Young Dementia Network

Supporting social care practice for people with young onset dementia and their families

This resource is designed for use by social care professionals to assist in their role in supporting people with young onset dementia and their families. The aim is to improve understanding of the unique issues which can arise and to suggest some creative person-centred ways social care professionals can help people manage these. The content reflects findings from the **DYNAMIC project** which looked at social care planning and provision for people with young onset dementia and their families.

An introduction to young onset dementia

Dementia is considered 'young onset' when symptoms develop before the age of 65. Although rarer than dementia in older people, it is estimated that there are currently over 70,000 people living with young onset dementia in the UK.

Younger people with dementia have different needs to people who develop dementia later in life. They may have a mortgage, dependent children at home and be caring for others. **The Angela Project** found that social care is key to enable people to live well with young onset dementia and the DYNAMIC project highlighted the role of social care professionals in enabling this.

Although Alzheimer's disease is the most common form of young onset dementia, there are a greater number of rare dementias represented in this age group compared to dementia when older. It is helpful to understand these rarer dementias as many start with symptoms other than memory loss. You can find out about the different types of rare dementias on the **Rare Dementia Support** website.

The value of feeling understood

A clear finding from the DYNAMIC project was that feeling understood and being treated as a person were underlying aspects that contributed to positive experiences of social care for people with young onset dementia and their families.

Joined-up care

The DYNAMIC project was focused on social care, however the needs of people with dementia in midlife and families cross boundaries between health and social care. It is therefore important for social care professionals to link with colleagues in healthcare teams to ensure holistic and joined-up care.

Key aspects of social care in young onset dementia

Work, employment and retirement

Young onset dementia often affects a person's ability to work. Sometimes by the time a person receives a diagnosis, they have already left their job. Of those with young onset dementia interviewed as part of the DYNAMIC project, only one person remained in employment. Researchers heard how a loss of income and lack of adequate support caused some people significant emotional distress.

In the UK, dementia is legally recognised as a disability, so people are protected from discrimination within the workplace. Social care professionals can help by signposting to resources or services which can support the person to understand their rights and receive appropriate specialist advice and support. If the person with dementia is no longer able to work, social care professionals can signpost them to alternative occupation or meaningful activity and/or link them with occupational therapists who are experts in this area.

The DYNAMIC project found that family carers could be enabled to continue working, and therefore be more financially secure, if there was good social care for the person they support. People spoke of having someone to buddy with the person with dementia to enable them to engage in activities whilst the family carer was out at work. A referral to a local authority (or health service) occupational therapist could also help as they can provide aids or adaptations to promote safety and independence.

Meaningful occupation

Once a person with young onset dementia is unable to continue in employment, there is a transition to life without the structure and occupation of work. This adjustment can be challenging, both for the person themselves and their partner, if they have one.

Supporting people with dementia in midlife to remain socially, mentally and physically active can help but finding age-appropriate activities often requires social care staff to have skills of advocacy and creativity.

Judith's story

Judith was 39 years old when she was diagnosed with young onset Alzheimer's disease. She was working as a physiotherapist and was contractually obliged to tell her employer about her diagnosis. With support from occupational health, she was enabled to remain in her role with adjustments to minimise distractions, allow adequate breaks and provide her with specialist software for note-writing.

Eventually, changes due to her dementia meant that she took ill-health retirement. Judith and her husband Rohan looked for activities to occupy her time so he had peace of mind when working. This was achieved through joined-up working between a social worker and occupational therapist linking with the benefits team. Judith was supported to apply for Direct Payments which enabled her to have support from a personal assistant to do activities inside and outside the home, allowing Rohan to carry on working.

Jacqui's story

Following a diagnosis of frontotemporal dementia aged 49, Jacqui was unable to continue in her job. Living alone, she found she was spending long periods by herself feeling unfulfilled. She went to a local dementia café but there was no one her own age and the activities did not interest her.

The dementia café coordinator referred Jacqui to Adult Social Care, and her case was picked up by a social worker. The social worker spent time getting to know Jacqui and having learnt about her love of jazz and ability to play saxophone, found a local music therapy group for adults with autism via the internet. Jacqui was keen to join but on approaching the group was told she was not eligible to attend.

