health and social care might include:

- failure to observe necessary procedures to reduce the risk of infections in hospital and care settings
- failure to protect a vulnerable person in a residential care home who was killed by an abusive relative, or a failure to investigate any such death properly
- failure to assess and treat someone in care who was at risk of suicide
- a decision to move frail or vulnerable people from a residential care home resulting in illness or death
- a day centre user dying as a result of the administration of drugs by unqualified staff
- staff in a care home failing to follow a doctor's recommendation to check hourly on a resident during the night

Practice points

Organisations should have:

- regimes which ensure that the health and safety of service users, such as patients, residents or users of day care services, are prioritised
- regular risk assessments of the premises and of routine practices so that all risks are identified and managed
- strategies for identifying, minimising and managing the risks of transfers of service users from one residential home to another location
- appropriate management to check that health and safety requirements are adhered to by all staff
- training on health and safety so that all staff understand the importance of these procedures.

Practice example

Miriam is very frail and unable to feed herself while in hospital. The catering staff place her meal out of reach, and the nursing staff neglect to assist her with eating. As a result the catering staff remove untouched food and Miriam's lack of food intake goes unnoticed. Food and drink are basic requirements of life, and failure to have a system in place to provide help with eating or drinking where required could potentially be a breach of Article 2. Miriam should alert a member of staff and later on, she or her family might wish to make a complaint to the hospital, through the Patient Advice and Liaison Service (England) or Hospital Complaints Service (Wales).

The closure of a residential care home where the residents are frail poses particular challenges. Policies should be in place to ensure that the risks to residents are minimised and managed. They should, for instance, include a medical assessment of the risk of transfer when assessing residents' needs, consideration should be given to moving staff along with residents to new or refurbished homes, and transfers should be postponed until a time when any risk is minimised. For instance, moving vulnerable people during the winter months may increase the risk of fatal illness.

Further information

For more details of human rights implications, see the Age Concern Information sheet [link to: www.ageconcern.org.uk/AgeConcern/Documents/IS10_0404.pdf]

Article 3: the right not to be subjected to torture, inhuman or degrading treatment

Inhuman and degrading treatment can arise as a result of failure to assess an individual's need for services and a failure to provide necessary services in a timely manner and at an appropriate level. Article 3 could be relevant to failures by public services to protect vulnerable adults from abuse or neglect. In social or healthcare settings practices such as tying residents of a care home into chairs would almost certainly be inhuman, and it could be argued that failure to prevent and treat bedsores could be a breach of Article 3.

Under the National Health Service and Community Care Act 1990, local authorities have a duty to provide information, a duty to assess (section 47) and a duty to promote equality under the Race Relations Amendment Act 2000.

The threshold for breach of the Article is high, and not all treatment that we might consider being undignified would breach the Article. So, for instance, neither of the following was considered to breach Article 3:

- the restraint of a prisoner, including the use of handcuffs, during medical treatment and the presence of security officers during medical consultations and treatments, as any interference was proportionate to the risk the prisoner posed [R. (on the application of Botmeh) v GSL UK Ltd (2007)].
- the strip-searching of the mother and half-brother of a prisoner awaiting trial for drugs offences, given the suspicions with regard to the prisoner and the fact that there was an endemic drugs problem in the prison. However, it was noted that the procedures were lax and had been conducted with a regrettable lack of courtesy. Also, the strip-searching was found to be a breach of Article 8 rights, because the interference was not proportionate to the legitimate aim [Wainwright v United Kingdom (2006)].

Despite the high threshold it is important to understand that its purpose is to ensure that everyone is treated with dignity, and the approach of a good service ought to be aimed at preserving dignity, rather than on what level of indignity the law is prepared to tolerate. The focus should be on the dignity of people using services. Dignity means

treating each person as an individual and with the same respect as we would want for ourselves or members of our own family. (For more on the meaning of dignity, see [link to Dignity in Care intro page - definition]).

Further information

For more detailed guidance on aspects of dignity linked to abuse, see Abuse section in guide.

The Mental Capacity Act 2005 [add link to Section 2] offers another route to challenge wilful neglect and mistreatment because it made these criminal offences when looking after a person who lacks mental capacity. For details of a set of useful information booklets for the public and for people working in health and social care see: <http://www.justice.gov.uk/guidance/mca-info-booklets.htm>).

