

Young onset dementia: guidance for dementia support roles



Supporting people and families affected by young onset dementia (where symptoms develop before the age of 65) presents unique challenges compared to older individuals. Due to the person's younger age, there may be different issues to consider such as work, finances and dependent children. Supporting them can be more emotionally intense and complex, requiring greater advisor involvement and adaptability.

Often people in dementia support roles have little or no experience of supporting younger people through these challenges. The Young Dementia Network has created this guidance to help professionals such as dementia support workers, dementia advisors and key workers, but it can be used by anyone seeking information and advice.

This leaflet is intended to be used as a tool to help steer a discussion with a person with young onset dementia and their family members and can be used as a prompt to offer further information and support. The guidance is divided up into topics that can be discussed at a time that is right for the person and their family, and adapted to their needs and circumstances.

A list of useful resources can be found at the end of the leaflet.

Differences to consider when supporting a younger person

- Young onset dementia affects each person differently. The person's symptoms will vary according to the type of dementia and stage.
- Family circumstances may affect the support they require
- In younger people, early symptoms often impact thinking, planning, organisation, language, behaviour and relationships. Memory may be less affected in the initial stages
- Take time to research young onset dementia and its rarer types to ensure tailored, effective and empathetic support
- Wherever possible, allow the person with young onset dementia to take the lead at your initial meetings
- Take time to understand their priorities and what matters most to them
- Avoid overwhelming them with information – address issues gradually and at the right time
- Some people may not seek or require support immediately, but it is important to maintain trust and provide ongoing contact
- Local support for younger people may be hard to find, so it is important to be open-minded, creative and flexible and consider all available options



Family

- Provide support for family members, including children, as they come to terms with the diagnosis and the impact it has on them
- If applicable, signpost to age-appropriate children's resources and young carers' support groups. Encourage parents to inform schools or colleges so additional support can be arranged
- Find out whether the person is caring for elderly parents or others and provide advice tailored to their situation
- Offer advice on sharing the diagnosis with extended family and friends
- Recommend that the primary family member registers as a carer with their GP and local emergency care services, if available
- Share details of online or in-person courses for the person with young onset dementia or the family members to attend
- Encourage planning family days out, short breaks or holidays to create positive experiences and memories
- Offer support and advice around dealing with anticipatory/living grief

Work and employment

- Dementia is classified in England, Wales and Scotland as a disability in the Equality Act 2010, and in the Disability Discrimination Act 1995 in Northern Ireland. This means a person with the diagnosis has a legal protection from discrimination at work
- Support the person with young onset dementia in sharing their diagnosis with their employer and requesting reasonable adjustments to remain in work, if they choose
- Explore whether taking early retirement may be a suitable option
- Offer support for people who have lost their job due to symptoms prior to diagnosis
- Help partners or family members notify their own employers, as they may need time off or flexible working arrangements
- Part-time work or volunteering may provide a way to keep meaningfully occupied in the absence of a full-time job



Social and peer support

- Emphasise that life can still be active and fulfilling. Encourage the person to maintain their identity, hobbies, interests, occupation and sense of purpose
- Connecting with others in similar circumstances can be valuable. Age-appropriate support and service provision is patchy and may not be available in all areas but some peer support groups run online. Search Dementia UK's database of local and national groups and services: visit dementiauk.org/find-support
- Signpost to relevant national dementia, carers' and support organisations and explain the services they provide



