

## Support for people with learning difficulties in residential settings who develop dementia

**What happens when someone with learning difficulties develops dementia? This study explored the experience of 18 people with learning difficulties living in small-scale, community-based residential homes. It also looked at the knowledge and experience of service providers, staff, fellow residents and relatives. The research team, based at the Centre for Research on Families and Relationships, University of Edinburgh, sought to identify good practice, the impact of different models of provision and make recommendations for future development of quality provision. They found:**

- f** Lack of planning led to ad hoc arrangements that often failed to meet the needs of people with dementia, fellow residents and staff.
- f** Lack of coherent strategies and resources resulted in people being moved inappropriately to nursing homes for older people.
- f** When people did move to another setting, residential home staff continued to play a vital role in maintaining basic care for the individual.
- f** There was a lack of coherent, consistent practice in relation to diagnosis and follow-up care. Where baseline assessments were established there was a marked improvement in early diagnosis.
- f** The use of consistent, good quality, practice-based training was critical in determining the type of care given and the likelihood of someone remaining 'at home'.
- f** Staff often provided unpaid or underpaid support. They played down the increased complexity of individual care needs because they feared requesting additional help might result in the person being moved.
- f** Waking night staff were essential not only for dealing with night-time disturbances but also for providing one-to-one support. This also had a positive impact on fellow residents' ability to accept and cope with the person with dementia.
- f** In particular, staff in all settings struggled with pain management and helping people to eat well.
- f** Dementia-friendly built environments were rare. But in some cases staff had been imaginative and resourceful, demonstrating that such changes do not have to be expensive.

## Background

As their longevity increases, people with learning difficulties are experiencing the illnesses of older age, including dementia. However, there is a lack of useful evidence on how best to provide supportive, needs-led services. Looking at adults living in small-scale, community-based residential homes in the UK, this study explored:

- the current models of practice for supporting people with learning difficulties and dementia;
- the key issues relating to people with learning difficulties with dementia living in care home settings;
- examples of best practice.

The study drew on three models for providing services for this group:

- **Ageing in place:** individuals remain in their own accommodation with appropriate support provided (and adaptations where necessary).
- **In place progression:** staff are trained and the environment developed to become increasingly specialised and provide long-term care for the person with dementia within the learning difficulties service (usually not his/her present accommodation).
- **Referral out:** the person is moved to a long-term nursing facility or other type of accommodation, usually outside of the learning difficulties service.

## The care provided in the study

### 'Ageing in place'

All the service providers aspired to support the person with dementia to 'age in place'. The commitment by staff to keeping people at home was evident by the amount of work - sometimes unpaid or underpaid - which they undertook on behalf of the person with dementia.

This commitment to keeping people at home was frustrated by the lack of both appropriate environments and of suitable staff training. Where people were supported well, the site had good links with relevant outside agencies, in particular speech and language therapists and palliative care nurses.

**"For the time we needed intense nursing care we had people come in and advise us on palliative care."  
(Manager)**

Fellow residents were also given information about dementia and how it affected the individual concerned. There was evidence that residents' increased understanding enabled them to better support the person with dementia.

**"It was because of the dementia, he couldn't help it."  
(Fellow resident)**

The employment of waking night staff was significant. They were essential for dealing with night-time disturbances and reducing the stress caused to fellow

residents by the night-time behaviour of the person with dementia.

**"He wouldn't sleep, he would always get up at night ... It wakes me up."  
(Fellow resident)**

Waking night staff were also able to provide good quality one-to-one support at a quiet, calm time.

**"When it's night-time... there is only you, there are no distractions, there is nobody sitting talking all the time, confusing things around him."  
(Staff)**

### 'In place progression'

The study found little evidence of this. One site had developed a proposal for a specialist service within the grounds of the current care setting. This would provide a new building based on dementia-friendly design principles, with training and support for staff. At the time of going to print this proposal had failed to receive adequate funding.