Her social worker stepped in and negotiated for her to go for a trial session leading to her being accepted into the group. Although not a dementia specific provision, the shared experiences with other members met Jacqui's needs and preferences.

Peer support

Findings from the DYNAMIC project highlighted the benefits of peer support both for the person with dementia and the family carer. As young onset dementia is rarer, local opportunities to meet others living with the condition can be limited. It is important to consider the timing and location of carers' groups so that family carers can fit these in with their caring responsibilities.

Researchers heard about different forms of peer support as illustrated in the following examples:

They were told about two couples, where one partner in each had Lewy body dementia. They were buddied together through links with a support organisation. Although from different backgrounds, the two couples found a deep mutual understanding and benefits to supporting each other by sharing experiences and information.

A man with young onset dementia found peer support through a local padel tennis club. He enjoyed playing matches with other club members who, although aware of his dementia, saw beyond this and embraced his contribution to the club.

Supporting to remain safe and independent

Personal circumstances and the impact of young onset dementia are unique to each person. Tailored support is needed to promote safe functional independence.

Support for children and young people

Researchers heard about the importance of social care support for the whole family. Children and young people may be impacted by the economic and emotional pressures that young onset dementia creates and may take on unseen roles as carers.

It is important that support offered is appealing to children and young adults as one size does not fit all. The DYNAMIC team heard that schools and universities often provided opportunities for counselling which children and young people were willing to take up. Social care professionals can help by including the needs of children, young people and the family in their holistic assessments.

Adam's story

Adam developed young onset dementia in his early forties. He had enjoyed a highly successful career as a barrister but left work in the lead-up to his diagnosis. Adam had lived alone since his divorce a few years earlier, and his brothers, who lived many miles away, were concerned how he would continue to manage on his own.

He was fortunate to be connected to a local young onset dementia service where a key worker, in collaboration with Adam's brothers, built a support network incorporating his preferences to maintain independence whilst effectively managing risks.

This bespoke support included the development of a WhatsApp group involving Adam's friends and brothers, a smart watch and a carefully matched support worker to enable regular, suitably strenuous, varied and enjoyable physical exercise.

Personal stories have been anonymised and stock imagery used throughout this leaflet.

Financial and legal issues

Researchers heard from people about the serious financial impact on families of losing one or both salaries, especially for people who had children or young people still at home.

While incomes were reducing, social care needs were increasing and meeting these needs could be costly. These and other financial and legal issues are explored in **DYNAMIC's finance resource**. Social care professionals have a key role in signposting people with young onset dementia and their family members to the right teams to advise on financial issues.

Planning for the future

Young onset dementia has an uncertain path but is a progressive and life-limiting condition. The DYNAMIC team's research showed there is a benefit to planning ahead for future needs. Sensitive proactive social care support could help prevent crises and meet increased needs.

Discussing views on future care and setting up contingency plans reduces the emotional cost to people with young onset dementia and their families and financial costs to everyone.

The opportunity to influence and change things for the better

People with young onset dementia are often under-served and overlooked. Social workers are well-placed to feed back to commissioners when their specific needs are unmet.

Sharing anonymised case stories with those who commission services is a powerful way to bring change for the better. Developing a good social care strategy for managing young onset dementia could provide a useful model that would also apply to other complex conditions.

Kathryn's story

Kathryn has cared for her husband Richard since his diagnosis with posterior cortical atrophy, a rare form of dementia, eight years ago. She gave up work prematurely two years ago, when juggling her caring duties alongside her job became too much. Their two sons help when they can, but both have full-time jobs and live away from home.

A long-term friend and neighbour of the couple lent a hand when Richard had a fall. Following this, Kathryn became more more concerned about the future when she herself had a health scare. Although this turned out to be nothing serious, it prompted her to seek help through Adult Social Care to put in place back-up care should it be needed at short notice.

Having this safety net gave Kathryn peace of mind knowing that Richard was on the radar of an appropriate care provider who was familiar with him and understood his needs.

Useful resources

Employment

Dementia UK
Information on how **young onset dementia may affect employment**, including self-employment and how to manage the changes, plus guides for **employees and family members** and **employers**.

