



# Growing older with a learning disability and dementia

This briefing brings together the findings from several studies in order to report on the importance of families and relationships in the lives of people with a learning disability, who are growing older and experiencing dementia.

## Home for Good

### The experience of people with a learning disability and dementia in residential care

This project sought to develop an understanding of the experiences of people with a learning disability and dementia who live in residential care settings. It explored how the changed behaviour of the person with dementia was perceived and experienced by other people living with them and the impact this had on relationships.

#### Key Points

- The onset of dementia leads to changes in behaviour that can and often do affect relationships
- In any group, the behaviour of one member can greatly impact on the whole group
- Fellow residents have an understanding and high level of acceptance of the implications of dementia
- Residents also experience anxiety and distress due to disturbing behaviours of those with dementia, such as shouting, banging, kicking and night time activity
- Levels of understanding and tolerance were higher among residents when the reasons for the behaviour or disruption had been explained

#### Method

Interviews were conducted with staff and residents in six sites located throughout the UK. The interviews explored the impact of dementia on relationships within the residential care setting. Settings included private, statutory and voluntary sector settings. The age range of residents was 30-70 years.

## Findings

### Tolerance

In most sites staff commented on a high level of acceptance of the person with dementia by the other residents. This tolerance was extended to both the changes in behaviour of the person with dementia and the increased time allocated to the person with dementia by staff.

'Other residents realised if the workers weren't there it was because they were looking after 'R' and they made allowances for that' (staff)

'He could lie and shout in his bed and be really noisy and he kept her up at night but because she is so fond of him she never complains in a bad way' (manager)

### Understanding

Generally there was an understanding that the person had an illness that caused the changes, and that the person was unable to control the illness and its consequences. When dementia was discussed with residents they were able to explain:

'Yes it was because of the dementia, he couldn't help it' (co resident)

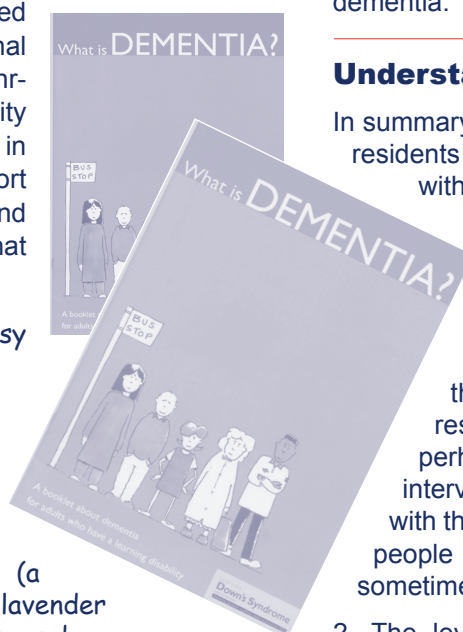
'There is nothing to be done. He just had the illness. You can't do anything about it. You just get it' (co resident)

Levels of understanding and tolerance were higher when the reasons for the behaviour or disruption had been explained to the co resident. Some places had used the booklet 'What is dementia?' (Kerr and Innes 2001). This had resulted in a positive impact on personal relationships as exemplified through the willingness and ability of co residents to find ways in which they were able to support the person with dementia and influence the environment so that it was more acceptable.

'I read him stories about pussy cats or dogs' (co resident)

'I don't shout at him, I try and hug him sometimes' (co resident)

'I give him his smelly dog (a toy dog filled with a heated lavender bag)...it keeps him happy, try and help him' (co resident)



### Difficulties

Even with a degree of knowledge and understanding most residents experienced difficulties in certain areas. Some residents would become angry if the person shouted at staff when they were trying to help.

'He would say things like "she is only trying to help you" so it was quite upsetting (the shouting) for them as well' (staff)

Anxiety was attached to the levels of noise, particularly shouting and banging.

researcher: 'What do you think was the most difficult thing about his illness?'

co resident: 'The shouting'

'Every time people sat him down for his tea he'd start shouting, as if somebody was hurting him, and nobody touches him' (co resident)

Where friction had occurred it was usually when the behaviour of the person with dementia had become noisy or disruptive, especially at night.

'He keeps me awake all night' (co resident)

'Worry about him falling down the stairs' (co resident)

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

'Starts screaming, just screams, wakes all the girls up' (co resident)

These comments by other residents suggest that there is an understanding of some of the implications of the illness but anxiety and distress tend to focus on the disturbing behaviours, such as shouting, banging, kicking and most dramatically, night time behaviours. Nevertheless there is clear evidence of co residents' concerns for each other and for the person with dementia.

