

# First Signs

**Celebrating the  
achievements of  
the Dementia Advice  
and Support Service:  
a project for people  
in the early stages  
of dementia**

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# Acknowledgements

The Mental Health Foundation would like to acknowledge the generous support which the Dementia Advice and Support Services (UK) Project received from the following organisations:

- AXA UK plc
- Barnwood House Trust
- The Beatrice Laing Trust
- The Bernard Sunley Charitable Foundation
- Constance Travis Charitable Trust
- The William D Foord Trust
- Donald Forrester Trust
- Garfield Weston Foundation
- The Haremead Trust
- J & JR Wilson Trust
- The John Ellerman Foundation
- Lloyds TSB Foundation
- Louis Nicholas Residuary Charitable Trust
- The Roger de Haan Charitable Trust
- RPH-Promotor Stiftung
- The Tudor Trust

We are also grateful to the Department of Health for England for funding the development of the web-based Learning Network [www.mhilli.org](http://www.mhilli.org)

This project has also benefited from the generosity of many individual supporters.

Thank you to our National Advisory Group, listed below, for supporting the project.

Ms Jane Bell, Deputy Chief Executive, Alzheimer's Society  
Dr Patrick Brooke, GP, Newbury, Royal College of GP's  
Dr Tom Denning, Old Age Psychiatry Advisor, Department of Health  
Ms Jan Dewing, Senior Fellow Dementia Care, RCN Institute  
Mrs Carol Dick, CPN early onset dementia, Newcastle  
Mr Andrew Fairbairn, Consultant Old Age Psychiatry, Newcastle  
Professor Jane Gilliard, Director, Dementia Voice  
Mr Tom Owen, Research Officer, Help the Aged  
Ms Valerie Lipman, Research and Development Manager, Age Concern England  
Mr Peter Scurfield, Auditor, Audit Commission  
Ms Barbara Stephens, Chief Executive, For Dementia

**This report is dedicated to the people with early dementia and their relatives who used the pilot services and the workers who took such care to understand and meet their needs.**

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## **The Mental Health Foundation**

The Mental Health Foundation is the UK's leading charity working to promote mental well-being. It campaigns for the rights and needs of people with mental health problems and people with learning disabilities. The Foundation's key aims are to improve people's lives, reduce stigma and discrimination and encourage better understanding. It achieves this through conducting and supporting research and encouraging improvements to local services. The Foundation provides online, printed and verbal information to the public and people working in relevant fields. The organisation aims to maximise knowledge, skill and resources by working with service users, government and service providers.

The Mental Health Foundation will be referred to as the Foundation throughout this report.

## Executive summary

This report is a celebration of the Mental Health Foundation's Dementia Advice and Support Service (DASS) UK Project.

The report was inspired by an event held in late March 2003 in Kendal when most of the DASS site co-ordinators and their colleagues presented papers on their work and experiences. It marked the end of the two-year period of Foundation funding for the pilot sites and the first stage of disseminating the sites' successes to the wider world.

This report outlines the background to the Mental Health Foundation's DASS (UK) project, touching on the policy and research context of early intervention in dementia services. The introductory section also sets out the four different aspects of the project and shows how they were all designed to be complementary: the national advisory group, the six pilot sites, the evaluation of these and the web-based learning network.

The next section of the report describes the achievements of each of the six pilot sites and the lessons learned.

- Nottingham considers the difficulty of ascertaining whether a person has been diagnosed with dementia or not before being referred, and if they have, whether or not they have been informed of that diagnosis.
- Glasgow looks at two aspects of an advice and support service for people with early dementia – counselling and providing information.
- South Lakes considers two further elements – befriending and the value of groups.
- Calderdale give some thought to how an advice and support service responds to the particular needs of ethnic minority people and also offers a carer's view (a member of their steering group) on the need for the service.
- North-West Wales share their learning about how to find volunteers to help people with dementia maintain involvement in their local community.
- Winchester provides a case study in how such services can fit in to the local partnership working between the voluntary sector, primary and secondary health care and social services.

The next section of the report considers whether the national and local objectives of the project have been met, firstly by considering the responses to a series of questions that were put to grantholders and secondly by reflecting on the observations and conversations that have been conducted over the three years of the project.

The final section looks at the current policy horizon, which has now moved on significantly since the project was first conceived, and considers some other initiatives that are looking to improve services during the early stages of dementia.

A full evaluation of the project will be available next year.

# Background to the project

In 1999, the Foundation decided to extend its core work into the field of older people with mental health problems. Before this date it had funded two research initiatives and a small number of community projects but had not invested substantial resources in this arena<sup>1</sup>. This shift in emphasis was fuelled partly by recognition of the growing numbers of older people in the UK with mental health problems, particularly dementia. The Foundation also felt, through research that it could have an impact on the services aimed at this large group of people and their families<sup>2</sup>.

The Foundation had been aware for some time that there was a significant deficit in early intervention services in dementia care. It had conducted a feasibility study in 1998, which found that, despite the existence of widespread support for accessible advice and information services for people with early stage dementia, there were very few services to meet these needs<sup>3</sup>. On this basis – and the wider policy and research context – it set up a steering group to review the potential for taking forward an early intervention service across the UK. The review involved consultation with a range of policy makers, service providers and researchers and resulted in the Foundation deciding to commit a substantial financial resource to a project developing services for people in the early stages of dementia and their families.

The project was a response to a growing awareness of the benefits of early intervention and diagnosis of dementia and the needs of people in the early stages of a dementia.

## Policy context

A number of health care policies, which promote the development of patient-focused care, prevention and early intervention for people with dementia and their families have been implemented in recent years. In England and Wales, the National Service Framework (NSF) for Older People has specifically identified the importance of early diagnosis in enabling people and their families to respond effectively to the prognosis of dementia<sup>4</sup>. The NSF sets standards that most people with dementia will be diagnosed and cared for within primary care, with the support of social care and mental health services. In addition, it clearly indicates that the treatment of dementia, 'always involves explaining the diagnosis to the older person and any carers and where possible giving relevant information about sources of help and support.' (National Service Framework, p. 98).

The Audit Commission's Forget-me-Not studies<sup>5, 6</sup> also place considerable emphasis on early diagnosis and the involvement of patients and carers in the process of diagnosis, assessment and treatment<sup>7</sup>. In Scotland, the recently passed Local Government Act<sup>8</sup>, places emphasis on community planning and partnership and integration of services for older people including those with dementia. It also highlights the need for early diagnosis and the Chief Medical Officer's report, *Adding Life to Years* identifies the importance of recognition and treatment of dementia at an early stage<sup>9</sup>.

## Research context

During the 1990s research interest in early diagnosis of dementia expanded significantly. The evidence base includes the findings of research funded by the Foundation, in particular two projects: one that explored the views and experience of people receiving a diagnosis of dementia<sup>10</sup> and one which explored the role of psycho-therapeutic groups for people with dementia<sup>11</sup>.

Recent therapeutic advances have renewed calls to improve detection and management of people with dementia because of the potential for rational drug or gene-based preventive treatment or the modification of the disease process<sup>12</sup>. When administered at an early stage, anti-cholinesterase drugs (marketed as Donepezil, Rivastigmine and Galantamine) have the capacity to improve memory functioning and reduce anxiety among patients with mild to moderate Alzheimer's disease. Their use also enables greater participation in activities of daily living<sup>13, 14</sup>. A new type of drug has also developed which may assist people in early stages of dementia.

Service-user oriented research also points to the need for early diagnosis. It offers people with dementia and their relatives a number of decision-making opportunities<sup>15</sup>. In particular these relate to practical, legal and financial provisions for the future and include:

- taking a long-desired trip
- resolving family disputes or rifts
- making a will
- sorting out financial matters for a spouse or other relative<sup>16</sup>.

People with dementia may also wish to take part in their own care plans for the present and future. They may even choose a particular care home and express a willingness to accept care home entry should the need arise, reducing the burden of guilt on their family. Early diagnosis offers a chance for those concerned to come to terms with dementia; to understand its prognosis at a stage in the illness when they are still able to understand and to make use of information about their condition and treatment options<sup>17</sup>. Early diagnosis of dementia also seems to be the preference for the majority of people with dementia, and their relatives<sup>18</sup>.

For relatives, both information provision and psycho-social support have been found to be effective. Providing information for relatives of people with mild to moderate dementia has been shown to reduce the burden of care and improve their ability to continue caring at home for longer<sup>19</sup>. Mittelman et al (1996)<sup>20</sup> found that providing relatives with a programme of six sessions of counselling, involvement in a support group and follow-up support reduced the likelihood of the person with dementia being admitted to a care home. This was compared with a control group and the effect was most marked where the help was given at an early stage of the illness. Other work suggests that if carers are aware of the existence of psycho-social support this may improve their morale, irrespective of whether they actually access the services<sup>21, 22</sup>.

Research has shown the practical benefits of maximising a patient's autonomy<sup>23, 24</sup>, which adds to the moral argument of 'right to know'. Both of these have gained considerable ground in a number of medical spheres<sup>25</sup>. As Pinner states, drawing on evidence from diagnostic practice in the cancer field: 'The moral doctrine of diagnosis disclosure ... is derived from a respect for the patient's autonomy as well as beneficence' (2000, p 514)<sup>26</sup>.

Overall, it is now widely acknowledged that there are considerable medical, social and psychological benefits to early diagnosis. Opinion is increasingly in favour of diagnosing dementia early and offering information, support and advice to both the person with dementia and their relatives as early in the dementia trajectory as possible<sup>27, 28, 29, 30</sup>.

## The needs of people in the early stages of dementia and their families

This growing evidence has led to increased knowledge about what older people, in the early stages of dementia, want from services. Their core needs are: information, emotional support and therapeutic intervention, including drug treatments, rehabilitative assistance and other therapies. Families and relatives also need information and support<sup>31</sup>. The range of needs has been helpfully summarised by Alzheimer's Scotland as follows:

- health care needs, including diagnosis, assessment and treatment
- information on the illness, coping techniques, financial and legal issues, services available and planning ahead
- advocacy support to assist in accessing services
- practical support including rehabilitative approaches to managing memory loss, disorientation or difficulties with daily living skills
- emotional support including one-to-one support and support groups
- social support to combat isolation and stigma, and to ensure that they can continue their usual level and range of activities or even develop new initiatives
- financial support to offset income loss for younger people with dementia or relatives who give up work<sup>32</sup>.

If needs are not met the quality of life for people with dementia is likely to be significantly reduced. It is not unusual for people to withdraw from the routine of daily living and suffer loneliness and depression. The provision of adequate and timely assistance can help to sustain and even enrich the quality of their lives despite the illness<sup>33</sup>.

People in the early stages of dementia tend not to need assistance with personal care and family members are unlikely to consider themselves in the role of 'carer'. Their role initially is that of supporter, helping the person to come to terms with living with dementia and to plan for the future. However when someone is diagnosed with dementia – or even has dementia related symptoms – the outlook for the relatives also changes. Long-standing family roles may be threatened. Relatives want support, advice and information from services at the early stages. This reduces the risk of carer stress at a later stage and breakdowns in relationships<sup>34</sup>.

## Aims and objectives of the Dementia Advice and Support Service

The overarching aim of the DASS project was to influence policy and improve the availability and quality of information, advice and support services for people in the early stages of dementia and their families<sup>35</sup>.

The project had national umbrella objectives and local objectives for each of the pilot sites.

The six national objectives were:

1. To assess how early intervention services can be most effectively provided.
2. To explore how best to recruit and retain volunteers who will deliver the home-based service.
3. To explore the extent to which such services can maintain independence and ensure timely support from services when needed.



4. To explore whether and how such a scheme might defer the need for long-term care of hospitalisation and how it might ensure the transition is well planned and well-managed.
5. To assess how such a service can best interface with existing services.
6. To inform the ongoing debate about the importance of early diagnosis.

The project consists of four separate but linked dimensions:

1. Six early intervention advice and support pilot services
2. A single evaluation process of all six pilot services
3. A web-based multi stakeholder 'learning network'
4. A national advisory group.

### **The pilot sites**

Although the focus of this report is the pilot sites, it is important to recognise they form the core of the larger DASS project and that the DASS project itself is located within the Foundation's wider programme of work entitled Mental Health in Later Life<sup>36</sup>. The six pilot services were grant-funded by the Foundation to provide a home-based service to people with early dementia and their families. Funding was conditional upon a number of service principles, devised at the beginning of 1999.