Practice points

- Local authorities have a responsibility to ensure that any care home in which they place residents has adult protection or safeguarding services that will help practitioners, families and friends as well as residents take up their concerns about inhuman and degrading treatment.
- Every local authority and healthcare organisation should have policies and procedures in place to protect vulnerable adults from abuse or neglect and to provide redress should abuse occur. Relevant to this would be a robust complaints procedure and a whistle-blowing procedure.
- Staff's rights to whistle-blowing may be important to remember when they feel that they are witnessing inhuman or degrading treatment. [add link to Whistle-blowing in previous section]
- Local policies about adult protection or safeguarding give details of local contacts.

Practice example

In a decision relevant to social and healthcare, the Court of Appeal ruled that the denial of state benefits to late applicants for asylum was incompatible with Article 3 [CA 18 March 2003].

Most degradations occurring in the realm of health and social services, however, arise from a lack of thought rather than malice or intended inhumanity. For example, a regime where food is given at the same time as a person is using the toilet may be explained – but not excused – by understaffing and lack of training. Staff need to be alerted to the unacceptability of such degrading behaviour and a new regime implemented that restores dignity to the service user.

Article 5: a right to liberty and security

This means that a person can be detained only in certain circumstances, following a proper, lawful procedure that provides the detainee with opportunities to challenge their detention.

Tribunals and courts that hear challenges to detention must conform to a high standard of procedural protection. When three prisoners challenged the operation of the parole board, the court found that the structure of the parole board and the way that it was controlled by the Secretary of State were such that it did not enjoy the independence from the executive necessary for a court under Article 5. [R. (on the application of Brooke) v Parole Board (2007)]

The significance of Article 5 was illustrated by what has become known as the Bournemouth case (see [link to: Mental Health Act 2007 in Section 2]). The European Court of Human Rights held that the routine detention of incapacitated adults in the UK was in breach of their Article 5 rights. In its judgment the European Court said that:

the key factor in the present case [is] that the healthcare professionals treating and managing the applicant exercised complete and effective control over his care and movements.

and

the applicant was under continuous supervision and control and was not free to leave.

As a result, the government introduced the Deprivation of Liberty safeguards (under the Mental Health Act 2007).

Understanding the Deprivation of Liberty (Bournemouth) safeguards

Briefly, the managers of care homes or hospitals who identify that a person who lacks capacity is being (or risks being) deprived of their liberty, must apply to a 'supervisory body' for authorisation of the deprivation of liberty, unless it would be appropriate to detain the person under the Mental Health Act 1983 or 2007.

When a person in this position is staying in a care home the supervisory body will be the relevant local authority. Where the person is in a hospital it will be the relevant primary care trust, or, in Wales, the National Assembly for Wales. In an emergency, the care home or hospital management can itself provide an urgent authorisation supported by written reasons for a maximum of seven days.

The safeguards are explained in more detail in the forthcoming Code of Practice (link to <http://www.justice.gov.uk/docs/mca-cp.pdf>). This is an essential read for practitioners working with people with 'mental disorders' in care homes and hospitals.

Practice points

- It may be difficult for care homes or hospitals to recognise that someone is being deprived of their liberty. Organisations must ensure that they have systems in

place to consider whether care plans deprive an 'incapacitated' adult of his or her liberty. Staff must keep these cases under review and ask the question about deprivation of liberty explicitly whenever a change is made to the care plan. This should be recorded in the person's health and care records.

- Indications that liberty has been deprived could include: sedating a patient who is resisting admission, any decision that the person would be prevented from leaving if they made a meaningful attempt to do so and refusals of requests by carers for the person to be discharged to their care.
- The Code of Practice to the Deprivation of Liberty safeguards will be invaluable and should be easily accessible to staff in care homes and hospitals, and training should be taken up as soon as it is available.

Further information

For more general information see 'Human Rights in Healthcare – a framework for local action', Department of Health, March 2007 (<http://www.dh.gov.uk/en/Publicationsandstatistics/Publications>).