Financial, legal and daily living

- Emphasise the importance of future planning eg writing or updating a Will and setting up a lasting power of attorney for both health and welfare and property and financial affairs, or power of attorney in Scotland and enduring power of attorney in Northern Ireland. Ensure it is registered with the person's bank and other financial institutions
- Advise the person to inform their bank about the dementia diagnosis, as additional safeguards can often be put in place to protect their accounts
- Discuss potential benefit entitlements, such as Personal Independence Payment and Carer's Allowance. Provide guidance on where to access application forms and support, for example through your national government website, Citizens Advice or the local council
- Recommend seeking independent financial advice from a qualified advisor, particularly for matters such as financial planning, pensions, mortgages, and managing debt
- The DVLA (or DVA in Northern Ireland) and motor insurance company must be notified immediately that the person has received a dementia diagnosis. Explain that driving may still be possible, subject to a medical review or driving assessment at a local centre
- Advise notifying utility companies (electricity, gas, water) and the local council of the diagnosis, as dementia is considered a disability and priority support or a Council Tax discount may be available
- Explain how to apply for a Blue Badge, taxi vouchers and free bus passes
- Provide advice on housing support if needed

Health and wellbeing

- Receiving a dementia diagnosis is life changing. The person and their family members may benefit from counselling to process feelings of grief and the impact of the diagnosis on future plans and expectations
- Offer the person guidance on maintaining relationships with their partner, children, family, friends and work colleagues
- Share strategies for protecting mental health, boosting confidence and reducing social isolation
- Recommend activities that promote wellbeing and help mitigate long-term mental health challenges
- Participation in clinical trials or dementia research may be an option for some people and can provide a sense of purpose and contribution
- Important clinical decisions, such as wishes for future treatment (eg cardiopulmonary resuscitation) and advance care planning, should be considered early due to potential changes in decision-making capacity
- Highlight the benefits of staying active – provide information on local dementia-inclusive sports or gym sessions or suitable activity groups
- Recommend using ID cards for both the person with young onset dementia and family members in case assistance is needed when out and about, or in an emergency.
- Suggest completing the online form on The Herbert Protocol website; a UK-wide scheme helping police find vulnerable missing people, including those with dementia
- Support may be required around issues such as intimacy, menstruation and menopause

Practical advice

- Encourage the person and their family to keep a record of the person's likes, dislikes, interests and history using tools such as Dementia UK's life story template, or a create a photobook
- Suggest simplifying daily life by decluttering, delegating tasks and simplifying routines
- Offer guidance on home adaptations, practical aids, technology and assistive living equipment
- Support family members and carers with techniques for managing dementia symptoms
- Explain that as the person's dementia progresses, different strategies may be needed to help them communicate, such as visual aids
- When appropriate, guide families on sourcing home care, overnight or live-in care, and age-appropriate respite or care homes



Useful resources

Young Dementia Network

Resources for people in dementia support roles including a diagnostic clinic leaflet sharing information about national charities that can provide information and support; ID cards for younger people with dementia and their family members; information for social workers; and guidance on managing the financial impact of young onset dementia. The research section of the website includes a listing of current research studies.

youngdementianetwork.org/dementia-support-roles

youngdementianetwork.org/current-research-studies

Dementia UK

The young onset dementia section of the website includes age-specific information and leaflets about understanding young onset dementia, different symptoms, getting a diagnosis, next steps after diagnosis, employment, finance, supporting children, menopause and choosing a care home, as well as a database of young onset dementia groups and services across the UK.

dementiauk.org/young-onset-dementia

dementiauk.org/find-support

The website also contains information on topics such as driving, making a Will, lasting power of attorney, advance care planning, applying for a Blue Badge, creating a life story and a guide for employees and working carers.

dementiauk.org

dementiauk.org/employment-and-young-onset-dementia

Dementia UK's 'Dementia: what next?' free online sessions provide expert information and advice on a variety of topics around dementia, financial and legal guidance and planning for the future.

dementiauk.org/dementia-what-next

Anyone with a question or concern about dementia can call the Admiral Nurse Dementia Helpline on **0800 888 6678** or book a phone or video appointment in a virtual clinic: dementiauk.org/get-support



The Young Dementia Network is hosted by Dementia UK and is an online community for everyone living with, working with or interested in young onset dementia. It campaigns to bring about improvements for people living with young onset dementia now and in the future.

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



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