

Young onset dementia: guidance for dementia support roles



This young onset dementia guidance is primarily for professionals such as dementia support workers, dementia advisors and key workers who may not usually support people with dementia who are under the age of 65 years old. People affected by young onset dementia were instrumental in creating this resource and identified the areas that were most important to them.

The resulting guidance is intended to help steer a discussion with a person with young onset dementia and their family, acting as a prompt to offering further information and support. It can be used flexibly and adapted to the individual's needs and circumstances.

Some points to consider

- Young onset dementia affects each person in different ways
- In younger people, the ability to think, plan, organise and comprehend language, behaviour and relationships may be more affected than memory in the early stages
- Everyone's situation is different; some people may not want or need support straight away
- If possible, allow the person with young onset dementia to take the lead at your initial meetings
- Try to understand their individual circumstances and what needs to be addressed first
- Do not overload the person with information. Not everything needs to be dealt with straight away

The guidance has been divided up into separate topics that can be discussed with the person with young onset dementia and their family at a time that is right for them.

What needs to be considered straightaway

Emotional

- Receiving a dementia diagnosis is life changing. The person may need counselling to come to terms with their grief and altered future plans
- Offer support for family members to adjust to the diagnosis and the impact it has on them
- Life can still be active and fulfilling. Advise the person how to move forward after a diagnosis and maintain their identity, hobbies, interests, occupation and to feel needed

Practical

- Support the person with young onset dementia to share the diagnosis with their employer. Help them to request reasonable adjustments to stay in work, if they wish
- Explore whether taking early retirement may be an option
- Offer support for people who have lost their job as a result of their symptoms prior to diagnosis
- Help the person's partner (if they have one) or family members to notify their employer. They may need to take time off or work more flexibly
- The DVLA and car insurance company must be notified immediately that a person has received a dementia diagnosis. They may not have to give up driving. Advise them if they want to continue to drive, they may be asked to undergo a medical check or take a driving assessment at a local driving assessment centre

What needs to be considered in the short-term

Practical

- Signpost children (if they have them) to age-appropriate resources and young carers support groups. Suggest parents notify the child's school, or college so additional support can be accessed
- Offer support with family issues and signpost to relevant support organisations
- Ask if the person with young onset dementia is supporting elderly parents or has other caring responsibilities
- Advise the primary family member to register as a carer with their GP and with local emergency care services, if available
- Advise how best to share the diagnosis with other family members and friends

Financial and legal

- Discuss the importance of writing or updating a Will and setting in place Lasting Power of Attorney (LPA) for both health and welfare and property and financial affairs. The LPA should be registered with the person's bank and other financial institutions
- Advise the person to inform their bank of the dementia diagnosis – it may be possible to set up additional safeguards on their bank accounts
- Discuss what benefits they may be entitled to eg Personal Independence Payment, Carer's Allowance. Advise where to access the forms and support if needed to fill them in eg Citizens Advice / local council
- Seeking independent financial advice from a qualified financial advisor may be advisable for some people, especially around financial planning, pensions, mortgages and debt

Health and well-being

- Taking part in clinical trials and dementia research may be an option for some and can make the person feel they are contributing and making a positive difference
- Clinical decisions need to be made around future treatment and advanced care planning eg cardiopulmonary resuscitation. This needs early consideration due to potential changes in capacity

What needs to be considered for day-to-day living

Emotional

- Accessing support, socialising and meeting others in similar circumstances can be beneficial. Advise how to connect with others for mutual support via national or local groups
- Offer advice around maintaining relationships with their partner, children, family, friends and work colleagues

Practical

- Advise where to find local age-appropriate support
- Share details of online or in-person courses for the person with young onset dementia or the family members to attend
- Advise that electricity, gas and water companies are notified that the person has dementia or lives with someone who has. Dementia is considered a disability and they will be a priority if there is an issue
- Consider ways life could be simplified by de-cluttering the home environment, passing on responsibility for some tasks to others and reducing daily routines
- Offer support around accessing adaptations to the home and practical aids, technology and equipment

- Support and advise family members and carers in practical techniques to manage dementia symptoms

Health and well-being

- Signpost to relevant national dementia, carers and support organisations and explain what each one does
- Advise how to stay active and the importance of this. Signpost to local and national living well and activity groups
- Share links to facts about young onset dementia and information about different types of dementia
- Signpost to ID cards for both the person with dementia and family members for use if help is needed or in case of emergency



What to consider if the need arises

Emotional

- Advise the person how to look after their mental health and find ways to boost their self-esteem and confidence and reduce social isolation
- Offer activities which can help reduce the impact of longer-term mental health issues
- As the person's dementia advances, using visuals may help communication

Practical

- Advise how to apply for a Blue Badge, taxi vouchers and free bus pass
- Time away or going on holiday as a family can be a great opportunity to have a break and build memories
- If required, advise where individuals can get support with housing matters
- When appropriate, advise around sourcing home, overnight or live-in care and age-appropriate respite and care homes
- Suggest a record is kept of the person's likes, dislikes, interests, family and work history. The 'This is me' template, a written life story or photobook can be useful for this

Further information and useful resources

Young Dementia Network

Resources include our diagnostic clinic leaflet and ID cards for people with young onset dementia and their family members

youngdementianetwork.org

Information about young onset dementia

dementiauk.org/young-onset-dementia

Driving and dementia

dementiauk.org/driving-and-dementia

Employment and young onset dementia

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

Finance and young onset dementia

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

Young onset dementia groups and services across the UK

dementiauk.org/find-support

Young onset dementia resources such as books, blogs, publications and films

dementiauk.org/young-onset-dementia-resources

The Young Dementia Network is hosted by Dementia UK and is a collaboration between people affected by and working in the field of young onset dementia. It campaigns to bring about improvements for people living with young onset dementia now and in the future.

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

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

This guidance was originally created in 2019 by the Young Dementia Network in collaboration with two young onset dementia peer support groups, Lifting the Cloud, Derby and PACE, Oxford. It was funded by a DEEP grant and updated in 2022.