Practice example

Mrs Bailey made arrangements to enter a care home when she could no longer walk and needed a lot of help looking after herself. Over the past months she has become increasingly confused and has been diagnosed with vascular dementia. She often tries to leave the home to 'go to school' and staff persuade her to come back. This seems to be the sensible thing to do, but at a care review, her key worker raises with the home's manager the question of their right to do this: might this be construed as depriving Mrs Bailey of her liberty? They decide to contact the local office of adult services and ask to have the legal position clarified.

Article 6: the right to a fair trial and innocence until proved guilty

This concerns the requirement for civil rights to be fairly determined, and for criminal trials to contain full procedural safeguards. Article 6 has been the most litigated of the Convention articles, particularly in the criminal sphere. Cases have made it clear that Article 6 rights arise when, for instance, a care worker is placed (even temporarily) on a list of people prevented from working with vulnerable adults (the Protection of Vulnerable Adults, or POVA, List, introduced by the Care Standards Act 2000).

The basic right is to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law, and each of these elements of the right is important. Article 6 does not only apply to court hearings. Decisions by public bodies which deprive people of their rights should comply with the Article. The Charity Commission has produced principles for fair decision-making. These set out, for example, that decisions and decision-making processes should be open, fair, timely and impartial, that decisions should be communicated in a way that will not overawe or confuse the recipient, that the decision is, and can be seen to be, free from personal prejudice or bias and making sure that case files or other records demonstrate a clear

trail of the decision-making process and never expressing biased or unsubstantiated opinions.

Further information

For more on the Charity Commission's guidelines, see <http://www.charity-commission.gov.uk/supportingcharities/ogs>)

Practice points

- Ensure that service users have information about their legal rights.
- Maintain a list of local services that are experienced in working with people who may have communication difficulties or other needs (translators, for example).
- Provide service users' legal representatives with advocates and communication specialists where this is necessary.
- Provide staff with practical training on legal developments when this is appropriate to their role and responsibilities.
- Develop procedures that make decision-making involving an individual's rights transparent and fair, and ensure there is sufficient opportunity for individuals to put their case to the decision-maker.

Practice example

Mrs Turner says Mr Brown touched her inappropriately and, as part of the safeguarding adults procedure, the matter is being investigated and the police have been called. The situation is unclear, because Mrs Turner has dementia and has accused other men of having touched her but the allegations have never been substantiated. On the other hand, although Mr Brown denies having touched Mrs Turner, he has been known to display inappropriate sexual behaviour. Safeguarding procedures must ensure that Mr Brown is not labelled as a sexual offender and that he has access to independent legal advice.

Article 8: the right to respect for privacy, home and family life

All rights of citizenship are relevant to private and family life under Article 8. A few examples of its wide range of influence include:

- the right to respect for one's house and belongings
- the right to choice in personal relationships
- the right to confidentiality of personal data.

Article 8 limits the state's interference with individual and family autonomy except in certain circumstances, such as taking a child into care or replacing the 'nearest relative' under mental health law. However, normal social and healthcare practices relate to an individual's health and private life, and practitioners need to have a regard for the right to respect in many different areas. Below are just a few examples.

Article 8 and respect for the person

If the rules of somewhere such as a group or residential home prevent residents from forming and maintaining friendships or personal relationships with other people (such as partners, parents and children) they may be in breach of Article 8. Failure to provide

community support which leads to someone being admitted to hospital under a section of the Mental Health Act 1983 or 2007 may well be a breach of Article 8. Indeed, in future, courts may decide that there are positive obligations on the government to enable people with learning disabilities or mental health problems to take part in the life of their local community.

Another aspect of respect for the individual arises with regard to assessments for social care services. Local authorities and other public bodies should ensure that assessments are carried out without avoidable delay, and that individuals are provided promptly with the social care they have been assessed to need (as required under the NHS and Community Care Act 1990). It is not good enough to say, for example, that a person need not be assessed under because they would be likely to have to pay for any services.