Ritchie, L, Lebec, L and Allen, R (2025). Young onset dementia and employment. In Oyebode, J and Rook, G (Eds), **Young onset dementia reconsidered: a solution focused approach** (pp162-175). Open University Press

Kilty, C, Cahill, S, Foley, T and Fox, S, **Young onset dementia: implications for employment and finances**, Dementia 22, no. 1 (2023): 68-84

Smeets, B, Niels, J, Kirsten P, Boots, L, Bakker, C and de Vugt, M, **Too young to sit at home: a qualitative study conducted among employees with young onset dementia and their relatives**, Aging & Mental Health 28, no. 8 (2024): 1119–1128

Williams, J, Richardson, S and Draper, E, **A beginning and not the end: work after a diagnosis of dementia**, Work, Employment and Society 32, no.1 (2017): 219-229

Meaningful occupation

Hussey, J and Oyebode, J (2025). Meaningful activity. In Oyebode, J and Rook, G (Eds), **Young onset dementia reconsidered: A solution focused approach** (pp176-191). Open University Press

Issakainen, M, Maki-Petaja-Leinonen, A, Heimonen, S, et al, **Experiences of influencing one's own life when living with working-age dementia**, Ageing and Society 43, no. 8 (2023): 1934-1953

Roach, P and Drummond, N, **'It's nice to have something to do': early-onset dementia and maintaining purposeful activity**, Journal of Psychiatric and Mental Health Nursing 21, no. 10 (2014): 889-895

Peer support

Dementia Engagement and Empowerment Project (DEEP)
Provides links to around 80 groups across the UK where people with dementia can find peer support. Its aim is to engage and empower its members with friendship at the heart. It highlights how incredibly powerful it is to be amongst people experiencing similar things.

Dementia UK
A **unique database** to search for young onset dementia support groups and services across the UK.

Together in dementia everyday (tide)
tide holds an online monthly young onset carers' group which provides a safe space for family carers to share their experiences.

Young Dementia Network
Hosted by Dementia UK, the Network is an online influencing community for everyone living with, working with or interested in young onset dementia. It works to increase knowledge, understanding and awareness of young onset dementia.

Mason, C (2025). Peer support. In Oyebode, J and Rook, G (Eds), **Young onset dementia reconsidered: a solution focused approach** (pp270-284). Open University Press

Remaining safe and independent

Alzheimer's Society
Information on how **assisted technology** can help and how to get hold of it.

Young Dementia Network
'Supporting people living alone with young onset dementia' webinar.

Holthe, T (2025). How technology can help people living with young onset dementia. In Oyebode, J and Rook, G (Eds) **Young onset dementia reconsidered: a solution focused approach** (pp59-79). Open University Press

Children and young people

Alzheimer's Society
Information on **how to explain dementia to children and young people** and **suggestions on offering support**.

Dementia UK
Leaflet around **supporting children and young people**. The charity has a Consultant Admiral Nurse for Children and Young People; referrals can be made via its **Helpline**.

Lorenzo's House
A global, virtual organisation designed to empower the children and families affected by young onset dementia. It offers online virtual opportunities to connect, share and learn from young people's experiences.

Young Dementia Network
'Supporting children and young people affected by parental young onset dementia' webinar. The website has a collection of research studies related to children and young people.

Sikes, P and Hall, M (2025). The wellbeing and identity of children and young people who have or have had a parent with young onset dementia. In Oyebode, J and Rook, G (Eds), **Young onset dementia reconsidered: a solution focused approach** (pp259-269). Open University Press

Planning for the future

Carers UK
Offer help and advice to carers for **contingency planning**; includes a link to creating a **back-up plan**.

Dementia UK
Speak to a dementia specialist Admiral Nurse on its free Helpline 0800 888 6678, or make an appointment at a **virtual clinic** or a **Nationwide branch**.

Quinn, C, et al (2025). **Professionals' views on social care planning and provision for people with young onset dementia and their families in England: findings from the DYNAMIC study**. International Journal of Geriatric Psychiatry, 40(9), e70155

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To find out more about the Young Dementia Network and to join, visit: **youngdementianetwork.org**
or email: **youngdementianetwork@dementiauk.org**

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Hosted by Dementia UK