

Learning Disability Project

Patient safety issues

People with learning disabilities

Reasonable adjustments

Keys to successful support

Clinical tools

Supporting consent

Supporting carers

Training & education

Supporting Material

Imperial College Healthcare
NHS Learning Disability
Strategy

Easy read version of strategy

Improving support to people with learning disabilities

The Trust has embarked on a two year project to improve health outcomes & safety for patients with learning disabilities and other vulnerable patients

Medicine CPG has employed an Acute Liaison Nurse for Vulnerable Patients who will work alongside a number of work streams, including equality & diversity, dignity and safeguarding.

The post holder will:

- Ensure that the trust complies with relevant legislation, including the Human Rights Act, the Disability Discrimination Acts and Mental Capacity Act
- Set standards of care for vulnerable patients and those with complex needs
- Develop care pathways for vulnerable patients and those with complex needs
- Implement workforce development strategies; including action learning
- Ensure that information is available for people with learning disabilities in an accessible 'easy read' format

For further information contact:

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Patient safety issues for people with learning disabilities

A number of recent reports and investigations have highlighted that people with learning disabilities often fail to get appropriate and safe healthcare when accessing acute hospital services.

The National Patient Safety Agency (2004) have highlighted the risks facing people with learning disabilities when coming into acute hospital settings, including:

People with learning disabilities are particularly vulnerable in acute hospital services, leading to varying degrees of harm

Swallowing difficulties are very common which if not managed safely they can lead to respiratory tract infections, a leading cause of early death for people with learning disability.

Illness or disease is often missed or undiagnosed resulting in delays in correct diagnosis and treatment. This could lead to undetected serious health conditions and avoidable deaths.

The Disability Rights Commission has used the term '**diagnostic overshadowing**' to describe the tendency for clinical staff to attribute disease and illness to an individual's disability or mental health condition.

Information is rarely available in a format that a person with a learning disability is able to understand.

All NHS Trusts are now required to review how they ensure the safety of people with learning disabilities and to put in place strategies and **clinical tools** aimed at reducing health inequalities and ensuring safety for this group.

The Trust has employed an Acute Liaison Nurse to support the Trust to make positive changes; reporting to the **Safeguarding Committee** and supported by the **Learning Disability Project Board**.

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Video

<http://www.nhs.uk/video/pages/medialibrary.aspx?Id={83DF3FD2-5D8B-4773-87FA-941734D0EB9F}&Uri=video/2008/October/Pages/HeavyLoad.aspx>

4 minutes

http://www.nhs.uk/video/pages/medialibrary.aspx?Id={E19D37EB-997F-4BAA-B015-D695B9386D3F}&Uri=video/2008/april/Pages/cs_downsyndrom.aspx

3 minutes

Supporting patients with learning disabilities in an acute hospital setting

Patients with learning disabilities will need special consideration to ensure that they receive care and treatment which meets their specific needs and maintains their safety

Learning disability includes the presence of:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood and has a lasting effect on development.

Frequently many people with learning disabilities also have physical and/or sensory impairments, epilepsy or autism.

It is estimated that around 10,000 people with a range of learning disabilities will be residing in the area covered by the Trust.

Around 1,500 individuals with severe or complex learning disabilities are known to the **Community Learning Disability Teams** locally.

Remember, learning disability is a label which describes only one aspect of a person.



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Vulnerable Patients Information Form

Handy Hints Leaflet

Supporting people successfully

Preparation is crucial to supporting people with learning disabilities successfully; whether carrying out examinations, investigations, treatment or supporting an admission onto a ward.

Below are some guidelines to assist you to provide safe and high quality care to people with learning disabilities and other vulnerable patients.

Use the **Vulnerable Patients Information Form** to gather information about the person's support and access needs.

Ensure that you know how to use the **Learning Disability Admissions & Discharge Pathway**

Improving communication

Speak to the person with a learning disability first and only check details with carer/health facilitator if something is not clear.

Show the person any equipment that you will be using. Show them where it will go and explain why you are using it, in **simple language**.

Tell the person if anything that you are doing might hurt them.

Use language at an appropriate level and ensure that you have been understood by looking for non-verbal as well as verbal signs of agreement.

Person with a learning disability may not understand the link between how they are feeling and the event that has/is going to happen. **Using pictures and objects assist understanding**.

Relate to things that are in the person's experience and that they will understand e.g. take tablets with breakfast and dinner, rather than twice per day.

Avoid using jargon words, even if they seem to be in common usage e.g. 'the menopause', or phrases that could be taken literally e.g. 'the change'. We all use more jargon words than we are aware of. Remember to simplify language, as well as letting the person with Learning Disabilities know what is expected of them.