As a minimum, each pilot site was to offer: information, advice, support, volunteer befriending and help in accessing existing services. Other services they could choose to offer included: respite for carers, supporting the user at home, advocacy, legal advice and counselling. The sites also had local steering groups to ensure that each developed to its full potential and linked in to funding streams to sustain the project when the funding ended.

### **Evaluation of the pilot services**

Evaluating the effectiveness of the early intervention schemes is one of the key aims of the DASS project. Dementia North is conducting the evaluation as one piece of work across all six sites. It is led by Professor Caroline Cantley and delivered by Monica Smith. As far as the Foundation is aware it is the first evaluation of this scale of an early intervention service for people with dementia and their families.

There were eleven local objectives set for the pilot sites to achieve. These were:

1. To explore ways to involve users in planning and monitoring the service
2. To define the local need for such a service
3. To explore ways of obtaining funding and support from existing agencies
4. To maximise local voluntary support
5. To provide those newly diagnosed with dementia (predominantly people in the early stages) and their carers easy access to a personal home-based information, advice and support service
6. To provide a volunteer befriending service
7. To enhance carers' coping skills through emotional support
8. To encourage and support the accessing of more intensive services which are needed by both the dementia sufferer and their carers
9. To identify gaps in local home support and develop plans to extend provision
10. To estimate the cost of providing the service
11. To explore the availability of long-term funding

The key objective of the evaluation is to provide evidence of the pilot schemes' effectiveness and how far the objectives have been achieved. More specifically it aims to:

- gather evidence about the role and value of the pilot schemes for users and families
- enhance our understanding of which particular services – befriending, advice, information, advocacy, developing carers' coping skills – are most effective
- based on evidence from the range of pilot sites, offer comment on key characteristics of the 'successful' early intervention scheme
- contribute to the debate about early intervention services enhancing quality of life and extending community-based living
- explore the impact of the schemes on the network of local services for people with dementia and their families.

The evaluation is also gathering information about costs and the use of volunteers. It started in Spring 2001 and delivers its final report in September 2004.

## Learning Network

The Learning Network (See appendix A) is the third key dimension of the DASS project. It is designed to provide a forum for the exchange of ideas and discussion, and the development of a 'knowledge bank' around the role and impact of early intervention schemes. It also acts as a mechanism for disseminating information about the pilot sites to each other as well as to health and social care agencies, dementia services and people with dementia and their families. In addition to providing information, the network hosts web-based discussions around a number of key themes. These include: the person with dementia, friends and family, ethnicity and dementia, and primary care and dementia. Named individuals who are experts in their field 'lead' on each theme. The network was launched in June 2002 and a number of areas are actively incorporating discussions, bulletin boards, facilitating links and sharing details about research projects and service developments. From April 2004 it will continue to be part of the Foundation's web-based information about aspects of mental health in later life.

## National Advisory Group

Representatives of relevant voluntary and statutory agencies (see Acknowledgements) sat on the National Advisory Group. They assisted in shaping the nature of the project and visited the twelve shortlisted sites to assess their suitability. During the life of the pilot sites, the group met to consider progress and how policy developments might impinge on or be informed by the pilot services. Two members of the group were linked with each one of the pilot sites to provide a link and enhance communications.

Regular progress reports were made to the National Advisory Group as well as the range of funders who enabled the project to be undertaken.

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- 36 see endnote 1 above

# DASS pilot sites

## The selection process

This short section outlines the process of selecting the pilot sites and reviews the initial stages of their development.

### Attracting potential pilot sites

An advertisement was placed in the Guardian inviting agencies to bid for funding to set up a local advice and support service for people in the early stages of dementia as part of the DASS project. Organisations were asked to submit a written expression of interest of 1,000 words maximum detailing:

- a brief outline of their experience of local need
- how the service might develop locally
- which agency might potentially host the project
- how it would link with other services and;
- what local resources might be available to support the project.

Sixty-nine organisations expressed an outline interest. These were from organisations in England, Wales and Scotland; none were from Northern Ireland.

### Site selection

The most appropriate bids were presented to a multi-disciplinary advisory group and a shortlist of 12 was drawn up. Visits were made to each site during which each bidding team presented their 'case' for funding.

The sites were then asked to draw up detailed budgets of how they would run a service if they were granted £15,000, £30,000 or £45,000 a year. While the pot of DASS money was restricted the number of sites depended on the level of funding requested.

The next stage of selection was contacting the signatories to the bids to find out how strong local support was: if the funding were to be granted for two years, there would need to be early engagement with the local service commissioners.

Six sites were chosen from the 12. These reflected a number of key dimensions of interest to the Foundation: geographical spread, rural/urban distinctions, deprived areas/wealthy areas and areas that contained an ethnic minority population. There was also a mix of provider agencies. Although the original intention was for all providers to be voluntary agencies, a secondary care trust took on the provision of one site in a primary care trust as there was no suitable voluntary agency.

The six sites were recommended to the November 2000 meeting of the Foundation trustees: three to receive £60,000 and three to receive £90,000 over a two-year period. Those having more funding had either incorporated an ethnic minority population that would require an additional resource to meet need (Nottingham and Calderdale), or a very large catchment area (Glasgow).

In parallel the evaluation team was appointed, following a two-stage tendering process and a National Advisory Group was also established (members are identified in the acknowledgements of this report). This replaced the advisory group that was set up to oversee the selection process of the sites.

## Getting underway

Once the trustees had approved the plan, the sites were asked to submit detailed budgets. Following this Jayne Lingard – the UK Project Manager – visited each site to outline the wider aspects of the project, introduce the concept of the Learning Network and explore how the sites could work together to develop the work.

## Sharing the journey

A meeting was held with all the pilot site co-ordinators to facilitate introductions and discuss the aims of the DASS Project and pilot sites.

The co-ordinators were also introduced to key staff from the Foundation including the evaluation research worker, Monica Smith, who consulted with the co-ordinators about the evaluation process and data collection requirements.

One outcome of the meeting related to a change in terminology. A decision was made to drop the term 'dementia sufferer' and adopt the term 'people with dementia'. Further, the term 'carer' was rejected in favour of 'family and friends'. Both were felt to reflect the values of an empowering service, rather than a disempowering one, as well as suggesting an accessible service.

Two further national meetings were held with the co-ordinators. The first identified the common issues that the co-ordinators were facing in their services and within the provider agencies. These were fed into the national advisory group for comment. The second was the Celebrations Event upon which this report is based. The presentations from this day form the core of the following accounts of the pilot sites. While they share common themes they each focus on a different dimension of the service provision, thus offering both the breadth and depth of the 'DASS experience'.

## What happened on the ground

### **NOTTINGHAM – the truth about telling the truth**

#### **Dementia Advice and Support Service, Nottingham Alzheimer's Society**

##### **The pilot site area**

Total Population:	267,700
Over 65s:	38,490 (14%)
Ethnic Minority:	40,423 (15%)
Steering Group chair:	Andy Millward, Social Services
Grantholder:	Paul Dunnery, Nottingham Alzheimer's Society
Service Co-ordinator:	Julia Jefferson
Grant offer:	£90,000 over two years

Nottingham is a post-industrial city with a GDP (Gross Domestic Product) significantly higher than the national average. This does not reflect the resident population's fortunes however, as the wider conurbation of Greater Nottingham has a population of some 620,000.

Nottingham's original application to the DASS project was strongly supported by a wide range of agencies. Social Services led the application – the only one of the six sites that was led by a statutory agency. This influence continued with the chair of the steering group being from Social Services. Andy Millward was responsible for the on-site social workers in seven health centres who screen referrals for full care assessments. They were thought to be ideal conduits for referrals to an advice and support service for people in the early stages of dementia.

## Lessons learned

### *Tell the truth*

The work in Nottingham echoed Rebekah Pratt and Heather Wilkinson's research *Tell me the Truth*<sup>1</sup> which found that people with dementia prefer to be told the truth about their diagnosis. Emotional support is one of the most valuable elements of an advice and support service for those coming to terms with the diagnosis – the realisation of the truth, and the implications for them and their families. The DASS work in Nottingham, allowed the opportunity to explore and consider the complexity of this in practice.

### *Provide support at an early stage of diagnosis*

The service in Nottingham is aimed at people who:

- are concerned about memory difficulties and are considering approaching their GP for advice
- are in the process of diagnosis and may be awaiting results
- have recently received a diagnosis.

### *'Early' can have different meanings*

The service in Nottingham is for people in the early stages of dementia, although the term 'early' can be ambiguous; and if a person or their relative has not received a diagnosis until the illness has progressed beyond the early stage, the diagnosis can still be a 'bolt from the blue'. In terms of information and emotional support, both parties may feel very much in the early stages. The team in Nottingham found that this situation is more likely to be the case for families from ethnic minorities who – for a variety of reasons – may be less likely to seek advice early on.

### *Look out for reluctance to talk about dementia*

Partly due to their differing attitudes to the value of a diagnosis of dementia, in the early stages of the project, the team found some GPs were reluctant to refer. The co-ordinator was often asked by the referrer to refrain from using the word dementia or Alzheimer's. This request came from a number of sources, mostly family members but also some professionals. This complicates the process of providing information and support.

*'People with dementia may seem to have no insight into their condition; they may deny it completely or just not want to accept what is said to them. We have found that these reactions can be part of the long road to acceptance – the psychological adjustment or coping strategy, which most of us go through when something very unpalatable is happening to us. This makes it less straightforward to provide practical or emotional help. Families and friends on the other hand, are more likely, although sometimes reluctant, to understand what is happening and may focus more on practical needs and the emotional*

*support to help them manage the circumstances, behaviour and risks associated with the illness.’ Julia Jefferson, service co-ordinator*

### **People with dementia share common feelings**

The team learned that the common factors between people with dementia and their supporters are fear, distress, anger, anxiety, frustration, dread, denial – all the feelings experienced with the onset of any significant illness and especially where mental capacity is threatened. To understand more about the people being referred to them, the team analysed the referrals to their service to see who had received their diagnosis and who had not. The findings are as follows:

### **There is limited insight into the condition**

Out of 92 people with dementia referred for service to Nottingham DASS:

- 55% (51) had received a diagnosis at the point of referral to the service
  - 54% (27) had insight into their condition
  - 46% (24) had very limited, or no apparent insight
- 45% (41) had received no diagnosis or were waiting to hear their results
  - 38% (16) had insight
  - 62 % (25) had limited or no apparent insight.

### **Distress is inevitable**

The Nottingham team concluded that disclosure is the first point when families and professionals could offer support in a dementia-type illness. Denial and lack of insight may be a part – albeit a difficult part – of the adjustment process, which support services and enlightened family members can understand and work with together.

*‘Distress may be inevitable but we must be prepared to deal with this as part of the “disclosure care”. Grasping this point is key to effective continuing care. Many of the clients of the DASS service have shown this to be the case.’*

### **Case studies**

During its first two years, the service talked with people who had received a diagnosis and their families about how they felt about this process. The following are anonymous examples based on real cases to give an idea of the range of people and their needs and the issues around their diagnosis.

### **Knowing is hard**

When Mike received a diagnosis of dementia it was a shattering blow. He said: ‘It was so hard being given this diagnosis. I had had an awful year with so much ill health and now this. My wife was with me when I was told and it was very distressing but they were very kind, and we have talked it over with family and friends – no secrets from anyone – and now it doesn’t seem so bad. It has made all the difference being able to talk things through with you though, both of us feel much better’.

### **Constructive denial?**

Doris, is a retired nurse, living with her husband. She was given a diagnosis of Alzheimer’s disease, which she understood and has insight into but flatly refused to believe. Her husband requested that the word ‘Alzheimer’s’ was not used. Support for the husband has been helpful but visiting has now ceased as he feels that confronting the reality is unhelpful for Doris.

**Full acceptance**

Lilian is a retired academic. She lives alone and has been given a diagnosis of Alzheimer's disease. She has clear insight and wants to know as much as possible. She said: 'I need to know about this illness. It is wonderful to talk to someone who understands and doesn't hurry me. I don't feel foolish when I am with you, I feel like my old self.'

**Second-hand news**

Ellen lives alone and her family live far away. The diagnosis was given to her son and Ellen insisted that he told her. Ellen said: 'No one wants to be told this, but its better to know than not to know, but they should have told me, not him, I'm not stupid yet!'

**Planned disclosure**

Kath lives with her husband who was given her diagnosis. He was not sure if Kath should be told or not and approached the Nottingham Alzheimer's Society for help. The worker visited shortly after he told her and spent much time with them both.