Article 8 and respect for an individual's home

Service users' rights to live in the home of their choice are an obvious example of a right protected by Article 8, and there has been important litigation on this issue. The decision of the health authority in the case of Mrs Coughlin (see [link to box in Section 2]), for instance, was successfully judicially reviewed because her needs had not been properly considered. The commitment made by local authority that the home would be permanent had not been properly taken into account, and there had been no demonstration of public interest in the closure. Not all commitments made to a service user will lead to a successful judicial review, however. In the case of Mr Lindley, the court found that he had not relied on the assurances made to him, to his detriment. Moreover, the local authority's knowledge of Mr Lindley's needs had developed since it made the assurances, and it was right for it to have changed its conclusions as to how his needs were to be met. Further, even if there was an enforceable expectation, it was contrary to Mr Lindley's welfare needs for the local authority to be required to move him to a new care facility. [R. (on the application of Lindley) v Tameside MBC (2006)]

Article 8 and personal autonomy

Article 8 also protects personal autonomy to a greater extent than care workers might expect. It means staff of public bodies, such as nurses or care assistants, must respect individual decisions unless interventions are legally sanctioned and required. This would include, for instance, the right of a person to behave against medical advice. This may be counter-intuitive to health and social care workers, because that behaviour might lead to a fatal outcome.

Article 8 and privacy

This Article also has an impact on in the ways in which we obtain and keep confidential information – asking someone for details of their medical condition in the hearing of other people, for example, may be a breach of the privacy protected by Article 8. In certain circumstances, it might be necessary and proportionate to share confidential information, but disclosure of confidential information has to be proportionate, which means people should only be given the information on a 'need to know' basis. What is required is an assessment of the reasons for disclosing information and a balance must

be reached between those reasons and the common law duty of confidentiality and a service user's rights to privacy.

Further information

For general information on the Data Protection Act (1998) see <http://www.justice.gov.uk/whatwedo/datasharingandprotection.htm> which sets out principles which safeguard confidential information for citizens.

For healthcare see:

<http://www.dh.gov.uk/en/Policyandguidance/Informationpolicy/Patientconfidentialityandcaldicottguardians/index.htm>

And for social services see:

http://www.dh.gov.uk/en/Publicationsandstatistics/Legislation/Actsandbills/DH_4015584

Department of Health guidance on rights and risks is available to download from [link to: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_074773]

Article 8 is the most open to interpretation and prompts particular dilemmas, because a service user's assertion of Article 8 rights might conflict with professional and legal duties. A court has to balance society's interests against those of the individual, between the rights enshrined in Article 8 and the rights and responsibilities of other people. (For more on these possible conflicts, see next section [link to Section 6].) What should be kept in mind for now is that this Article is qualified and not absolute. What this means is that the right can be interfered with, but only where that interference is necessary, legitimate and proportionate.

Particular difficulties may arise when a service user lacks the capacity to make decisions or consent to care or treatment.

Practice points

- Local authorities should take into account both the individual service user's wishes and, where appropriate, those of his or her family and friends when making decisions about residential care and similar major moves. If it is hard to work out what a person's wishes may be, in some circumstances an advocate may be appointable (see IMCA provisions of the Mental Capacity Act 2005 in the Code of Practice and the Department of Health training materials).
- Assessments for social care and other services should be carried out without due delay and appropriate services should be provided so that care and support are adapted to the needs and preferences of the individual as far as possible.
- Assessments should take into account all risks of service provision, including the risk of closure of a service. Something such as the closure of a care home or closing down a service may by itself seem to be only an organisational matter, but its loss may impinge on service users' human rights.
- Service providers should record the decision-making process, ensuring that every effort is made to determine the service user's preferences. This is particularly

important when service users do not have the capacity to make specific decisions for themselves

- Personal information should be stored securely and should only be accessed by people with authority to have it.
- Organisations should provide training for staff on the importance of confidentiality, pointing out the ease with which an individual's rights to privacy can be breached and how this can be prevented.
- Effective complaints procedures need to be in place. These include organisations that are contracted to supply social or healthcare services under service level agreements; and should let people know how to take complaints about maladministration further, to the relevant Ombudsman system.

Practice examples

Mrs Jones worries that she has to disclose information about her medical condition to her community nurse in circumstances where other people can overhear. This is possibly in breach of her Article 8 rights to privacy. However, there is a notice in the waiting area of the health centre saying that patients are welcome to talk to the practice manager if they have any comments about the service. Mrs Jones does this and the health centre makes better arrangements about privacy.

