Developing services for younger people with dementia

IN THE UK an estimated 18,500 people between the ages of 45 and 65 have dementia (Alzheimer’s Society, 2003a). Comprehensive services for older people with dementia have been widely established for many years, while services for younger people with dementia appear to have been overlooked (Williams, 1995). The National Service Framework for Older People (Department of Health, 2001) addresses dementia but it lacks clarity and detail on the specific and unique needs of younger people who have dementia, thus leaving them in danger of falling between service providers.

The impact of young-onset dementia on individuals

According to the Alzheimer’s Society, younger people with dementia are a distinct group whose needs differ from older people’s (Alzheimer’s Society, 1994). Often more aware of their condition, younger people with dementia may feel a greater need to understand what is happening to them and experience greater frustration as a result (Keady and Nolan, 1997). They are also more likely to be physically fitter than older people and need services that are appropriate for their age (Alzheimer’s Society, 1994).

Younger people with dementia have different family and life circumstances. They are more likely to be in full-time employment and, as their condition worsens, they may be made redundant or forced to take early retirement. Their spouse or partner may also have to give up work to care for them. Even if the carer can continue working, combining paid employment with carer responsibilities can be a source of considerable emotional and physical strain.

Younger people with dementia also tend to display a more extensive range of disturbed behaviour such as aggression, restlessness, frustration, expression of fear, distress, disruption, unpredictability and sleeplessness (Keady and Nolan, 1997). Naturally, such behaviours can cause heightened carer and family stress.

How young-onset dementia affects families

Children may be adversely affected by watching a parent or close relative deteriorate with dementia. It can make them become angry or withdrawn and they may believe that they have caused the illness or worry that they may inherit the disease (Alzheimer’s Society, 2003b). Adolescents are particularly sensitive to the views of their peers, who may fail to understand the disorientated behaviour of a parent (Robertson, 1996). The parents of people with young-onset dementia can also become distressed at having to watch their child face a disease that is normally associated with older age.

Looking after somebody with this type of dementia can impact on all areas of daily life for partners and spouses. Carers may feel that they have lost the companionship of a friend and the intimacy of a lover at the same time as juggling other responsibilities such as children, a job and older parents (Alzheimer’s Society, 1996).

Developing an appropriate service

A team of community mental health nurses in Doncaster recognised that younger people with dementia and their carers needed a different type of service provision. An audit was carried out from September 1998 to March 1999 to identify the prevalence of dementia in younger people in the local area. The results of the survey highlighted several key issues (Box 1).

A semistructured interview was subsequently used to explore carers’ perceptions of service provision. Twenty younger people with dementia and their carers were identified through the care coordinators and existing records from the mental health service. They were asked about the impact of the diagnosis on their lifestyle and on their relationships.

Results

Most of the younger people with dementia and their carers said that long-term friends no longer visited and they felt isolated. One carer commented: ‘The only time I have contact with the outside world is when we attend hospital appointments.’

Carers also felt that they had lost the art of conversation, social skills and confidence. Many found themselves excluded from family parties due to the behaviour of the person with dementia.

Transport was a major contributing factor to feelings of isolation. Five younger people with dementia were identified who could no longer drive. One, who had not yet stopped driving, said: ‘When I stop driving, I will lose a lifeline.’ Carers living in rural areas who did not drive found that they were no longer able to go out. Other carers who did drive had problems with the behaviour of the person with dementia when they were in the car. One carer commented: ‘My wife would attempt to get out of the car when it was stationary at traffic lights’.

A major theme emerging from the evaluation was that younger people with dementia did not want day care. Instead they wanted to mix socially with people of their own age in the community. One said: ‘I don’t want to sit around discussing the Second World War, I wasn’t even born then.’

Carers wanted a range of flexible services specific both to the needs of the younger person and to themselves. Both groups wanted the opportunity to socialise in an
made to feel inadequate if he or she made mistakes and the carers would not be embarrassed by any behaviour.

The coffee shop project
In response to the comments received, and after discussion with an occupational therapist, the development worker arranged informal gatherings in a local pub. It was from one of these meetings that the idea of a ‘coffee shop’ environment was born.

The coffee shop would be an informal resource centre, with support provided via leaflets, books and the internet. Professionals and agencies could also hold surgeries to offer services such as counselling, relaxation, help with obtaining benefits and legal advice. Most importantly, younger people with dementia and their carers could meet and support each other.

To achieve these aims it was decided that a drop-in facility would be the most appropriate. A similar project, called the Alzheimer’s Café, has already been developed in Holland (Riksen, 2002). We all agreed that our café should be known as the ‘coffee shop’ and would be based in the community so as not to exclude people with varying forms of dementia. The coffee shop opened in early 2001 and is run by designated community mental health nurses and Alzheimer’s Society staff.

After much hard work in building up the group’s confidence and knowledge base, younger people with dementia and their carers have now formed a community group known as the PROP (‘people relying on people’) group. It currently comprises 13 young people with dementia (eight male, five female) and 14 carers (six male and eight female). The participants are aged between 40 and 50, although some individuals have been as young as 30. We do not enforce an upper age limit because once someone is diagnosed they stay with the team.

Although every younger person with dementia is invited to attend the PROP group not all take up the offer. The team’s community nurses support those who choose not to join the group, or who are unable to because they cannot travel or because their condition is too advanced.

It has been difficult for some of the staff to move away from the traditional stance of ‘knowing best’, and to allow group members to do things their own way. The next step is to enable the PROP group to employ their own support worker at the coffee shop.

The PROP group meets regularly to plan various social activities and holidays. Social events are organised in various locations around Doncaster so that everyone who lives in the rural areas can join in. Group members who can drive provide lifts for those who are unable to make their own way. In this way the group enables younger people with dementia to feel involved in the decision-making process and to feel that they are being heard and valued. Carers and younger people with dementia can also arrange individual consultations or group meetings to discuss any concerns.

An occupational therapist oversees creative writing, which focuses on the life stories of the younger people with dementia and local history. These stories are used to plan activities and inform care planning. Most importantly, they allow the person with dementia to have a voice. One said: ‘It is good to leave a part of you behind so that people can get to know the real you.’

Many visitors to the coffee shop have commented on the openness and honesty that the younger people with dementia and their carers share in talking about their problems and on their strong use of humour.

Future plans
Doncaster’s geography can make it difficult for people who live in the outlying areas to access the central base. Although group members are reliant on each other for transport this informal arrangement cannot be sustained. Therefore, an extended outreach service is being planned.

The audit also revealed the importance of employment issues both to younger people with dementia and their carers. Although staff workshops have been used to raise awareness of dementia and depression in the workforce and to highlight the legislation regarding disabilities and family-friendly policies, the service offered to employers needs to be expanded.

An advisory group has been set up to develop a strategy for long-term care and respite. It consists of two younger people with dementia and two carers (on behalf of the PROP group), a clinical nurse specialist and a social worker. For those individuals who want residential provision, two options are being considered:

■ Discussions are under way with an independent care provider;
■ The service for younger people with dementia has begun negotiations with the housing department with a view to obtaining suitable premises.

Conclusion
The Doncaster service has evolved because of the strong partnerships with younger people with dementia and their carers. This collaboration has been important and will continue so that the needs of the client group will not be overlooked in the future.

REFERENCES

For related articles on this subject and links to relevant websites see. www.nursingtimes.net