**Gradual acceptance**

Marion, a sprightly intelligent lady underwent a Mini Mental State Examination by her GP before she or her family were aware that there was anything to worry about. Her immediate response was: 'this has ruined my life', 'I wish I had never been told; things will never be the same again'. After much emotional support by DASS and referral for a full diagnosis her reaction was different: 'I want to know for sure if anything is really wrong, and then I will be able to get on with my life. I want it all to hurry up. The process is too slow'.

**Collusive denial**

Nellie lived alone and refused all services. There had been no diagnosis and the family requested that the word Alzheimer's be withheld. However, Nellie had some insight into her problems and said: 'I know things are not right and that there is something wrong with me, but I don't want to worry the girls. I always feel better when I have been able to talk to you, especially as you are not part of the family – I can say what I like.' There was an unspoken agreed mutual secrecy within the family. The family continued their protective approach and Nellie was never told her eventual formal diagnosis of Alzheimer's.

**Future work – disclosure or non-disclosure? That is the question**

It may be instinctive to protect people from sadness and distress even though this is an inevitable consequence of any illness. The Nottingham team found many questions that need to be answered. Should family or friends with long-term knowledge of the person be consulted prior to disclosure of a dementia diagnosis? Whose views would they be representing if they requested that a disclosure be withheld? Are relatives the right people to disclose a diagnosis? Will the person with dementia accept a diagnosis of dementia from a relative? How will it affect the relationship?

The team believes that, for some people, not disclosing may be appropriate and sensitive. However, this raises questions such as: will this increase or decrease the strain which the family experiences? Does lack of disclosure restrict the offer of support which can be provided? Does it honour their rights as a citizen?

From their work in Nottingham, the team believes that in order to deliver an effective advice and support service, discussions need to take place between and among professionals.



*'This is a complex ethical dilemma and we need to shed further light on the subject. People with dementia are far more likely to be told their diagnosis today than they would have been 10 years ago, yet the practices of professional workers in the field of dementia regarding diagnosis and disclosure are many and varied. More needs to be understood about the effects of disclosure on the person with dementia and their families.*

*Telling the truth is an essential principle but the process, the timing and the follow up is crucial. A consensus of opinion is required between service providers and family and friends regarding the practice of disclosure within an established ethical framework. Services need to respect that people should have the choice whether to be told or not, so that if they choose not to know, sensitive approaches can be taken, and if they choose to know, appropriate support can be offered.'* Julia Jefferson, service co-ordinator

Background reading is listed in Appendix C.

## GLASGOW – counselling and information

### The First Hand Project, Alzheimer's Scotland – Action on Dementia

#### The pilot site area

Total Population:	577,869
Over 65s:	90,692 (16%)
Ethnic Minority:	21,517 (3.7%)
Grantholder:	Edwin Wilkinson, Regional Manager, Alzheimer's Scotland
Local Commissioner:	Jan Whyte
Service Co-ordinator:	Fiona Wilkinson
Information Worker	Angella Fulton
Outreach Worker	Liz Kincaid
Grant offer	£90,000 over two years

The Community Fund and Comic Relief also provided funding.

#### Lessons learned

##### ***Counselling people with dementia has some new challenges***

The team found that counselling people with dementia is not very different from counselling people without dementia. It might be necessary to speak more clearly, slowly or use simpler language and to check out more frequently that the counsellor and client understand each other. People with dementia may remember little if any of the previous sessions, but over the course of a number of counselling sessions, particular themes will become apparent. Even where the person is not able to recognise the counsellor's name or face, as the session begins, they seem to remember the positive relationship they have with the counsellor, which continues to grow and develop over time.

##### ***Offer counselling at an early stage***

Glasgow was unique among the pilot sites in having a trained and experienced counsellor as part of the service. This enabled a particular pattern to be established for the service.

*'We decided the best way to identify and support people with dementia and their families immediately post-diagnosis was to link with a memory clinic and outpatient clinic and be available when people attended for diagnosis of early memory problems and follow-up.'*

*'From the Mini-Mental State Examination<sup>2</sup> a fairly accurate idea of roughly what type and how serious the memory problem is can be obtained. People who have never been before receive a diagnosis. Others who are receiving cognitive enhancing drugs will get feedback on their progress. The psychiatrist then told the person and their family members about the First Hand Project and introduced me as I was in the room next to his. We received about ten referrals a month this way.'* Fiona Wilkinson, service co-ordinator

On occasions when the co-ordinator was not able to attend the outpatient clinic, there were difficulties or delays in establishing contact with a number of the people referred. When she was not introduced immediately, although patients took away a verbal recommendation and leaflets, they might then have come to believe that they were not suitable for the service or forgot about

it or became anxious about meeting another professional or about asking for help. The co-ordinator found that being present, offering immediate support, personally introduced by the consultant was a very effective approach to engaging people in the advice and support service.

### ***Diagnosis can come as a shock***

The co-ordinator found that when she met them, people were shocked and distressed. Some expected the diagnosis and it confirmed their worse fears. For others it came as a shock. Some people knew about dementia, having previous experience of it in a relative perhaps, but for many people, it was something they knew very little about.

One or more family members usually accompanied patients to the clinic and they were seen together. Both their practical and emotional difficulties were discussed and the co-ordinator gave them initial information about the First Hand Project as well as information about dementia as appropriate to their level, insight and needs.

*'The doctor agreed that it was important that I, as a counsellor, saw families at the point of diagnosis. There was a degree of stress and distress for both the person with dementia and other family members. It was complex to listen and attend to all parties simultaneously (one or more of whom had a cognitive deficit). It could also be difficult to elicit information about their current situation and individual needs and manage the conflicts often generated by their differing perspectives. These demands called both on my knowledge of dementia and related issues and on my experience as a counsellor.'*

Fiona Wilkinson, service co-ordinator

People's needs when attending the memory clinic differed from those in the outpatient clinic only because the latter were less shocked, having been given the diagnosis a month or more earlier. They had often formed a clearer picture of the issues with which they were having most difficulty. Nevertheless, they were often extremely distressed as they had time to contemplate their situation.

### ***Provide information and further referrals at an early stage***

At the initial consultation, the co-ordinator assessed how best the First Hand Project could benefit the individual. Referral to the Alzheimer's Scotland Welfare Benefits Service was also offered. Many people appeared to benefit from this initial consultation. Often they were helped to listen to each other and to understand and to relate to each other better. They generally left the consultation appearing more relaxed and hopeful that much would be done to support them.

The most suitable member of the service team made further contact promptly to provide additional information and support. Where they required further counselling, the co-ordinator was able to make an appointment with them on the spot to visit them at home or in the city centre offices; whichever was more convenient for them.

### ***Analysis shows common concerns***

The co-ordinator analysed the service records to find the most common areas of difficulty that concerned people with dementia and their families at this first consultation. Very often, additional problems such as addiction, abuse and other health problems exacerbated these difficulties. She found that:

They were troubled about:

- accepting the diagnosis
- changes in behaviour
- changes in roles and relationships
- changes in levels of independence
- the lack of support from friends and family.

They were often having difficulty in:

- accessing services
- their relationship with other professional helpers
- sexual relations with their partner.

They were often worried about:

- the daily stress and anxiety of memory problems
- driving issues
- relationship problems
- feeling overwhelmed by the demands of caring.

They struggled with:

- anxiety caused by the Mini-Mental State Examination
- anger, aggression, fear, sadness
- frustration, guilt, grief, bereavement
- loneliness and isolation.

### ***Loss is a major issue***

*'Much of the counselling I provided focused around the issues of loss and the struggle to deal with the confused emotions of the grieving processes. People with dementia and their families experience multiple losses. They may be mourning the person they used to be, for their loss of health, or memory, of abilities, their sense of self and self-esteem. There may be a loss of privacy as endless streams of professionals come into their lives. Changes within the family can cause relationship problems as well as the general difficulties of daily life to cope with at the same time. There is a profound feeling of loss of control added to the relatively new experience of cognitive impairment.'* Fiona Wilkinson, service co-ordinator

### Information is key

The information worker offered information in a follow-up visit from the clinic. She believes in providing personalised information as part of a therapeutic relationship. Information that people wanted fell into nine broad areas:

#### Diagnosis:

- how had it been done?
- what did it mean?
- prognosis

#### Treatments:

- what could be offered
- is there a cure?

#### Accessing local services:

- caring for the home
- nurses

#### Benefits:

- care monies
- extra income

#### Coping strategies:

- calendars
- reminders

#### Driving:

- what to do
- what are my rights?

#### Money/legal matters:

- power of attorney
- future decisions

#### Future planning:

- what options are there?
- which services?

#### Assessment:

- how do I get help?

Although people's information needs fell into the above categories, the context, the speed at which they could absorb it and the format they responded to varied widely. Sometimes, the information worker just had to listen – the person she had gone to see wanted to tell her the whole story. Later, she saw them adjust and become experts in their own condition – how to live their life with dementia – something no one else can tell them about.

*'I often find the value of my contribution is saying: "It is fine to carry on doing x, y or z." One lady just stopped doing everything after her diagnosis. She just sat in her chair – she was really depressed. She believed that she was waiting to die. After two months of being visited, she was brave enough to tell her friends and is now back doing all of her activities again. It was just a question of helping her to regain confidence – that even though she had dementia, her life can still go on.'* Information Worker, Glasgow

The most moving account about people thinking they can't do things anymore concerned a couple:

*'You could see they had been a very intimate couple, yet since the diagnosis they stopped touching each other. I did not spend time exploring why – instead I asked the man to show me how to waltz, as I knew that they had done a lot of dancing previously. He understood me and started to show me how to do it. Then I said: "I've got two left feet – why not show me by using your wife as a partner?" The husband and wife took up the dancing pose, but then both cried and hugged each other for a long time.'* Information Worker, Glasgow

### **Feedback from clients**

The doctor at the memory clinic and his patients evaluated the service very highly and it was possible to demonstrate through feedback that people had benefited from immediate and personal contact with a counsellor experienced in the area of dementia. There were many positive comments from people about the service.

*'I feel confident that Fiona will be there for me, to give me advice too. It makes such a difference to have someone that can put you in the direction of help, to have support and explanation in plain English and help you plan for the future.'*

*'Getting the diagnosis was quite overwhelming on the day. We both felt the need for someone who understood our position. Counselling had a calming effect on us. I could accept the changes in my mother better.'*

*'I get so confused. It helps to talk about how I feel. My girls are very caring but it's hard to be so dependent. Other visitors talk all on the surface.'*

*'At the start I didn't want people coming in to help me but, when the counsellor came, I looked into her eyes and said – she's alright.'*

*'I was helped a lot by the time, care and concern of the counsellor. There was no rush, just quiet care.'*

## **SOUTH LAKES – working in groups**

### **South Lakes Alzheimer’s Society, Kendal, North-West England**

#### **The pilot site area**

Total Population:	102,301
Over 60s:	21,541 (21%)
Ethnic Minority:	818 (1.2%)
Steering Group Chair:	Margaret Gibson, Alzheimer’s Society
Grantholder:	Lalik Nasmyth, Branch Manager, Alzheimer’s Society
Co-ordinator:	Jill White
Grant offer	£60,000 over 2 years

Cumbria is one of the most sparsely populated counties within England. As a very rural area, the South Lakes is a popular destination for retired people, usually those who have enjoyed holidaying in the area. Generally the population does not experience deprivation, although social isolation is a feature of life, not least because public transport is very limited. South Lakeland is a popular location for people wishing to retire. Consequently the number of older people in some parts of the area is much higher than the national average.

#### **Lessons learned**

##### ***Provide separate services to meet different needs***

The Alzheimer’s Society branch runs day care and homecare services (under contract to the local authority) for people with dementia living in the area. An early advice and support service was thought to be a welcome complementary addition. It was decided at the start that the best way of meeting the aims of the project was to set up two separate, but closely linked services: one providing family support and the other a befriending service.

**The family support service:** this provided home-based support and information to people with dementia, particularly those newly diagnosed, their carers and friends and family. However, the lack of other advice and support services meant that the service had several referrals of people in the later stages of a dementia illness. It was difficult to turn these away, particularly as referrals from GPs of people in the early stages of dementia were not occurring.

The team developed a comprehensive range of information, using existing materials, adapting others and composing new ones. This range of information can be found on the Mental Health Foundation’s Mental Health in Later Life website at [www.mhilli.org/dass/dassproject.htm](http://www.mhilli.org/dass/dassproject.htm)

**The Befriending Service:** this aimed to co-ordinate the recruitment, training and supervision of volunteers interested in befriending people with dementia and their carers, both at home and in residential care. The Befriending Scheme aimed to reduce the isolation experienced by those with dementia and their family by providing a ‘friend’ to support them through life’s everyday chores and pleasures.