Miss Sharma reports her distress to the Commission for Social Care Inspection when she has observed that care workers often shout across the corridor to one another details of the continence status of residents in which her aunt lives. She feels that this does not show respect for the residents' privacy and dignity. The inspector takes this up with the home manager and the matter is resolved. Practices in care homes concerning matters such as this raise particular issues about the respect for human rights. Age Concern, with a number of other organisations, has produced an excellent leaflet, 'Behind Closed Doors: Using the toilet in private', which provides useful information on best practice. The leaflet is available on <http://www.bgs.org.uk/Publications/dignity/BehindClosedDoors.pdf>

Article 8 and mental capacity

The Mental Capacity Act 2005, which is built on human rights principles, helps resolve difficulties that arise through impaired mental ability. It protects and empowers people who lack capacity to make decisions or to consent to care and treatment in a variety of ways. Two particular aspects are that of acting in the best interests of the individual concerned, and that of restraint.

Acting in a person's best interests

The Mental Capacity Act 2005 (sections 1–4) supports the common law principle that any decision or action taken on behalf of a person who lacks capacity to make this decision or consent must be in his or her best interests. What actually is in someone's best interests depends on the circumstances of each individual case. Interventions, such as medical treatment, will be lawful where there is both a necessity to act, and any action is in the best interests of the incapacitated adult as long as

- you abide by the law and Code of Practice, respecting people's wishes and any advance decisions
- any action is proportionate
- when you have a choice of actions you choose the alternative which is the least restrictive of the service user's freedom.

The MCA's Code of Practice (<http://www.justice.gov.uk/guidance/mca-code-of-practice.htm>) is a key document for practitioners, who must have regard to it. It also applies to people who have been granted lasting power of attorney or who have been made court-appointed deputies.

Restraint

In the rare circumstances that restraint needs to be used, staff will be protected from liability (for example, criminal charges) if certain conditions are met. There are specific rules on the use of restraint, both verbal and physical, and the restriction of liberty, and these are outlined in Section 6 of the MCA Code of Practice, which notes that restraint should only be used as a last resort, or in exceptional circumstances.

If restraint is used, staff must reasonably believe:

- the person lacks capacity to consent to the act in question
- that it needs to be done in his or her best interests
- that restraint is necessary to protect the person from harm
- that it is a proportionate or reasonable response to the likelihood of the person suffering harm and the seriousness of that harm.

Restraint can include physical restraint, locking a door and verbal warnings to stop someone going somewhere or doing something but cannot extend to depriving someone of their liberty. Staff must be trained in this area, and they must record when and why they have restrained a person.

Restraint may also be used under common law (as distinct from the Mental Capacity Act 2005) in the rare circumstances where there is a risk that the person lacking capacity may harm someone else. Again, staff must make a record when and why they used restraint. The Code of Practice for the new Deprivation of Liberty safeguards, when it is issued, this will cover areas that might relate to issues of restraint.

Services users, or other people on their behalf, can complain if they think restraint has been wrongly used. Frontline practitioners are advised to seek advice about the legal position of people who they think are possibly being detained without legal safeguards. Whistle-blowing under the Public Interest Disclosure Act 1998 is an option for staff who feel that their concerns are not being addressed.

Further information

See <http://www.dti.gov.uk/employment/employment-legislation/employment-guidance/page16186.html>

Practice examples

Samantha and Ben, who live in a group home for people with learning disabilities, start a sexual relationship. Samantha's social worker talks to her independently about this decision and about the risks. Ben's community nurse has a similar conversation with him. The practitioners ensure as far as possible that both have consented to the relationship and see their role as supportive. The rights of Samantha and Ben have been respected because the practitioners have worked with them to try to ensure that their best interests are considered but also that they have retained autonomy. The practitioners will record their discussions in the case records.

