

Social care planning and provision for people with young onset dementia and their families: current practice and resources for improvement.

Background

Social care needs of people with young onset dementia and their families are very different from those of older people. Younger people are at a different life stage and may still be working and/or have families to support. Access to appropriate social care post-diagnosis is crucial for people with young onset dementia and their families. Yet care is hugely variable, frequently lacking, and poorly coordinated. In this study we wanted to identify issues and examples of good practice to produce resources to improve social care for people with young onset dementia and their families. The project is split into two stages. Here we report on the first stage of the project.

Study aims

- To better understand the social care needs, experiences and preferences of those living with young onset dementia and their supporters.
- To explore levels of awareness, knowledge and practice among professionals regarding social care needs, care planning, and provision for people with young onset dementia.

What did we do?

Working with experts by experience and our project team we developed two studies to explore these aims.

Study 1

We spoke to 33 people to find out about their social care experiences and support needs. All were or supported a person whose dementia developed under age 65 years. Eleven were people with young onset dementia and 22 were family carers. The majority had children or young people still at home and some also cared for older relatives. Interviews took place in person, online or by phone.

Participants reported a general lack of choice and flexibility in support. Some of those with dementia were offered no services at all after diagnosis, and others found they were excluded from services they attempted to access. Those who did find an age-appropriate group or support service that met their needs, spoke of the benefits of shared experience. Feeling understood and being treated as a person were basic aspects that contributed to positive experiences of social support.

Family carers highlighted difficulties balancing work and caring, although some had supportive employers. Some spoke about the importance of social care for the person with dementia, whilst they were at work. Some family carers felt that the person with dementia would benefit from having a 'buddy' to keep them socially, mentally and

physically active. Family carers valued peer support for themselves where it was available, but its timing and location did not always fit with their caring responsibilities.

Loss of one or both salaries impacted on family finances. This could cause upset and stress. While incomes were reducing, social care needs were increasing and meeting these needs could be costly. Some family carers made decisions to pay for care, despite fearing this could lead to long-term financial hardship.

People desired social care support for the whole family. There was a general absence of appropriate or appealing support for children and families. Some parents were aware that their children had taken up opportunities for counselling at school or university.

Difficulty in finding and accessing support was consistently reported. People were frustrated when services varied from area to area and wanted more consistency across the country. Many spoke of a lack of understanding about young onset dementia amongst social care staff. We heard how delays in being offered and accessing support could lead to crises and increased needs. People highlighted key periods where more sensitive proactive social care support would have helped.

Study 2

We created a short survey for health and social care professionals working in England. We wanted to examine awareness, knowledge, and practice among professionals regarding social care needs, care planning, and provision for people with young onset dementia. The survey was available online.

The survey had 139 responses from a range of health and social care professionals. We found that a wide range of situations triggered referrals to social care. Often these were in response to crises occurring and tended to relate to the needs of the carer. Referrals for advice and guidance around financial impacts were common. People completing the survey varied in their knowledge of young onset dementia and their confidence with social care planning. They did provide some areas of good practice in social care provision. These focused on person-centred and reablement based approaches; multi-disciplinary and multi-agency working; support from peers and the third sector; seamless care pathways and dedicated young onset dementia services; support for carers; and personal budgets.

What are we doing with these findings?

The findings of these two studies will help us with the next stage of the study where we will be creating resources to improve social care for people with young onset dementia and their families. We will share our findings through publications and presentations. We will also be running webinars in conjunction with Young Dementia Network.