### ***Recruiting volunteer befrienders can be difficult***

However, despite using every means to recruit befrienders, the only two that were used were volunteers for the Society before the project began. The team found this was not just to do with trying to fund befrienders for people with dementia. 'Chatting to other local organisations, volunteer recruiting is increasingly difficult. Age Concern also has a befriending service, but it is not available for people with dementia. We decided eventually to recruit a paid befriender and advertised in the local job centre and this is working very well. However, now we have Community Fund money to continue for another three years, we will continue to try to recruit volunteer befrienders.' Jill White, service co-ordinator

### ***Some help could be provided through groups***

In addition to the family support work, one member of the team became involved in some group work with a local mental health professional. Here, she describes how this came about:

'When the advice and support service was set up in this area, it was not considered necessary to offer support groups because the South Lakes Carers Association already ran very successful and well attended groups. However, this did not meet the needs of people with early dementia themselves. We were approached by the senior occupational therapist at the local hospital (Westmorland General Hospital in Kendal), and asked to help facilitate a conjoint support group.

We did this and became convinced that there was a strong need for a group which offers specialist support to both people with early dementia and their family members. We found that educational groups were an effective tool to empower and sustain both the person with early dementia and their partner or supporter. Education, both about the illness and effective coping mechanisms, make a dramatic difference to people's daily lives.'

Through the life of DASS, staff were involved in running three separate and distinct types of support groups for people with early dementia and their supporters.

### ***Conjoint support group***

Four couples attended a community centre for nine structured sessions. One of each couple was a person with early dementia. The team reviewed every session and discussed what worked, what didn't, and whether this should influence the delivery of the subsequent session. They adapted the programme and the materials to meet the needs of the individuals they were working with.

Feedback from the group was excellent, and one participant commented that he had used the knowledge and understanding gained from the group to provide a foundation for daily living and coping. Another said he now had more skills and strategies to cope, and said when he hadn't phoned for a while: 'I know you are there if I need to talk to someone, and sometimes that's all you need.'



### ***Analysis of pros and cons of the conjoint support group***

#### **Pros**

- Explored emotional issues in depth in a safe and supportive environment.
- Length of programme ensured that issues could be addressed within the timespan to ensure carers and people with early dementia were not left without support with emotional issues.
- Format ensured that people with early dementia and carers had the freedom to talk over issues with others in similar circumstances without feelings of 'betrayal' or being 'disloyal' because their partner was also there and involved.
- Offered coping strategies to provide a foundation which can be used as a framework for the future:
  - changing perspectives/understanding each others' perspectives
  - feeling safe to admit it's hard/expressing grief
  - deeper understanding of the nature of the illness
  - knowing what to expect
  - not feeling aloneon-going support offered by the DASS service.

#### **Cons**

- Could be too intense for the person with dementia
- Group became very close and shared very intimate details, and then disbanded.

### ***Educational support group***

A series of six sessions were designed to offer information on support services available in the community. They introduced participants to services they might need in the future and how to access them. They encouraged them to start setting up support networks now that could be brought into play as needed, rather than being accessed at a time of crisis. There was also practical advice, people were given a chance to talk, socialise and meet others in similar circumstances.

### ***Analysis of pros and cons of the education support group***

#### **Pros**

- Less formal and structured
- No emotional input unless initiated by participant, so no pressure on them to talk or open up unless they wish to
- Knowledge of 'what's out there' and how to access it
- Not being on their own
- Opportunity for participants to socialise and build networks.

#### **Cons**

- No avenue for expression of emotional frustration or anger with circumstances (particularly for caregivers), so it tended to 'spill out' and disrupt the educational thread
- Time-limited.

### ***Bi-monthly support group and lunch club***

This arose out of the educational support group, and was initiated by participants. It was an informal get-together held in pubs and restaurants. The group lead and decided on topics, speakers etc. There was also a general open discussion where they raised their own issues. The lunch club has been a huge success. It provided a very safe environment for people with early dementia to socialise. In terms of input/output, it reaped the greatest rewards. People softened, relaxed and shared jokes and mild rebuke because they've forgotten what they ordered for lunch. They also remembered, that life can be good fun – that actually they can be good fun and good company – that they can laugh and crack jokes and it doesn't matter in the safe surroundings if they can't remember the punchline.

#### **Pros**

- Group 'owned' by people with early dementia and their supporters
- Very informal – opportunity to discuss emotive issues and provide one-to-one support if necessary
- Participants can (and do!) talk about their own issues and dilemmas which are then addressed by other members of the group who share their knowledge and experience
- On-going – providing regular support
- Everyone can relax and just enjoy a social situation without worrying about social formalities and the potential embarrassment of memory problems.

#### **Cons**

- No control over topics and no way of protecting some people's sensitivity to certain issues
- Danger of individual perspectives dominating instead of experienced and professional advice being proffered.

The name of the three groups was very different: each had its own unique contribution.

*'Some DASS clients have attended all three groups – some have become 'old hands', and offer help and support themselves to others more recently diagnosed. Maybe that's one of the greatest benefits that the groups offer people – acknowledgement and validation of their expertise and unique understanding about people with early dementia.'* Jill Whilte, service co-ordinator

## CALDERDALE – ethnicity and access to services

### Age Concern

#### The pilot site area

Total Population:	192,405
Over 65s:	30,002 (16%: highest in West Yorkshire)
Ethnic Minority:	13,468 (7%)
Steering Group Chair:	Alistair Vincent, Team Leader, Mental Health Trust
Grant Holder:	Tim Swift, Age Concern Calderdale
Co-ordinator:	Caroline Marshall
Grant offer:	£90,000 over two years

Calderdale consists of a number of market towns in an area of hilly moorland and valleys. There are a number of prosperous urban communities, including the south of Halifax and most of the greater Brighouse area. The South and West of Calderdale includes a number of prosperous smaller communities, with commuting to Manchester and Leeds. Other parts of Calderdale – particularly Brighouse and Todmorden – experience significant economic and social deprivation. Two electoral wards appear in the DETRs priority list of most deprived wards. The area is predominantly white with a significant community of Pakistani (Mirpuri) origin, concentrated in West Central Halifax. This is a very deprived community with one of the highest rates of male youth unemployment in the country.

### Lessons learned

#### ***Adapt the service to work with people from an ethnic minority***

When planning how to use the grant to provide a DASS pilot site, the project decided to appoint a part-time service co-ordinator. This meant that money was available to also appoint a specialist development worker for the Mirpuri community who was of Pakistani origin and speaks both English and Urdu. She understands and is very aware of the cultural and religious needs of the local Pakistani community and is familiar with the network of services that presently exist.

#### ***Spend time introducing a service***

During the initial funding period the Dementia Advice and Support Service team continually worked at raising an awareness of dementia, promoting the arrival of this new service, and recruiting volunteer befrienders. The development worker helped in accessing the local Pakistani community and identifying local need to influence the development of the whole service.

*'Our first steps were simply introducing the word 'dementia' and educating people to reduce the great stigma attached to dementia. We recruited two female volunteer befrienders to support clients at home. We also spoke to community groups including church groups, social groups, statutory and voluntary organisations and GPs. We ventured into local shops and meeting places, promoting the service at events such as galas and open days. I hoped our presence at these events would send a positive message to members of the Pakistani community that the service will understand their language and cultural differences.'*

Caroline Marshall, service co-ordinator

Eye-catching and reassuring literature was produced and distributed widely throughout the town from GPs surgeries to post offices and chemist shops. An information pack was offered to service users during a home visit.

### ***Provide information in appropriate languages and formats***

The development worker soon identified that this literature, produced in English, was really of no use to people who did not understand the language. Therefore it was translated into Urdu and distributed around the area. People picked up leaflets from the local chemist.

*'We were delighted that people were showing an interest in DASS and eagerly awaited their telephone calls but were very disappointed when we did not receive any calls from Pakistani clients. It occurred to us that although these people may need the service they may worry that if they rang, they would get through to an English speaker. This inspired us to record a bi-lingual message on the answerphone inviting people to leave their details so that one of the team would get back to them. This has proved to be useful as we do now receive a number of messages spoken in Urdu.'* Caroline Marshall, service co-ordinator

The team worked hard on designing an information pack that was informative about DASS with details on dementia with useful contact numbers. Again, as the pack was all in English the team needed to address the problem of how appropriate it was for Pakistani clients. An option was for it to be translated and produced in Urdu but the team identified that there are many Pakistani people who have limited literacy skills. This inspired them to record a CD and audiotape that contained the information. As the recording is in English and Urdu the team realised that it could benefit many clients. Those who may have poor eyesight or those who find difficulty in concentrating on reading text can relax and listen to the information at their leisure.

Several clients with early stage dementia from within the Asian community were identified. However, these numbers were low in comparison to the likely numbers of ethnic minority local residents who could be expected to be experiencing memory problems and do not compare well to our relative success in identifying white clients. Thus there is still a considerable amount of work to do to identifying people in need from ethnic minority groups.

### ***Reach families through presentations in schools***

*'Through presentations to school groups we hope to educate the students and their parents about the signs of dementia and how they could get help for a family member who is experiencing these symptoms. We will maintain our profile within the local Asian community and continue to seek innovative approaches in order to reach those who would benefit from our service.'* Caroline Marshall, service co-ordinator

### ***Awareness raising is an issue***

The development worker identified the difficulties the ethnic minority community face when dealing with matters relating to mental health. She particularly noticed that there is a lack of awareness about dementia within the Asian community.

*'Although the main aim of the DASS project was to identify service users in the early stages of dementia. I found many of the referrals were of service users who were in moderate to advanced stages of dementia. This is mainly due to the fact that many Asian families were either in denial or accepted dementia to be a natural part of the ageing process.'*

Some of the issues that a professional may face while working with an Asian service user are best demonstrated in a case study. The client and their details have been anonymised.

### ***Case study***

A request was made by social services to make a home visit to Mr Khan aged 75. Mr Khan and his family were known to social services because they were assessing the family's needs as they have a child with Down's syndrome<sup>3</sup>. The assessment raised concerns about the level of care Mr Khan required and the ability of his daughter-in-law to cope.

The development worker contacted the family by phone, explaining that social services had referred Mr Khan to the DASS project. She arranged a date and time to visit the family at home. The main purpose of the initial visit was to establish whether formal diagnosis had been made of Mr Khan's condition and whether any other services were in place to support the family.

No support was being provided. The daughter in-law stressed how she was struggling to understand why her father-in-law had become so demanding, forgetful and verbally repetitive over the two years. It was apparent she had no knowledge or understanding of dementia. They had visited the GP on a number of occasions and were informed that Mr Khan's problems were part of the aging process for which there is no treatment. This highlighted a gap in knowledge within the local health services.

The daughter-in-law mentioned that her father in law was bathing three to four times a day due to his incontinence problem. Mr Khan is a devout Muslim who prays five times a day and needs to be clean at all times. The development worker asked if Mr Khan was using incontinence pads, but the daughter-in-law did not understand what she was referring to. With their permission the development worker contacted and arranged for the incontinence nurse to make an assessment. She also arranged for an occupational therapist to do an assessment for a ground floor shower to be installed, as Mr Khan had fallen down the stairs on a number of occasions when returning from the bathroom. She suggested the daughter-in-law arrange to see the GP again and request a diagnostic process be carried out. She assured the daughter-in-law that she would support her in pursuing this.

The development worker left a CD in Urdu for the daughter-in-law to listen to so that she was able to understand what dementia was and also about the DASS service.

Mr Khan was diagnosed with multi-infarct dementia<sup>4</sup> and is now attending a culturally appropriate day care centre three times a week. Regular home care services also attend to Mr Khan's personal care needs, supporting the daughter-in-law in her role as his main carer. Regular contact is maintained with his daughter-in-law and advice and support is regularly given.

## NORTH WEST WALES, BANGOR – beating isolation

Memory support service, Alzheimer's Society

### The pilot site area

Total Population:	293,268
Over 65s:	60,106 (20.5%)
Economic Profile:	Deprived rural
Grantholder:	Alwyn Rowlands, Regional Manager, Alzheimer's Society
Steering Group chair	Bob Woods, Dementia Services Development Centre Wales
Coordinator	Osian Evans
Grant offer:	£60,000 over two years

North West Wales is a large, mainly rural area and is designated as economically deprived within Europe. It is a bilingual area where many older people speak Welsh as their preferred language. There are two local authorities – Anglesey and Gwynedd.