Carla, who has lived in a supported housing project since leaving care, has put her health at risk by eating an excessive amount of cakes and biscuits. The project workers decide, as they owe her a duty of care, that they should restrict her spending money so that she cannot binge on sweet things. In this example, Carla's rights have been infringed. She has the capacity to make decisions; it is just that the staff think that what she is doing is not right for her. They may feel strongly that they are acting in her best interests, but they are overlooking her right to autonomy: her Article 8 rights mean that Carla has a right to her money and to make decisions about how to spend it. The project workers should tell Carla about why they are concerned, and put those concerns in writing; they should also ask for advice for themselves about the best way to progress, for example, from the local health promotion service.

Article 10: the right to freedom of expression

Everyone has the right to hold opinions and to express their views on their own or in a group. This applies even if these views are unpopular or disturbing.

The Article makes it clear that it is legitimate for the state to impose restrictions on freedom of expression in certain circumstances. These constraints must be prescribed by law and be necessary in a democratic society, in the interests of national security, territorial integrity or public safety, for the prevention of disorder or crime, for the protection of health or morals, for the protection of the reputation or the rights of others, for preventing the disclosure of information received in confidence, or for maintaining the authority and impartiality of the judiciary.

This Article can cause difficulties because different people have different levels of tolerance. One person may see it as a freedom to express him or herself by listening to loud rock music; another may find the noise intrusive.

Practice points

- Work alongside residents and their advocates to develop a policy on freedom of expression and keep the policy under review.
- It is appropriate to allow people to display posters, for example, in their own room that may not be tolerated within communal areas.

Practice example

Some of the staff working in a group home are very upset by anti-abortion publicity material to which two of the home's residents subscribe. The atmosphere of the home is tense. Everyone can see that people have the right to self-expression in theory but it is hard for both groups to manage this in practice. There is no legal answer to this problem, but the manager is likely to have to exercise her skills at people management, and to provide opportunities to listen to everyone who is concerned. She might suggest that the residents make certain rules about what is best for communal areas of the home and what might be best kept in people's bedrooms.

Article 14: prohibition of discrimination in the 'enjoyment' of Convention rights

This is not a freestanding article – it can only be claimed if the discrimination affects an area which falls under another article of the Convention.

The grounds for discrimination are very broad; the article forbids discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status. Remember the important limit: it can only be invoked when another article of the Convention has been engaged. In effect, it piggybacks on the other articles of the Convention.

There is much potential for litigation in areas where health and social care services are concerned. It is, for example, illegal to discriminate against adults with learning disabilities in connection with any of their Convention rights. This means, for example, that practitioners should with others to examine the quality of provision of public services, including healthcare and housing, for people with learning disabilities and consider their ability to access these services.

Practice points

- Staff should be alert to possibilities of discrimination. They should not automatically limit people's experience, for example, because of their disability. Any limit on activities should be justified, and those limits kept under review.
- Staff should receive training in how to avoid discrimination and know where to get advice. They should be aware of the services provided by the for Equality and Human Rights Commission.

Practice example

Daniel, a disabled person who also has a severe mental health problem, is told he is not going to receive support services which will enable him to remain in the community. He feels this may be because of his mental health problem. The refusal of support services, he argues, is in breach of his Article 8 rights. He additionally claims breach of Article 14. Daniel has the right to ask for an explanation and if he is not satisfied with this he can seek legal advice. The Equality and Human Rights Commission will provide advice if practitioners feel that they are not able to find an easy and independent source of legal expertise to assist in a position such as Daniel's.

Remember that this is a summary, for full details see
www.echr.coe.int/convention/webConvenENG.pdf

Summary of further legislation that supports Dignity in Care

Care workers in health and social care have a whole range of legal and professional responsibilities both to the people for whom they provide services and to others, such as their fellow workers and unpaid carers. These responsibilities are very important. Human rights should not be used as an excuse for failing to discharge those responsibilities. The Bichard inquiry (www.bichardinquiry.org.uk) into the murders of Jessica Chapman and Holly Wells highlighted concerns that confusions about the operation of human rights and data protection legislation caused failures to record essential information about alleged sex offenders. It was not the Human Rights Act that caused the difficulties but the failure to understand how it operates. The key point is that the human rights of any one individual do not override duties to ensure public safety. The response to this inquiry led to the Safeguarding Vulnerable Groups Act 2006 (link to relevant paras in Section 2)

Quality in care

Circumstantial influences on dignity, such as the living conditions in care homes or the standards in day centres, are governed by a whole host of regulations.