### 'Referral out'

In a number of sites people had been 'referred out'. The first person to develop dementia within these settings was highly likely to be 'referred out' because the service was not 'dementia ready'. Many of the staff and managers felt a sense of guilt when this happened. People who developed dementia subsequently stayed in the setting for longer.

**"She [the trainer] really enlightened us about all the symptoms and things of it and a lot of good practice that we didn't know and this is when everybody thought, 'oh look at all the mistakes we made with 'J'.' "  
(Manager)**

Where people had been referred out, there had been a clear lack of training for staff, no attention paid to the built environment and little support from other services.

**"Things even as simple as giving someone a shower or a bathmat, you know how the décor of the place is very important ... if the flooring is not right, they are very hesitant when they walk ... the layout of the room can be very important ... finding out these things made such a difference."  
(Day staff)**

Staff perceptions were that, as people developed nursing care needs, organisations such as the Care Commission might insist that they required a move to a nursing home or hospital setting. This partly explained staff reluctance to ask for help.

**"... sometimes you're frightened to ask for too much because I think if we had pushed at the beginning with M they would just have said well we'll need to move him. You are worrying about how much you ask for because we didn't want him to go anywhere."  
(Staff)**

There was evidence that the experience of being moved on was detrimental to individuals' well-being.

People were often moved to a setting where staff were untrained and unfamiliar with the needs of a person with learning difficulties and/or dementia.

**"The trouble is the staff there have their dementia training but don't know about Down's." (Manager)**

Often staff from the individual's former home had to visit to take care of the person. But staff felt, despite this intervention, the quality of life for people who moved to these settings was poor.

**"We can't let another resident die in the hospital." (Manager)**

**"They are put in there [Nursing Home] to die, they last about 2 to 3 months and that's it. It is hard when you look after someone for 10 years to give them into someone else's care who will not give them the care they need." (Manager)**

## Diagnosis

The availability, timing and management of a diagnosis had a significant influence on the care provided. Each of the six participating sites had at least one resident with a diagnosis of dementia yet very few people had undergone diagnostic tests. Many people had no formal diagnosis and were only 'suspected' of having dementia.

**"He was a learning curve for us because we hadn't experience .... it must have been going on quite a while before it was said, right this isn't J being J." (Manager)**

Some people became distressed, knowing something was wrong with them but they didn't know what. Staff could not discuss their illness with them.

**"We couldn't talk to him about it because he hadn't been diagnosed." (Manager)**

Only two sites were conducting baseline assessments with service users at regular intervals. In one site, this had resulted in the early detection of the condition.

**"She [the psychologist] had done the baseline assessment a couple of years previous, then she was called back to redo further tests, it was evident there was a decline by 2001." (Manager)**

Even where a formal diagnosis was given, there was a lack of consistent, coherent, systematic or relevant training given to staff or any formalised route for the management of the individual's care.

**"We need training on learning disability and dementia, it's so different from adults with dementia, it really is a different sort of thing, they need to do something." (Day staff)**

## Issues around personal care

Eating and drinking figured prominently as areas of concern, tension and conflict. This study highlighted a particular dilemma around the use of percutaneous

endoscopic gastrostomy (PEG feeding). Through trial and error many of the staff developed ways of coping with problems:

**"We made things for him to pick up with his fingers." (Staff)**

Staff were also concerned about pain management.

**"There was a lot of anxiety about am I doing this right or am I rolling him over in the right way or what ever is it that is causing him pain." (Staff)**

Pain can lead to people with dementia exhibiting 'challenging behaviour', such as violence, banging, swearing, spitting and 'wandering'. Staff regularly cited these kinds of behaviour, but the possibility that this might be connected with pain was rarely made.

**"He would complain more. It was not clear if that was associated with the dementia or if it was the fact that he was experiencing pain." (Staff)**

## Training

Sites varied as to the existence and quality of training. In all the sites, staff consistently raised the need for on-going and appropriate high-quality training.