### Lessons learned

#### *Importance of community contact*

The project co-ordinator was passionate about the need for people with dementia to get out and about and participate in activities alongside people without dementia. He was also very keen on tapping into local communities and promoting the development of real networks and relationships.

#### *Know your local population*

The team were provided at no cost with an office with furniture and equipment by the local NHS Trust, which boosted the project's grant. They saw two distinct groups needing an advice and support service for early dementia.

There are firstly couples who retire to the area having had happy holidays here. They have no local network of support, and when one spouse dies, the partner is left terribly isolated. The second group is local people who are experiencing the breakdown of local networks in their communities that they need for support.

*'It was planned from the outset that volunteers, some of whom may themselves have been carers of people with dementia, would provide befriending. Their role could vary from simple companionship to joining the person on walks. Various community organisations were approached for volunteer recruitment. All volunteers were to be appropriately screened and trained and relevant community groups offered education to promote their awareness of dementia. We never promised a volunteer, though, as we knew it would be tricky recruiting and getting the right match between service users and volunteers.'*

Osian Evans, service co-ordinator

### ***Make sure volunteers are appropriate for clients***

Listen to the client about their interests – a single retired professional woman who enjoys bowls or local history may not want to be visited by a woman who is keen on knitting and her grandchildren or vice versa.

Most service users want a volunteer with four main characteristics:

- easy to talk to, understanding and patient with their memory difficulty
- the same interests – who can talk about or do the things they like
- is the same sex – there is more possibility of having the same interests
- Speaks the same language – some older Welsh speakers struggle in English.

### ***Help volunteers to overcome fears***

Potential volunteers reported being afraid of people with dementia and lacking in confidence to relate effectively. The co-ordinator has a cheerful, relaxed manner, himself, and encouraged the volunteers to take a very informal approach.

*'It was important though to be clear about the nature of volunteering. There can be confusion in any case about the role of the various professionals who visit an older person, but their conduct tends to offer clear clues that it is a business or formal relationship. Volunteers need to be trained to be prepared to give clear signals about the boundaries of the relationship. This is important both to protect the volunteer's own independence and to prevent the person with dementia from being hurt by misunderstanding the extent of the relationship.'* Osian Evans, service co-ordinator

### ***Police checks can cause problems***

The co-ordinator found that police checks on volunteers were a problem. Firstly there was the cost, then the delay that could diffuse the initial enthusiasm of potential volunteers. It was also feared that having to be police checked might put some people off.

### ***Be aware of risk management***

The Social Services manager on the steering group suggested that volunteers be trained in the vulnerable adults policy. The other risk management aspect to be considered was that of the risk to volunteers themselves, so it was further suggested that training be provided in Social Services' Lone Workers Policy.

In one instance, a community psychiatric nurse discovered that a volunteer had been asked to get paracetamol out of a cupboard – and did. The nurse said that this should not happen. The importance of maintaining the trust of professionals in the volunteer service meant that the training of volunteers had to incorporate an explanation of the administration of medicines and people with dementia.

*'The geography of the area and limited transport options led to a need for volunteers to be very local. We approached neighbours and shopkeepers to see if they could suggest suitable volunteers. The confidentiality important in making such approaches was often compromised by the size of the communities involved. When looking for a volunteer in one remote village, we were told that the woman in the post office was known to be rather too keen to share information that her customers might wish to keep private. We originally planned to have a volunteer network, but found that they were too dispersed to be able to have regular meetings.'* Osian Evans, service co-ordinator.

### ***Try recruiting volunteers through existing clubs***

Recruiting local volunteers through approaching clubs and societies in the community has proved very successful, attracting 12 volunteers.

### ***Involve people in the local community***

*'In addition to trying to find befrienders for our service users, we explored options to incorporate some individuals into community activity to maximise their social interaction. We approached churches and the Women's Institute.*

*Where possible, we got people involved in local activities such as a walking club or luncheon club. In one case our client became a volunteer herself. Her spouse had a terminal illness, the concern of a particular charity and she became a volunteer in the fundraising shop despite her dementia, which was very satisfying for her.'* Osian Evans, service co-ordinator

### **Case studies**

The following examples of work demonstrate how people's individuality was taken into account when looking at befriending or participating in the local community:

#### **Robert's gardening skills were put to good use**

Since Robert had developed dementia he has had stopped going out and about due to his memory problems. His garden was immaculate and somewhat overdone due to his lack of alternative occupation. He was introduced as a volunteer to a local National Trust property to help with the gardens there. A briefing to the volunteer organiser on Robert's memory problems and what his supervision needs were was all that was needed for him to be included.

#### **David goes fishing**

David liked to go fishing but had stopped going since he could no longer manage on his own due to his memory problems. It was therefore ideal to find someone who could go with him as a buddy – and far more appropriate than asking someone to visit him at home and try to engage him in conversation – something that does not appear to feature in most fishing trips!

#### **Anna becomes a volunteer**

Anna was enabled to play a role as a volunteer for a knitting club with the support of a volunteer befriender. This gave her immense satisfaction and pleasure.

#### **Jean finds help at the church**

When Jean goes out, she tends to stray far from home. She is a member of the Catholic Church, so the local priest was approached. He suggested that a member of the congregation might agree to visit Jean once a week for tea and reminiscence, and she did. Another volunteer was introduced to go out with Jean to go shopping, bowling and for walks. A calendar displaying dates of volunteer visits, day care and Saturday club was put up showing her when to stay in and Jean's daughter crosses out the date at the end of the day.

### ***Support for the project***

The multi-agency steering group have been delighted with the achievements of the project, in a very short space of time. Bob Woods, the Chair of the group says: 'The project's ability to recruit and support volunteers tailored to the person and their situation has been a revelation. We have had good services for carers in the past, but this is the first time there has been something positive, designed for the individual person with dementia.'



## **WINCHESTER – multi-agency co-operation**

### **West Hampshire Mental Health Trust**

#### **The pilot site area**

Total Population:	107,222
Over 65s:	18,401 (17% of total population)
Ethnic Minority:	2,359 (2.2% of total population)
Steering Group chair:	Alan Fowler (Former Carer, Alzheimer's Society Branch Chair)
Grant holder:	Inger Hebden, Primary Care Trust
Co-ordinator:	Pauline Hayter
Grant offer:	60,000 over two years

Winchester is a relatively affluent English city with a pleasant living and working environment centred around the ancient cathedral. When compared with the rest of the population, citizens generally enjoy good health. The DASS project covered three city GP practices – a population of around 60,000. The Winchester site is interesting as it provides a case study in the development of health commissioning policy and practice in England and the relationship between statutory and voluntary agencies.

The Winchester service operated as a multi-agency project. The local Alzheimer's society, which already has a strong commitment to providing volunteer support, initiated the application to the Foundation. The local multi-agency Older People's Mental Health Service planning group made the application but, lacking the management structure to be the grant holder for the project, agreed the newly-formed Primary Care Trust to take on this responsibility and commission the service. This was eventually based in the West Hampshire Mental Health Trust, a local voluntary organisation having decided they did not have the capacity to take on a project focusing on dementia.

One of the risks of a multi-agency venture is of something being missed because each party thinks one of the others is handling it. However, the Winchester scheme is a success story that involved a team effort by many different people from several agencies.

#### **Lessons learned**

##### ***Gathering evidence-based commissioning***

To shape the evaluation, the Mental Health Foundation needed to know what information local planning groups require when assessing a new development for funding, whether through new investment or disinvestment. What sort of evidence of effectiveness is required? What other information is needed? How could the DASS project contribute towards the acquisition of this type of knowledge across the UK?

The service co-ordinator listed the indicators of effectiveness, in order of importance, as being the extent to which a service can:

- improve the health of local people
- prevent or delay unnecessary hospital admissions
- provide effective support to families and friends who are offering substantial amounts of care
- prevent crises of care or reduction

- prevent people being on waiting lists for services they do not really need and wasting NHS and Social Services time in tracking down alternative sources of help
- improve quality of life for the person with dementia.

### ***Difficulties in providing evidence***

The difficulty the DASS (UK) project faced was that, except perhaps in relation to the latter issue, it would be difficult to demonstrate that such services contribute significantly to the indicators in the short term. People diagnosed in the very early stages of a dementia illness may not need to receive much care for a few years. The network of understanding, monitoring and support that an advice and support service would create around a person as their dementia progresses should reduce the impact of the illness on both their independence and services.

The Mental Health Foundation funded in-depth evaluation of the services by 'Dementia North'<sup>5</sup> to look at what happened in the pilot services during the two-year period of the funding. What will not be able to be evaluated in this period is how far the DASS schemes impact upon admissions to A & E, general medical wards or wards specialising in people with dementia, or care homes. This raises the question of how a commissioner wanting to invest in health promotion and illness prevention approaches can get the evidence needed to 'prove' value for money or effectiveness.

The Mental Health Foundation's web-based learning network (Appendix B) includes a topic area that will invite people working on evidence-based commissioning to offer and seek information and advice that will contribute to creating good quality older people's mental health services and in particular in early intervention.

### ***Finding Continuing Funding***

The co-ordinator's monthly reports to the Steering Group included a detailed breakdown of the scheme's clients, sources of referrals and range of outcomes. At the time the scheme ended, there were forty-three people on the DASS register, and almost half were particularly vulnerable people living alone. Although ideally it would have liked to see the evaluation report from Dementia North, the PCT concluded that DASS had provided a valuable (and value-for-money) service, based on the data provided by the team and on the views of the Alzheimer's Society.

In early July 2003, the team received good news: a service for dementia advice and support would be funded by the PCT – indefinitely. The co-ordinator, said: 'It certainly was a steep learning curve for us all to meld the various organisations together to run DASS – this partnership working is the ideal but not easy. The Mental Health Foundation gave Winchester a brilliant opportunity to try it and the outcome has been a considerable success, not least because of the focus it brought to dementia care. The evidence is the readiness of each organisation involved to celebrate the achievements of the project!'

<sup>1</sup> Pratt and Wilkinson (20001) *Tell me the Truth: the effect of being told the diagnosis of dementia* London: Mental Health Foundation

<sup>2</sup> MF Folstein, SE Folstein and PR Mc Hugh 1975 [www.minimental.com](http://www.minimental.com)

<sup>3</sup> A genetic condition causing learning disabilities. In most cases, Down's syndrome is caused by an extra chromosome 21.

<sup>4</sup> Also known as vascular dementia. The second most common type of dementia which occurs as a result of lack of blood and oxygen to the brain in a series of tiny 'strokes'

<sup>5</sup> Dementia North is part of the Dementia Services Development Centres Network. For more information go to [www.dementianorth.com](http://www.dementianorth.com) or contact Dementia North's information officer, Bill, on 0202020394958

# Reflections on the achievements of the project and the pilot sites

This section reviews how far the DASS pilot sites have achieved their objectives and offers an overarching commentary. Supporting quotes from the pilot sites are used to illustrate the breadth and depth of experience and views. It also considers whether the DASS Project UK is achieving its national objectives.

As the grants came to an end, the UK Project Manager asked grantholders to comment on both the local and national objectives of the project. The objectives are listed here, along with some of the grantholder's responses to the questions that were asked (see Appendix B).

## Did the pilot sites achieve their objectives?

### Local project objectives

**Objective: to provide those newly diagnosed with dementia (predominantly people in the early stages) and their carers ready access to a personal home-based information, advice and support services.**

The pilot sites were all successful in providing a range of support services to people in the early stages of dementia and their relatives. They found appropriate referrals, supported people before and through the process of diagnosis, provided advice and information, offered visits at home or in a clinical setting, provided ongoing support over a period of time, and were flexible about when and what is offered. A widely noted deficit was the very limited number of referrals from GPs.

In addition to their work with individuals the sites have also raised awareness of dementia issues in their areas and highlighted the need for early diagnosis of dementia and support for people with dementia and their relatives during the process of diagnosis and adjustment.

### Responses from grantholders

*'DASS has worked with people with memory impairment and their families prior to a diagnosis and supported them through the process. We have received many enquiries and referrals from people who have a suspicion that a person they know has some memory problems.'*

*'The project has done a lot to raise the awareness of the usefulness of a diagnosis and has slowly changed some opinions.'*

*'The service cannot be effective until GPs are much better equipped to spot dementia and refer.'*

*'People need to be well-equipped with information before they seek a diagnosis – so the service needs to engage with people before the diagnosis is made.'*

*'An important distinction is between a) providing emotional and psychological support so as to empower the person and b) providing support for the person's [practical] functioning. We concentrated on the former.'*

*'Despite writing to every GP in the area, we only had one response and that was from a practice manager.'*

*'The provision of both home and clinic based advice is important as the location of advice depends entirely on the individual. The service needs to be flexible.'*

*'Support is better given in the home setting.'*

### **Objective: to enhance carers' coping skills through emotional support.**

In the initial stages of the project, it became clear that the terminology of this objective was inappropriate and – as noted earlier – the term 'carer' was substituted with 'friends or family'. The objective was effectively re-worded as: 'to prepare friends and families for a caring role' in the future. If a person's dementia is diagnosed early enough, most friends and relatives are not yet carers – they are 'carers in waiting.'