National minimum standards

The first National Minimum Standards for Care Homes for Older People were published in 2001. They consist of 38 standards, each with an outcome for people using services. They set out a set of requirements to ensure that care is focused on a service user's needs. The individual standards do not stand on their own, all the standards should be complied with and placed in the context of the Care Standards Act 2000 and its regulations.

National minimum standards in social care are an example of the chain of accountability. The interpretation of the national minimum standards in each care setting in England is the responsibility of inspectors from the Commission for Social Care Inspection. But, as the inspectors take a whole view of the care service and focus on the experience of the users of services, it is not always possible to define the interpretation of an aspect of the national minimum standards in isolation.

It is worth noting that, for employers, a particular lapse in standards can breach more than one area of law. For example, in a care home looking after incontinent residents, allowing pools of urine to lie on the floor would lower the living conditions of the residents to an unacceptably undignified level, but would also contravene the Health and Safety at Work Act (1974) for employees.

Food Safety Act 1990, Food Safety (General Food Hygiene) Regulations 1995 and Food Safety (Temperature Control) Regulations 1995

The Food Safety Act covers the preparation, storage and service of food and requires the registration of food businesses whether they are run for profit or not. A 'food business' includes canteens, clubs and care homes.

For more on guidelines on food quality, nutrition and dignity at mealtimes, see [link to Mealtimes in Dignity in Care site]

Legal responsibilities

The fact that a responsibility is a legal duty generally means that any action that interferes with a qualified right, such as the rights in Article 8, is going to be seen as legitimate and necessary. It does not answer the question about proportionality (whether the action is excessive).

The **Manual Handling Operations Regulations 1992** cover the transporting or supporting of a load (including people). While employers are required to ensure that they comply with the regulatory framework, this does not mean that an individual's human rights can be disregarded. What is required is a balanced approach that reduces risks for workers while at the same time maintaining the dignity, privacy and autonomy of those they are caring for. The problem of lifting an overweight person, for example, must be solved not ignored (see box).

Heavy lifting

The county council, concerned for the health of its employees, imposed a blanket ban on manual lifting of patients and other service users. Unfortunately this resulted in the certain people (known anonymously as A, B, X and Y) not receiving the community care to which they said they were entitled. There are detailed guidelines on manual lifting set out in the Manual Handling Operations Regulations of 1992, but the court held that these did not prohibit manual handling of people, nor operate a cut-off above which they would be too heavy to lift manually. Failure to lift these people could leave them stuck in a bath or on a lavatory, or suffering from bedsores. This created a potential breach of Article 3 of the Human Rights Act (the right not to be subject to inhuman or degrading treatment). Care workers' rights to a safe working environment must be respected, but these require safe working practices to be devised, not blanket bans that restrict levels of service. [R (on the application of A and B, X and Y) v East Sussex County Council (2003)]

Responsibilities to carers

Family and friends who act as unpaid carers often play a vital role in maintaining the dignity of service users, particularly when the person they are caring for is incapacitated, either physically or mentally. There are legal responsibilities to carers and some of these are contained in the following Acts:

Carers (Recognition and Services) Act 1995 (CRSA)

Carers and Disabled Children Act 2000

Carers (Equal Opportunities) Act 2004.

Other responsibilities to carers are contained in the Mental Health Acts 1983 and 2007 and the Mental Capacity Act 2005.

In summary, the responsibilities for practitioners are to assess carers' needs and to involve them in developing support for service users if that what both wish.

There may be circumstances in which responsibilities to carers appear to conflict with the human rights of service users. If a service user lacks the capacity to make a decision or to consent to care and treatment, then the provider of health or social care services must act in the best interests of that person.

It is generally in the best interests of the service user to have the carer involved in decisions about his or her care (but sometimes it is not). If there is a conflict between the best interests of the carer and the best interests of the service user, then the best practice is to seek advocacy and separate practitioners for both parties. It may be that independent advocacy services should be involved or commissioned to resolve the conflict. In some cases an independent mental capacity advocate (IMCA) might be able to act; the local authority and NHS trust will have details of how to contact this service locally and advise on what services it offers.