### Understanding responses to dementia

In summary, it is evident from these findings that other residents have significant reactions to the person with dementia. Their reactions range from fear, annoyance and irritation through ambivalence to an acceptance and understanding. To an extent the response was determined by three factors:

1. The nature of the relationship between the person with dementia and the other residents before the onset of dementia. It is, perhaps, significant that many of the people interviewed had had long-standing relationships with the people who had dementia. In many cases people had been friends for over 10 years and sometimes for all their adult life.
2. The level of knowledge and understanding that other residents had of the condition sustained their relationships.

3. The severity of the behaviour of the person with dementia. Night time behaviour, eating problems and aggression figured significantly in the behaviours that were most disturbing.

#### Implications for policy practice and research:

1. Each organisation must develop a policy to support and educate co residents on the needs of the person

with dementia. This policy should take account of the fact that some people may object to others knowing the diagnosis.

2. Within the care setting additional time is given to meet the support needs of co residents and to support positive relationships.

3. Additional research is required on the impact of family and friendship relationships within shared living environments and on caring relations.

## Sisters' caring Experiences of the long term care of siblings with Down's syndrome

The longer life expectancy of people with Down's syndrome now leads to many outliving the parents who care for them. This has led to a growing number of siblings who take on the role of carers for their brother or sister with Down's syndrome. These siblings often do not know that a family member with Down's syndrome is at a greater risk than the general population of developing dementia at an earlier age.

### Key Points

- Siblings of people with Down's syndrome often take over care when a parent dies or is no longer able to care
- This increased caring role often coincides with a time in the sibling's life when they also have other care commitments such as children or older parents
- The relationship between siblings is likely to be the longest that a person with Down's syndrome will have with anyone
- Whether or not the siblings live near each other does not affect the nature of their relationship
- Family members generally do not plan ahead for the future care of their relative with Down's syndrome
- Conflict may arise between siblings if they are in disagreement with each other over the care of their family member
- Siblings are reluctant to share any concerns with professionals due to their fear of being thought unable to cope
- Siblings are generally not aware of the link between Down's syndrome and dementia
- Siblings noticed changes in the health or behaviour of their brother or sister with Down's syndrome and dementia in advance of it being detected elsewhere. These changes were not communicated until they were also picked up by professionals working with the family

### Context

A higher incidence of dementia is known to occur among people with Down's syndrome. Very little research has considered the role of siblings who care for people with Down's syndrome and dementia. This study evaluated siblings' knowledge and understanding of dementia as it affects those with Down's syndrome, focusing on the ways families are structured, accommodation needs, end of life issues, the expectations of parents, and the influence of gender and health.

## Method

Six sisters of people with Down's syndrome were interviewed to determine their understanding and knowledge of dementia. The combination of a qualitative and quantitative approach was taken through individual semi structured interviews. The quantitative element gave background information about the sibling participant, such as age, accommodation, care etc. The longer qualitative component allowed siblings to give more detailed information about their relationship with their brother or sister with Down's syndrome throughout their life.

## Implications for future research and practice

- Little is known about the end stages of dementia among people with Down's syndrome, and this requires further research
- We need to know more about the role and experience of brothers who care for a sibling with Down's syndrome

- Siblings of people with Down's syndrome and dementia must be supported to communicate any health changes to professionals as soon as they are detected
- Siblings should be given specific information about dementia including the possible course of the disease and the different terms that may be used by professionals
- The physical design of buildings must be considered by service planners in order that people with Down's syndrome may remain in the same accommodation for as long as possible, if this is their choice

The overall picture is one of isolation and frustration among siblings who care for their brother or sister with Down's syndrome and dementia. The knowledge and understanding of dementia among siblings is currently inadequate to prepare them for their caring role.

## References

Wilkinson H Kerr D Cunningham C and Rae C (2004) *Home for Good? Preparing to support people with a learning disability living in residential settings when they develop dementia. Final report.* York. Joseph Rowntree Foundation.

Wilkinson H and Kerr D (2004) *Top Tips: fact sheet for caring for people with learning disability and dementia.* York. Joseph Rowntree Foundation.

Both above are available from the Joseph Rowntree Foundation – [www.jrf.org.uk](http://www.jrf.org.uk)

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## Authors

This briefing was written by Heather Wilkinson and Karen Watchman, edited by Sarah Morton

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'The knowledge and experience of dementia among siblings of people with Down's syndrome and dementia': a study carried out by Karen Watchman, Director of the Scottish Down's Syndrome Association, published by Down's Syndrome Scotland, Edinburgh

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