The sites did much of this work; offering advice and information to relatives, helping them emotionally and practically to prepare for the current and future demands of supporting a person with dementia, assisting them to manage behaviours and symptoms, and helping them apply for benefits/deal with work related issues. A number of sites developed specific programmes or support services for family and friends; these were very effective and often involved working in partnership with other professionals. Many of the sites also worked with carers of people in the more advanced stages of dementia as a consequence of receiving inappropriate referrals and of not being able to turn a person in need away!

### **Responses from grantholders**

*'We have been successful in obtaining funding for Carer Education programmes.'*

*'Carers say information, signposting, enablement and emotional support are most useful in preparing them for the future. I think having a contact, someone to talk to, even if they didn't actually do so, was most helpful.'*

*'Future carers found counselling, information and the couples' group most helpful.'*

*'We also highlighted to the future carers themselves that in order to be able to care for an individual they must consider their own health and well being which often gets overlooked. We have signposted them on to carers' groups and respite services that would be available if they so wish.'*

### **Objective: to maximise local voluntary support and provide a volunteer befriending service.**

In most areas, DASS pilot sites were in 'unwitting competition' with other voluntary agencies for a limited pool of volunteers, although for at least one volunteer, the unique nature of the project was a specific attraction.

Developing an ongoing befriending service proved a challenge for most of the sites. Supporting a person with dementia who may have limited insight and communication skills and who may display difficult or challenging behaviour is a very demanding role. For many volunteers it was too demanding to 'stay the course'. Small close knit communities and the demands of rural living were also challenges in finding appropriate volunteers.

## Responses from grantholders

*'We are fishing from the same pool for volunteers.'*

*'Excellent cooperation between agencies who help each other to share meagre volunteer stock.'*

*'DASS is a service that is not replicated by any other organisation and therefore has not had to compete with others in order to recruit volunteers to work with this client group.'*

*'We have had little problem in developing the befriending aspects of the service.'*

*'We used every means to recruit volunteers for befriending but without success.'*

*'There were insufficient volunteers recruited to justify the cost.'*

*'Befriending people with dementia is particularly demanding.'*

*'The role of volunteer befriender working with clients who have a diagnosis of dementia can be extremely demanding. As a DASS volunteer, a person will often be expected to work alone within the client's home. The client may have limited communication or be displaying unusual behaviour. This can be quite daunting for a volunteer and requires a person with particular qualities to undertake the task.'*

## Objective: to explore ways to involve users in planning and monitoring the service.

Overall, it is clear that people with dementia were not significantly involved in planning or monitoring the pilot sites. However, some former carers and relatives of people with more advanced dementia have been members of the steering groups and DASS users were routinely consulted about the sites' services and were also involved in the evaluation process. Feedback from users was used to improve both the pilot sites service and – in at least one area – wider services for people with dementia. It is useful to note that at the beginning of the pilot site period there were few models of partnership working in the dementia field upon which to draw.

## Responses from grantholders

*'Someone with dementia will become involved as a local memory clinic is properly set up.'*

*'The National Alzheimer's Society project 'Learning to Live with Dementia' will hopefully come up with pointers on how to involve people appropriately in such projects.'*

*'Specific service initiatives were a response to the comments and wishes of people with dementia.'*

*'We regularly and routinely sought feedback on the service. We did not receive any complaints but many positive responses.'*

*'We adopted a user-led approach in identifying the need for a service that can be attended by both the person with a diagnosis of dementia and others affected by that diagnosis. As a result, DASS, the psychology department and the day staff of the Community Mental Health Team joined forces to form a new style of service. Once set up, members contributed to its evaluation via a diary and a confidential suggestion box. They agreed for*

*this feedback to be used at a presentation attended by social services staff, psychiatrists, mental health nurses, psychologists and voluntary organisation workers. The presentation was made by staff and memory group members.'*

### **Objective: to encourage and support the accessing of more intensive services as needed by both the person with dementia and their relatives.**

This objective was achieved in both directions: the sites referred to more intensive services when appropriate but they also received a number of referrals from statutory agencies. The roles they performed included: making calls to services, enquiring about eligibility criteria, informing users and carers about the range and types of local services, facilitating links for users, and advocating on behalf of users and relatives. Often, the fact that users have built up a positive, trusting relationship with a DASS worker enables a link with another, more intensive service to be made.

### **Responses from grantholders**

*'Many people were referred to us by the statutory authorities.'*

*'We made telephone calls and arranged appointments and accompanied people, but this was in the minority of cases.'*

*'There are no services in the area for people with dementia who are under 65 years of age and service are just general elderly mental health services.'*

*'In the case of carers accessing services such as carers' groups or respite, many have not identified themselves as a carer at this early stage and few DASS clients have chosen to join any carers support groups.'*

*'We often liaised with other relevant agencies on their behalf.'*

*'Some people have been reluctant to accept their diagnosis and the severity of their needs and not been willing to access any other services. DASS has supported them while using gentle persuasion to highlight the benefits of the other services. The trusting relationships have enabled services to be introduced in a timely manner.'*

### **Objective: to identify gaps in local home support and develop plans to extend provision.**

Evidence suggests that the sites have been very effective in identifying gaps and deficits in home support services and care practice. A number of the pilot sites were involved directly in training staff in home care. Staff also raised awareness about early stage dementia on a day-to-day basis as well as by giving formal presentations. In this way they highlighted the need to extend provision.

### **Responses from grantholders**

*'Training is given in both local authority areas to home care workers but they do not have scope [within their resources] to give that 'little bit extra.'*

*'We were involved in training home care staff in the first year, but we had little contact with Home Care Services.'*

*'The project will influence our existing home support services and we will raise the issue of support at home for people in the early stages of dementia with commissioners and providers alike.'*

*'DASS has performed presentations to home care services to raise an awareness of the existence of dementia and encourage staff to refer to them if they identify any symptoms of memory loss.'*

**Objective: to define the local need for such a service.**

In relationship to this aim, one project summarised the key issues raised by all the sites: 'There is a curious failure to properly recognise the significance of dementia as a condition; it is not simply a 'part of growing old', but is in fact a diagnosis of a terminal illness. Yet in all the discussion of life-threatening conditions, palliative care, and end of life services, it is barely recognised that Alzheimer's disease is a far commoner illness than any of the cancers and other degenerative diseases.'

Many workers commented on how little evidence existed in their area about the prevalence and incidence of dementia although this was not universal.

*'A prevalence and incidence needs assessment tool would be useful: a ready reckoner of how many people in each group are likely to have dementia and how many each year should be presenting for the first time as in need of diagnosis and the ensuring support.'*

*'We have been surprised that it has not been possible to access more accurate figures about the rate at which dementia and other memory loss should be identified. The proposed 'ready reckoner' suggested for the Service Development Guide would therefore be extremely useful, particularly if it included some estimate of age profile.'*

**Responses from grantholders**

*'The local public health team provided accurate information on levels of need.'*

*'A prevalence and incidence needs assessment tool would be useful: a ready-reckoner of how many people in each age group are likely to have dementia and how many each year should be presenting for the first time as in need of diagnosis and the ensuing support.'*

**Objective: to estimate the cost of providing the service.**

Most sites were able to give an accurate estimate of how much it cost to deliver their services. They also believed they provided value for money as they prevent or delay the use of intensive services, particularly care home placement.

*'We believe we delay entry to care and perceive that our service represents a big saving.'*

*'We have costed the service so that we know how much it is to run, but not on a per head basis.'*

*'We estimate that to provide a service to our total population of 550,000 would cost £300,00 per year. We estimate that to produce around 18,000 worker hours, it cost £176,974 including all overheads.'*

**Objective: to explore ways of obtaining funding and support from existing agencies in the short and long term.**

During the two years of the Foundation funding of the sites, the services were largely disappointed in the level of financial commitment they received from local statutory services. Many felt that they were 'out of the frame' for dementia-related commissioning activity and that

the emphasis was on memory clinics and medical provision. The changing nature of funding systems and structures added to the sites' sense of having an uncertain future.

In terms of actually obtaining funding in the longer term the pilot sites have had mixed success. It was an expectation of the Foundation – which offered funding for two years – that should the pilot sites prove successful, local statutory services would 'pick up the tab' at the end of this period. While a number of commissioners have stated they need 'hard evidence' of effectiveness before they can commit funding and await the final report of the evaluation (Spring 2004), a number of sites have received 'interim' or 'short term funding from local commissioners. One has received a Community Fund grant and one has received long-term recurrent funding from the local Primary Care Trust.

At the time of this report going to print the funding status of the sites was as follows:

- Nottingham: bridge funding from social services pending a longer term decision, which is likely to be joint funding by social services and the PCT.
- Calderdale: awaiting a decision as to whether social services will match primary care trust funding.
- Glasgow: no funding, as the decision was to integrate the advice and support function into the statutory service's community mental health teams for older people as they are developed.
- South Lakes: received Community Fund money for three years but not successful in obtaining any local funding.
- North-West Wales: Access to Supporting People money via social services has enabled the service to continue at about half capacity.
- Winchester: Long-term recurrent funding is to be made available.

In terms of 'other types of support' the sites have been successful in obtaining much 'goodwill' and practical input from other services.

### **Responses from grantholders**

*'We had hoped the PCT would pay for a worker to attend the memory clinic but in the end there was no money.'*

*'Memory clinic funding seems to be targeted only at medical staffing.'*

*'To fund this ourselves would require a 20-fold increase in fundraising. The only long-term option is a contract from social services or health.'*

*'Funding ... has been more challenging. Partly this has been due to the continuing flux and uncertainty in local health and social care agencies, and a particularly difficult financial situation in 2003-04. The primary care trust agreed continuing funding for 12 months only, on the understanding that this would be matched by social services; however, this has not so far materialised.'*

*'We had office space provided at no cost.'*

*'People gave their time in attending the steering group or being speakers for educational groups.'*

*'Support came in the form of referrals – actually using the service was an expression of support.'*



*'The presence of the DASS pilot has made a difference to the way the Memory Assessment and Treatment Service has developed, and is shaping expectations of the support that will be available to people with memory loss.'*

## **National Project Objectives**

As noted at the beginning of this report the National DASS Project contains three other core components in addition to the pilot sites: the national advisory group, the evaluation and the Learning Network (See Appendix A). Project work also included opportunities to present and comment on behalf of the Foundation at conferences and national level policy meetings e.g. Seminar on Reviewing Standard 7 of the NSF for Older People (May 2002). The publication and distribution of this report, the publication of the evaluation report and the planned service implementation guide and training materials also form parts of the project. Although the pilot sites' funding is now finished, the project continues its work in these other ways. All of these parts of DASS will contribute to the achievement of the national aims.

At this mid-way stage, the national project manager reflects on progress against the national objectives of the project.

### **Objective: to assess how early intervention services can be most effectively provided.**

The evaluation exercise will provide robust evidence about the role and effectiveness of the six pilot sites all working to the same objectives and with the same funder. A review of the role and effectiveness of other forms of early intervention service could usefully supplement this process. The Foundation hopes to include the learning from services other than the DASS pilot site in its Service Development and Training Guide.

### **Objective: to explore how best to recruit and retain volunteers who will deliver the home-based service.**

As noted in the local objectives, this is a really challenging issue. It remains an objective, which requires thorough examination, in order to understand better who is available to provide volunteer capacity and how best this can be used to meet the needs of people with dementia. The use of paid workers in Glasgow and South Lakes proved to be a better use of resources for these two sites, although North-West Wales's success in community integration is a model that clearly works in a more rural and isolated area.

### **Objective: to explore the extent to which such services can maintain independence and ensure timely support from other services when needed.**

The majority of referrals to the pilot sites focused on people in the later stages of dementia – at least initially – although more referrals of people in the early stages were made later on, once the local population and care system understood the pilots' role. To some extent the services were ahead of their time: the identification of people in the early stages of dementia is only just starting to gather momentum, two years after the projects began. This is due, in part, to the National Institute for Clinical Excellence ruling on the availability of early dementia drugs in 19th January 2001, as well as a greater emphasis on the value of early intervention more widely (See Section 4). The evaluation will provide some evidence of the extent to which the sites maintained user independence and ensured access to timely support from other services.