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Office of the Public Guardian Website

[Making Decisions a Guide](#)

[A guide to consent for people with learning disabilities](#)

Video

http://www.direct.gov.uk/prod_consum_dg/groups/dg_digitalassets/@dg/@en/documents/digitalasset/dg_070412.wmv

http://www.direct.gov.uk/en/DisabledPeople/HealthAndSupport/YourRightsInHealth/DG_10016888

Supporting individuals to consent to care or treatment

Giving consent is an integral part of all healthcare or treatment for all patients. Consent must be given freely and by a person who has the mental capacity to make a decision.

Clinicians must assume that everyone can give consent unless he or she has assessed that the person lacks mental capacity.

Capacity must be assessed at the time a decision needs to be taken and relates only to the decision at hand.

Clinicians and support workers must take all practicable steps to enable the person to consent. This may involve explaining treatment in very simple terms, using pictures, diagrams or video resources or giving more time for the person to process information.

The Mental Capacity Act (2005)

The Mental Capacity Act which came into force in October 2007 safeguards the interests of people who may lack the ability to make decisions for themselves; either now or in the future.

The Act provides a legal framework to guide clinicians around supporting vulnerable patients to consent to care or treatment or when providing care or treatment in a patients 'best interests' for those who capacity.

Independent Mental Capacity Advocacy Service (IMCA)

The Act has created independent advocacy for patients who lack the capacity to consent, have no next of kin whom to consult and where serious medical treatment is being proposed.

It is the responsibility of the lead clinician (decision maker) to make timely referrals to the IMCA (where appropriate).

For more information see the Trusts policy on Consent

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Mental Capacity Act Pathway

Learning Disability Admission & Discharge Pathway

Vulnerable Patients Information Form

Clinical tools & pathways

A number of tools are available to support clinical staff including:

The **Vulnerable Patients Information Form** can be used to gather specific information about an individual to assist with care planning or making reasonable adjustments.

The **Learning Disability Admission & Discharge Pathway** is designed to ensure that good advice is sought from carers or specialist learning disability teams regarding meeting the needs of patients with complex support needs

The **Mental Capacity Act (Consent) Pathway** is intended to guide clinicians regarding supporting patients that may require additional support in order to consent to care or treatment or to guide decision making around best interests for those lacking mental capacity.

A **Vulnerable Patient Care Pathway** is being designed and is expected to be available early 2010.

Your feedback on the usefulness of the tools as well as this online resource would be appreciated

Please contact the Acute Liaison Nurse for Vulnerable Patients
darryl.chapman@imperial.nhs.uk

Imperial College Healthcare NHS Trust

Important Information on vulnerable patients

RED ALERT - Things you must know about me!

Name: _____

Date of Birth: _____ Religion: _____

These are the people who need to be contacted:

Names and roles: _____ Tel: _____

GP: _____ Tel: _____

Allergies: _____

Current Medication: _____

Medical Conditions: _____

Medical Interventions: _____

Behaviour that may be challenging: _____

Eating and Drinking Issues: _____

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Useful resources and links

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Carers Support Organisations

Supporting carers in an acute hospital setting

Carers are an invaluable resource with regards to information about how to communicate effectively with the person, providing a detailed history or indeed supporting the individual with anxiety or understanding.

Health Staff will usually need to listen carefully to families & support staff to ensure that appointments run smoothly and effectively.

Carers commonly comprise either informal family carers or paid support workers or learning disability professionals.

The role of informal carers is primarily to support communication or to provide emotional support and orientation to the ward environment.

Hospital staff should not rely on relatives or paid carers to provide personal care or physical support unless there have been explicit discussions and agreement about how continuity of care and safety will be achieved.

Carers who remain with a patient should be offered drinks and meals as well as opportunities to take breaks from caring.

A Vulnerable Patients Policy will be produced and is likely to include more detailed information with regards to how informal or familiar carers are utilised.

Your feedback with regards to the role of family carers or the usefulness of this information would be appreciated.

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Patient Reported Outcome Measures (POMS) for vulnerable patients

Handy Hints Leaflet

Training & Education

The Acute Liaison Nurse for Vulnerable Patients can provide support and informal training sessions to clinical staff teams within Medicine Clinical Practice Group.

We will work with people with learning disabilities & family carers to develop a high quality & interactive training resource.

Please contact us if you would like training or support for your team or department.

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Additional resources

Supporting material

Useful resources & links to other organisations

Community Learning Disability Teams

Westminster

020 7641 7411

Kensington & Chelsea

0207 313 6843

Hammersmith & Fulham

020 8383 6464

Westminster Learning Disability Partnership Website

Easy Health Website: easy read information for people with learning disabilities

Mencap

Type Talk (RNID)