Further reading

Human Rights

'A guide to the Human Rights Act 1998', 3rd ed, produced by the Department of Constitutional Affairs (precursor of the Ministry for Justice), available for download at www.dca.gov.uk/peoples-rights/human-rights/pdf/act-studyguide.pdf

See also the Liberty guide to the Human Rights Act at <http://www.yourrights.org.uk/>

Discrimination law

'Discrimination law handbook', Camilla Palmer et al, Legal Action Group, 2007

'Age discrimination handbook', Declan O'Dempsey et al, Legal Action Group, 2006

Community Care

'Community care and the law', Luke Clements and Pauline Thompson, Legal Action Group, 2007

'Using the law in social work', Robert Johns, Learning Matters, 2007

Glossary

Capacity – the ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is set out in section 2 of the Mental Capacity Act 2005 and elaborated upon in chapter 4 of the Code of Practice.

Common law – so called 'judge made' law. A system of law developed by the courts which depends upon judicial application of precedents decided in earlier cases. It is distinct from statute law which is legislation passed by Parliament.

Delegated legislation (or secondary legislation) Many statutes (which are primary legislation) give Ministers and other executive bodies, such as the Welsh Assembly Government, power to produce detailed regulations which are not debated by Parliament but have statutory force.

Declaration of incompatibility – this is a decision of the courts that informs Parliament that primary legislation may be in breach of the UK's obligations under the ECHR. Parliament is not obliged to change the law as a result of a declaration of incompatibility.

Equality and Human Rights Commission a non-departmental public body (NDPB) established under the Equality Act 2006 – accountable for its public funds, but independent of government. It has taken over the functions of the Equal Opportunities Commission, the Commission for Racial Equality, and the Disability Rights Commission as well as oversight of the workings of the Human Rights Act 1998. Its website is www.equalityhumanrights.com

Equity – principles of fairness developed by the courts to mitigate the harsh impact of certain common law rules. For example common law remedies are limited to damages (financial compensation) whereas equitable remedies such as specific performance (insistence that a party performs its obligations) and injunctions (orders preventing certain behaviour such as harassment) can be granted at the discretion of the courts.

European Convention on Human Rights – the document drafted by European nations who were members of the Council of Europe after the Second World War. It sets out the agreed rights and freedoms of individuals.

European Court of Human Rights – this court sits in Strasbourg, France and hears cases brought against those states who are parties to the European Convention. It acts as a final decision maker on allegations of non-compliance.

Guidance – this may be statutory or non statutory. It provides advice and assistance on the procedures for putting into actions provisions of statute. Statutory guidance –that is guidance authorised by statute - is more authoritative than non-statutory guidance. The Code of Practice under the Mental Capacity Act 2005 is an example of statutory

guidance. Guidance does not have the force of law, but good reasons, recorded in writing, are needed to justify deviations from guidance.

Human Rights – these are the rights and freedoms of individuals that have been agreed as fundamentally important in maintaining a fair society.

Human Rights Act 1998 – This Act contains, at Schedule 1, the fundamental rights set out in the European Convention and enables people in the UK to take complaints about human rights to UK courts.

Joint Committee on Human Rights – this is a committee of both Houses of Parliament which scrutinises proposed legislation with a view to determining whether or not human rights are respected. It also carries out inquiries into problematic areas such as human rights and terrorism, and human rights and vulnerable people. The website of the JCHR is [\(link\)](#)

Protocol – there are a number of protocols to the Convention. These are rights which are later additions to the rights under the Convention

Public authority – people who carry out functions of a public nature are likely to fall into the definition of public authority. The exact remit of public authority is still being worked out by the courts. Examples of organisations which are definitely public authorities are:

- central government
- local government
- courts and tribunals
- prisons
- NHS trusts

Statute – legislation passed by parliament. Statutes start life as Bills which are discussed in parliament. They become statutes – Acts – when they receive Royal Assent. Note an Act does not necessarily come into force when it receives Royal Assent. Different Acts have different implementation schedules which are either contained in the statute itself or announced later in parliament (for example, the Mental Capacity Act 2005 was not implemented until 2007, and then in two parts).

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