**"It is important for staff to be trained before anyone develops dementia within their service so that the service is 'dementia ready'." (Staff)**

**"We need training on learning disability and dementia, it's so different from adults with dementia... ." (Day staff)**

Where staff had received relevant and targeted training there was an appreciable difference in their confidence, the quality of care and support given and the reduction in levels of stress.

**"We were totally oblivious to it and it's amazing how training and being made aware can make a difference." (Day staff)**

## Perspectives of relatives

All of the relatives interviewed were anxious that their relative might have to move from their present accommodation.

**"I wouldn't like him to go anywhere else because I don't think that he will get as good a place as this. He's settled." (Relative)**

Like staff, relatives could be reluctant to ask questions:

**"I suppose in a way I would be scared to ask them what's going to happen, because they could say he might be moved into hospital." (Relative)**

## Dementia-friendly accommodation

With a very few notable exceptions, current accommodation - and, in some instances, proposed changes - paid scant attention to the principles of good design for people with dementia. Staff who had been given training were much more aware of these

issues. Some had been imaginative and resourceful their approaches, demonstrating that such changes do not have to be expensive.

"If the flooring is not right they're very hesitant when they walk because it maybe looks like a river." (Staff)

"... making the toilet door red and things like that so they know where things are." (Staff)

### Conclusions for policy and practice

The study identified some good practice and some areas for concern. From these findings the researchers suggest that the following ways forward:

#### Outreach as a new model of support

An outreach model could provide additional support to maintain the person in their own home. This could be delivered through a co-ordinated service provided by designated staff based in the locality, i.e. within a social work centre or a community learning difficulties team. This might incorporate the following provision:

- extra support staff for the residents without dementia, releasing time for permanent staff in the home to give to the person with dementia;
- palliative care services;
- other professional expertise, e.g. speech and language therapy;
- staff to give general advice and support on dementia;
- good quality dementia specific respite care.

#### Improving diagnosis

- clear guidelines on diagnosis and subsequent care;
- guidelines on baseline assessments, ideally to be carried out on everyone with Down's syndrome over the age of 30 years;
- training for staff on how to recognise the early signs of dementia;
- guidelines on the disclosure of a diagnosis of dementia.

#### Meeting the needs of fellow residents and relatives

- a policy to support and educate fellow residents on the needs of the person with dementia (which should take account of the fact that some people may object to others knowing the diagnosis);
- giving additional time to meet the support needs of fellow residents;
- taking account of the information and support needs of relatives.

#### For effective service provision

- flexible and responsive financial systems that acknowledge the rapidly changing care needs of someone with dementia;
- provision of waking night staff from an early stage in the illness.

#### Training needs

- systematic training programmes for all organisations providing support for people with learning difficulties who are approaching middle age;
- training scheduled so that staff are ready before residents develop dementia.

#### The built environment

- understanding by service providers of the impact of the built environment on people with dementia so that it informs building design;
- Awareness by Care Commissioners of the complexities of providing dementia appropriate environments.

#### People moving on

- where people must be moved on new settings should be suitable to meet the requirements of someone with dementia;
- staff in nursing homes and hospitals also need training on learning difficulties and dementia.

### About the project

The research team consisted of Heather Wilkinson, Diana Kerr, Colm Cunningham and Catherine Rae. The researchers worked in 6 sites. These were a mixture of voluntary, private and statutory provision throughout the UK. The age range of residents was 30-70 years. Interviews were conducted with 10 managers, 22 care staff, 13 fellow residents and 5 relatives. Focus groups were held at 2 sites with fellow residents. The study examined the cases of 18 people with learning difficulties and dementia. No direct interviews were held with people with dementia.

The three main models for providing services are taken from Janicki M. P. and Dalton A. J. (1999), *Dementia, Aging, and Intellectual Disabilities: A Handbook* (Brunner/Mazel Philadelphia).

### How to get further information

The full report, **Home for good? Preparing to support people with a learning disability in a residential setting when they develop dementia** by Heather Wilkinson, Diana Kerr, Colm Cunningham and Catherine Rae is published for the Foundation by Pavilion Publishing (ISBN 1 84196 127 2, price £14.95).