**Objective: to explore whether and how such a scheme might defer the need for long-term care or hospitalisation and how it might ensure the transition is well planned and well-managed.**

Exploring the link between early support and later take-up of services and/or use of long term care requires a long term, or retrospective, evaluation of a large group of people with dementia. The evaluation of the sites will provide some evidence about this objective but it is also useful to acknowledge that there is already 'soft' evidence of the sites' ability to enhance quality of life for both the person with dementia and their relative, and ensure appropriate use of 'other services'. It certainly seems likely that the DASS pilots defer the use of mainstream services and avert crises and maintain community based living for longer.

**Objective: to assess how such a service can best interface with existing services.**

All of the pilots developed strong relationships with a range of other services and professionals. The evaluation report will provide rich information on this.

**Objective: to inform the ongoing debate about the importance of early diagnosis and preventative intervention.**

The overall DASS Project has, and will continue, to contribute to the debate about the importance of early diagnosis. In addition, other Foundation work related to DASS also played a role. Rebekah Pratt and Heather Wilkinson's research – *Tell me the Truth* – which focused on the experience of people receiving a diagnosis of dementia, came out shortly after the pilot sites had begun, providing valuable evidence for the model. The DASS team at the Foundation also highlighted the issue at every opportunity: at conferences, in papers and in wider discussion with service providers and policy makers. The evaluation of the pilot sites in 2004 will also offer a significant contribution to this debate.

<sup>1</sup> Audit Commission (2002) *Forget me not 2002: developing mental health services for older people in England* London: Audit Commission

## Developing services in the future

The DASS project did not operate in a vacuum, the pilot sites were rolled out during a period of unprecedented policy and service development in the dementia field. Looking to the future, this section briefly reviews the emerging policy context and its implications for early intervention services for people with dementia.

### National policy context

There has been a plethora of policy change in the health and social care field since 1998, when the DASS project was originally conceived. A number of policies are directly relevant to dementia services. The *Forget-me Not* report<sup>1</sup>, which reviewed mental health services for older people in 2000 and 2002, and the National Service Framework<sup>2</sup> (NSF) which contains a specific Standard on Mental Health (particularly dementia and depression) were introduced after the start of the DASS project.

Despite an enhanced focus on dementia care, there is no NSF or other national target for providing dementia services in the early stages. While other sources of funding e.g. Supporting People<sup>3</sup>, could be used to fund this type of service, there is little evidence of this creative accounting to date. The ending of the Foundation funding for the pilots sites has also coincided with a particularly stringent time in health and social care funding; those services not regarded as 'essential' or dealing with an illness in its advanced stage tend not to be funded.

### Social Care Policy

A number of social care policies may offer opportunities to develop early intervention services. For example, the 'Fair Access to Care Services' eligibility criteria<sup>4</sup> (England) emphasise that conditions that are likely to progress and lead to the undermining of independence must be responded to as top priority. Dementia certainly falls into this category.

'The framework is based on individuals' needs and associated risks to independence, and includes four eligibility bands – critical, substantial, moderate and low. When placing individuals in these bands, the guidance stresses that councils should not only identify immediate needs but also needs that would worsen for the lack of timely help.'

The top band (termed 'critical') is as follows and, in our opinion, four out of the five indicators apply to people with early dementia, particularly of the Alzheimer's type:

Critical – when

- life is, **or will be**, threatened; and/or
- significant health problems have developed or **will develop**; and/or
- there is, or **will be**, little or no choice and control over vital aspects of the immediate environment; and/or
- serious abuse or neglect has occurred or will occur; and/or
- there is, or **will be**, an inability to carry out vital personal care or domestic routines;

The guidance goes on to state that:

*'Councils should develop methods of risk assessment to help them identify those individuals where risks to independence appear relatively low, but are likely to become more serious over time. In doing so, they should refer to LAC (99) 13 and LAC (99) 14, issued in support of the Prevention Special Grant (subsequently the Promoting Independence Grant). Councils should also consider the benefits of preventative action to support carers, and refer to the Carers and Disabled Children Act 2000 in this regard.'*

It would be difficult for any local authority to deny that the early assessment and support of someone with dementia would not directly meet these criteria, despite the fact that the pilot sites' experience suggests very few people in early stage dementia receive any support from social services.

## Health Care Policy

A number of health care policies also offer opportunities. These include:

### Patient involvement

Patient involvement is a key plank of recent health care policy. The NHS Plan states clearly that patients must be empowered and involved in planning their care:

*'NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works.'*<sup>5</sup>

People with dementia are a large group of service users who use both mainstream and specialist health services. Unless they are engaged with at a relatively early stage in the development of their illness, it is difficult for them to have a meaningful say in their care plans both in the present and when the illness is at a more advanced stage.

### Mixed economies of care

Much development has been made in shifting the balance and nature of health service commissioning over the last decade. The current emphasis on Primary Care Trust-led commissioning may offer distinct opportunities for investment in early intervention services for people with dementia. Most older people with memory problems consult their GP in the first instance and many feel that services offered in this type of setting are 'acceptable'. Current evidence is not positive in this regard however. The rather limited focus on 'memory clinics' as the early intervention service is concerning. At present – many would argue – memory clinics are not sufficiently well developed to ensure that they are not 'mental health service provider-led', something that we have evidence of from three of the DASS pilot sites.

The voluntary sector has been particularly critical of this development. In May 2003, the Sainsbury Centre for Mental Health's chief executive, Dr Matt Muijen, stated that: 'With foundation mental health trusts on the way, it is more important than ever that PCTs are given the clout they need to reshape mental health services to meet the needs of the communities they serve. [They] should be enabled to commission mental health services more freely than they can today. But to do this they will need excellent management and far better information about the needs of the people they serve.'<sup>6</sup>

There is some considerable doubt that the voices of people with dementia will be heard in this arena.

## Joining up the learning

DASS was not a unique project in promoting services for people in the early stages of dementia. There is a range of initiatives that have developed over the last few years specifically focusing on early diagnosis, support and advice to people with dementia and their families. Throughout the DASS project the Foundation has been gathering information about related developments and has made links with providers. A brief review of some of the more prominent services is offered below by way of illustrating the range and innovative capacity of early intervention schemes.

### Early intervention services

*Making the Journey Brighter*<sup>7</sup> (Alzheimer Scotland, 2003) identifies four broad categories of early intervention service models:

- groupwork
- direct support to maintain involvement in activities and promote independence
- provision of information and support around the time of diagnosis and afterwards
- self-help.

### Groupwork

- Rutherglen Dementia Support Group is a community-based project providing a six-week structured educational programme, leading onto a continuing fortnightly support and social group for people with early dementia. This is similar to the work of the South Lakes DASS site, although theirs did not follow through to offer longer term support in quite the same way.
- The Memory Remediation Group at Newcastle Memory Clinic takes a structured rehabilitative approach to providing coping strategies for dealing with memory problems, maximising people's capabilities for dealing with the challenges of their illness. Linda Clare has undertaken research into this approach and an abstract and a presentation on her work can be found at <http://www.cf.ac.uk/psych/ercd/speak/abstracts/clare.html>
- The Early Stage Dementia Support and Respite Project in Australia<sup>8</sup> is a nationally funded programme of early stage dementia support groups, which provides guidelines and standards for a six- to eight-week education course followed by ongoing monthly support groups for people with dementia and, separately, groups for relatives. The service in Calderdale is just beginning work along these lines. The key issue is the viability of actively supporting ongoing groups in the long-term.
- Cheston et al's work (2003), noted earlier, also focuses on psychotherapeutic groupwork with people with dementia, many of whom are in the early stages. This work has been highly effective in helping people with dementia manage their symptoms, share the experience of 'having dementia' and gain support from others. A full report on this work can be found on the learning network<sup>9</sup>.

### Direct support to maintain involvement and promote independence

- The 'Side by Side' Befriending Scheme in Nottingham<sup>10</sup> and 'Diff'rently the Same' in Glasgow both provide one to one support to individuals with early dementia, the former using volunteers to provide befrienders matched for interests and location, the latter using paid staff to provide weekly hours of support. Both schemes work with people in their own home and

local community, and aim to be highly person-centred. The Nottingham DASS found working alongside the 'Side by Side' scheme very effective.

- Memory clinics are a growing development in the UK<sup>11</sup>. They aim to offer treatment, intervention and support for people post-diagnosis; they tend to be based in health care settings. Many clinics also offer related services or have 'link' workers. The memory clinics in Dumfries and Galloway and in Fife both provide information and support services for people with early stage dementia<sup>12</sup>. Different models of 'linkage' exist: workers may be core members of community mental health teams or part of a primary care team and they often link with other specialist services.
- The Croydon Memory Service was developed as part of a tripartite initiative between the NHS Social Services and the Alzheimer's Society, providing comprehensive assessment for individuals experiencing subjective memory difficulties. This is a pilot site for the Department of Health as part of their Workforce Change Programme. More information about this can be found at [www.mhilli.org](http://www.mhilli.org)
- The relationship between the qualified professional staff of a memory clinic and the role of the voluntary agency's service was an area of exploration in the DASS project. Although the Glasgow DASS worked highly effectively with the memory clinic, the two key members of staff were an experienced mental health nurse and a psychology graduate with counselling qualifications. This was not the case in the rest of the pilot sites, which were staffed mostly by non-professionally qualified staff. Nor would such staffing be possible with the levels of funding available to most voluntary agencies seeking to run an advice and support project.
- In Calderdale, a memory clinic was funded and developed during the life of the DASS project and at first did not see a role for the service. Over time this has changed, and now the nurses working with people with early stage dementia can see their role as concentrating on monitoring the person's use of early dementia drugs while the DASS project offers more informal and community integrated support.

## Information and support services

- The Dementia Awareness Project in South-East Belfast was a community mental health nurse and support worker-led service located in a statutory setting (a community and mental health and social care trust). It was funded using older people's services development money. It gathered practice experience and learning outcomes in the field of early dementia service over a three-year period taking account of 500 referrals. David Sheard of the training and service development consultancy 'Dementia Care Matters'<sup>13</sup> provided supervision and support throughout the project and an evaluation was carried out by Queen's University Belfast and 'Education and Development', a consultancy specialising in community development. The project had a range of key functions – screening, supporting people with dementia in receiving a diagnosis, providing holistic assessments, giving advice to other practitioners involved with the person with dementia, developing an individualised 'early stage' support package, running a network of support groups/drop in and sourcing useful information. The project is now being funded as a mainstream service and will be called 'The Early Dementia Service'.

## Self-help

- Dementia Advocacy and Support Network International<sup>14</sup>, a web-based network of people diagnosed with dementia, shows the potential for people with early dementia to support themselves.
- Heather Wilkinson in Scotland carried out research into people's views on the sharing of their diagnosis of dementia<sup>15</sup>. Some of these people have continued to provide an informal network to one another and are about to work together to give their views on our learning network area on 'being a person with dementia'<sup>16</sup>.
- The Alzheimer's Society in England has developed a web area to promote discussion between people with dementia<sup>17</sup>. This is similar to the Mental Health Foundation's web pages called, "Being a person with dementia", which also, as yet, has not attracted any input from people with dementia other than those directly asked to contribute.

## A growing and developing scene

The above review suggests that there is a growing number of initiatives focusing on early intervention in dementia care for people with dementia and their relatives. They offer a range of services including support, information, advice and therapeutic intervention and exist in all areas of the UK. At present the service picture is very uneven with some areas or trusts offering much more than others and some GPs being far more aware of, and committed to, early diagnosis than others<sup>18</sup>.

Although service models vary and there is no 'blueprint' for the 'ideal early intervention service', the evidence base is building. A key addition to this will be the evaluation report of the DASS pilot sites which will deepen knowledge about what needs to be put in place, the aims, timing and setting of such services. This report offers a starting point for this expanding service arena; a review of a unique and far reaching service development which has pointed the way for early intervention services for people with dementia and their carers.

1 Audit Commission (2002) *Forget me not 2002: developing mental health services for older people in England* London: Audit Commission

2 Department of Health (2001) *National Service Framework for Older People* London: Department of Health

3 Local Authority Social Services Letter LASSL(2202)11

4 <http://www.doh.gov.uk/scg/facs/>

5 The NHS Plan <http://www.nhs.uk/nationalplan>

6 Commissioning Mental Health Services, Alan Cohen and Donald Light 2003 web ref – <http://www.scmh.org.uk/802569840056E832/vWeb/wpASTN5MBCFQ?opendocument>

7 Alzheimer Scotland, Action on Dementia (2003) *Making the Journey Brighter: Early diagnosis and support services for people with dementia and their carers* Edinburgh: Alzheimer Scotland,

8 <http://www.alzheimers.org.au/content.cfm?topicid=193>

9 <http://www.mhilli.org/dri/index.html>

10 [www.alzheimers.org.uk/BranchWebsites/Nottingham/sidebyside.htm](http://www.alzheimers.org.uk/BranchWebsites/Nottingham/sidebyside.htm)

11 <http://www.mhilli.org/network/specialistservices.htm#memory>

12 <http://www.alzscot.org/about/report/2002practicalhelp.html>

13 <http://www.dementiacarematters.com>

14 <http://www.dasninternational.org>

15 <http://www.mhilli.org/dri/index.html>

16 <http://www.mhilli.org/network/person.htm>

17 [http://www.alzheimers.org.uk/Real\\_lives/People\\_with\\_dementia/index.htm](http://www.alzheimers.org.uk/Real_lives/People_with_dementia/index.htm)

18 Wilkinson,H & Milne,A (2003) Sharing a diagnosis of dementia - Learning from the Patient Perspective, *Aging and Mental Health* Vol 7(4): 300-307

## Appendix A: The Learning Network

A web-based resource highlighting and addressing issues concerning those in the early stages of dementia. It was launched in June 2002 to run alongside the six DASS project pilot sites.

<http://www.mhilli.org/network/network.htm>.

The web pages are part of a wider website initiative to promote the mental health concerns of older people, and reduce the inequalities in health and social care access.

### Aims and objectives of the Learning Network

- To grow a website in stages: initially to improve and extend the availability of person-centred, easily accessible information, advice and support to people in the early stages of dementia and their families.
- To be an interactive website for all those involved in the experience, from those with early dementia and their family and friends to people working in services as clinicians or supporters.
- To encourage web-based learning and activity for older people who are at risk of being excluded from information sharing and decision-making about their care and support.
- To integrate early dementia web pages into a larger website that focuses on the mental health needs of people in later life ([www.mhilli.org](http://www.mhilli.org)) developed by the Mental Health Foundation to address these concerns.

### The ten areas of the Early Dementia Learning Network are:

1. **Being a Person with Dementia:** Sharing and understanding the experience of realising you have dementia.
2. **Family and Friends:** Sharing and understanding the experience of early realisation that your parent/sibling/friend is developing dementia.
3. **Dementia and Diversity:** Exploring and understanding the experience of dementia in different ethnic groups and cultures.
4. **Medicines and Drugs:** Information about drugs for dementia and project information.
5. **Primary Care:** Taking forward the work in the *Forget-Me-Not* report (2000) that highlights the crucial role of primary care in detecting and diagnosing dementia.
6. **Specialist Services:** Examining the best practice around early dementia e.g. physiotherapy; speech and language therapy; occupational therapy, psychiatry.
7. **Finance and Legal Issues:** Identifying available existing advice, materials, training required and gaps in knowledge.
8. **Employment and the under 65s:** Showcasing projects for younger people who develop dementia and associated lifestyle issues of younger people with dementia.
9. **Commissioning in Partnership:** Gathering together current evidence on commissioning services; developing primary care commissioning.
10. **Volunteers:** Identifying best practice around the recruitment, training and support of volunteers to befriend people with early dementia.

Join in and contribute to [www.mhilli.org](http://www.mhilli.org) – no log-in required.



# Appendix B: Questions asked of the sites and grantholders gathering data for the pilot sites for the report

(questions in italics)

## 1. To explore ways to involve users in planning and monitoring the service

*Can you say if you see any improved involvement as a result of the project?*

We are not aware if any people with dementia have been involved in any way in planning and monitoring services, although some carers or relatives of people with more advanced dementia have been in the planning group.

## 2. To define the local need for such a service

*Can you please state how you have defined local need for advice and support in the early stages of dementia?*

In the Service Development Guide, we will include a prevalence and incidence needs assessment tool. This will be a ready-reckoner of how many people in each age group are likely to have dementia and how many each year should be presenting for the first time as in need of diagnosis and the ensuing support.

*Would something like this have assisted in defining local need, and what information would you have needed?*

## 3. To explore ways of obtaining funding and support from existing agencies

*What support has the pilot service had from existing agencies either in money or in kind or as active support?*

*In what way have other services changed to accommodate or facilitate the DASS pilot service?*

*How have the local commissioning agencies explained why continued funding was not made available where this has been the case?*

## 4. To maximise local voluntary support

*To what extent have other voluntary agencies supported the work? e.g. Carer's groups, day services, lunch clubs?*

*Have you found that recruiting, supporting and utilising volunteers was an area where local agencies compete or co-operate?*

## 5. To provide those newly diagnosed with dementia (predominantly people in the early stages) and their carers ready access to a personal home-based information, advice and support service

*What is happening in the early detection of dementia in your area, and to what extent has the project influenced this? What is the role of GPs and their relationship with psychiatrists and geriatricians in responding to early dementia?*

*Do you think support is more effective by making home visits or by being available in places like surgeries and clinics?*

**6. To provide a volunteer befriending service**

This objective has proved difficult for most pilot services.

*Please say why you think this is.*

**7. To enhance carers coping skills through emotional support**

Early in the project, we realised that this objective was wrongly worded: if a person's dementia is diagnosed early enough, then as yet they would have no carer.

*What contribution has your DASS service made to preparing future carers for their role as a carer? What support did (future) carers find most helpful?*

**8. To encourage and support the accessing of more intensive services as is needed by both the dementia sufferer and their carers**

We note here that we used the term dementia 'sufferer' in the original objectives. Quite early on in the project, we began to perceive this language as creating an unhelpful image of a person whose whole life is nothing other than having dementia. The term 'person with dementia' seems to put the dementia second. This is in accordance with the discourse of disability where people need to be seen as people first, and their disability only part of them and their lives.

*How well did this work? How well did people with dementia fare in eligibility criteria for social care services?*

**9. To identify gaps in local home support and develop plans to extend provision**

We are interested in the extent to which home care services can support people with early dementia to live an independent life.

*What training do staff have?*

*Are their tasks time planned to allow people with dementia to be supported to do things rather than have things done for them?*

**10. To estimate the cost of providing the service**

*How long is a piece of string? And are we comparing apples and pears? A tough one!*

*What information have you developed to help with costing your DASS service in a way that is of interest to commissioners?*

**11. To explore the availability of long-term funding**

This has proved to be problematic and the ending of the DASS funding has coincided with a particularly stringent time in health and social care development funding. There are no national targets to develop early dementia services, something we had thought would be part of implementing the NSF for Older People.

*In what way is Supporting People money appropriate for funding such services?*

*Is the commissioning of memory clinics so provider-led that it is not possible to incorporate DASS into the model?*

**National Project Objectives**

You may be interested to read some of our thoughts on the national project objectives, and we would welcome your comments

**12. To assess how early intervention services can be most effectively provided**

The evaluation exercise will provide information about six services all working to the same objectives and with the same funder. It would now be useful to be able to gather evidence about other forms of early intervention and to compare their effectiveness. This will be part of the brief of the Service Development Guide, which will look at other services than the DASS pilot sites.

**13. To explore how best to recruit and retain volunteers who will deliver the home based service**

This objective needs to be thoroughly examined to understand better who is available to provide volunteer capacity and how best they can be used to meet the needs of people with dementia. Your views are welcomed.

**14. To explore the extent to which such services can maintain independence and ensure timely support from services when needed**

Anecdotal or case study examples of this would be very welcome.

**15. To explore whether and how such a scheme might defer the need for long-term care or hospitalisation and how it might ensure the transition is well planned and well-managed**

Our view is that the two-year period of the projects did not enable this exploration and it remains an important question about the efficiency of the service model. However, if people's dementia is to be diagnosed very early, a project exploring the link between early support and later take-up of services or avoidance of crises would need an impossibly long period of study.

The 'fair access to care services' eligibility criteria (England) lists conditions that are likely to progress and lead to the undermining of independence as top priority. The following sections in italics are taken directly from the guidance (My underlining).

The eligibility framework is graded into four bands, which describe the seriousness of the risk to independence or other consequences if needs are not addressed. The four bands are as follows:

Critical – when

life is, **or will be**, threatened; and/or

significant health problems have developed or **will develop**; and/or

there is, or **will be**, little or no choice and control over vital aspects of the immediate environment; and/or

serious abuse or neglect has occurred or will occur; and/or

there is, or **will be**, an inability to carry out vital personal care or domestic routines; and/or

vital involvement in work, education or learning cannot or **will not be** sustained; and/or

vital social support systems and relationships cannot or **will not be** sustained; and/or

vital family and other social roles and responsibilities cannot or **will not be** undertaken.

(then the next three categories are substantial, moderate and low)

With respect to prevention :

Councils should develop methods of risk assessment to help them identify those individuals where risks to independence appear relatively low, but are likely to become more serious over time. In doing so, they should refer to LAC(99)13 and LAC(99)14, issued in support of

the Prevention Special Grant (subsequently the Promoting Independence Grant). Councils should also consider the benefits of preventative action to support carers, and refer to the Carers and Disabled Children Act 2000 in this regard.

'What is important is for people with similar needs to be assured of similar care outcomes, if they are eligible for help, irrespective of the services that are provided to meet eligible needs.'

*It would be difficult for any local authority to deny that the early assessment and support of someone with dementia would not directly meet these criteria. To what extent is your local authority adhering to this guidance?*

Also, health care policy of patients being involved in planning their care and consulting on their needs equally is a mandate for early intervention and forward planning. The following extracts are taken from the NHS Plan.

'This has to change. NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works.'

*How can people with dementia have a say in their care in the more advanced stages of the illness unless they receive early intervention services? How aware do you think your local health care providers are about this?*

#### **16. To assess how such a service can best interface with existing services**

All of the services developed relationships with a range of other services. The evaluation report will provide rich information on this.

*What do you see as the first and second most important interfaces?*

#### **17. To inform the ongoing debate about the importance of early diagnosis**

The linking of Rebekah Pratt and Heather Wilkinson's work asking people about the value of their diagnosis has added to this. This report (*Tell me the Truth* – see <http://www.mhilli.org/dri/tellmethetruth.pdf>) came out after the pilot sites had begun and provided valuable evidence for the model.

*Do you feel more or less strongly about this issue now that you have been involved in providing a DASS?*

#### **18. To inform the ongoing debate about the value and effectiveness of preventive intervention**

**NOTE FROM THE EDITORS:** It is hoped the evaluation report will provide information for this purpose. In the interim, we have been raising the issue of early intervention at every opportunity and publishing articles and running workshops at conferences. We hope that you will also take every opportunity do this.

## Appendix C: **Background reading**

Background reading recommended by Julia Jefferson, co-ordinator, Nottingham DASS Pilot Site

1. Ahujn, A. and Williams, DRR. (2000) Disclosing the diagnosis of dementia *British Journal of Psychiatry*
2. Downs, M. (1999) How to tell? Disclosing a diagnosis of dementia *Generations* 23 (3) pp. 30-34
3. Pratt and Wilkinson (2001) *Tell Me the Truth* London: Mental Health Foundation
4. Downs, M. and Rae, C. (1997) General Practitioners' reasons for withholding and sharing a diagnosis of dementia In R. Fortinsky and M.G. Downs *Diagnosis and management of patients with Dementia: International Perspectives*
5. Pinner, G. (2000) Truth-telling and the diagnosis of dementia *British Journal of Psychiatry* 176, 514-515
6. Meyers, B.S. (1997) Telling patients they have Alzheimers Disease: Important for planning their future and no evidence of ill effects *British Medical Journal* 314, 321-322
7. Gilliard, J. and Gwilliam, C. (1997) Sharing the diagnosis: a survey of memory disorder clinics, their policies, on informing people with dementia and their families and the support they offer *International Journal of Geriatric Psychiatry* Vol 11, pp 1001-1003
8. Maguire, C.P., Kirby, M., Coen, R., Coakley D., Lawlor, B.A., O'Neill, D. (1996) Family members' attitudes toward telling the patient with Alzheimer's disease their diagnosis *BMJ* 313, pp. 529-30



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**Published February 2004 by**

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© The Mental Health Foundation 2003  
Registered charity number: 801130

**ISBN 1 903645 51 4**