



“We need the right information at the right time” - individual with young onset dementia

This young onset dementia guidance has been created primarily for dementia support workers, dementia advisors and key workers who may not usually support an individual under the age of 65 years old affected by dementia. It is intended to guide a discussion with the person with dementia and their family and should be used flexibly to adapt to the individual’s needs and circumstances.

It has been designed to be used as a prompt to aid the support that is offered but is not intended to tell people what is needed. People affected by young onset dementia were instrumental in creating this resource and have identified the areas they felt were important to them. The person being supported should have the opportunity to feel empowered by the prompts in this guidance. It should be utilised in a versatile way.

Things to remember

- young onset dementia is a condition that will impact each person in different ways
- the impact will increase as the person’s dementia progresses
- some people may feel that they do not require support straight away. It is recommended that you agree a timescale with them to follow up ie every six months, as it might be difficult for them to call you
- each individual’s situation is different. You will need to get to know about them in detail
- initial meetings should be led by the person who has dementia so the advisor can understand the individual circumstances and what needs to be addressed first
- offer a copy of this guidance to the individual
- continuity is very important
- do not overload the individual with information, not everything needs to be dealt with straight away
- do not use acronyms

How to use this guidance

The guidance has been divided up into columns in order to separate the topics that should be discussed with the person with dementia at a time that is right for them. It has also been colour coded to group the areas a younger person may need your support and advice with.

The Young Dementia Network is hosted by Dementia UK. For more information about the Network visit youngdementianetwork.org or email youngdementianetwork@dementiauk.org

Further information and resources about young onset dementia are available at youngdementiauk.org

What needs to be thought about straight away	What needs to be thought about in the short-term	What needs to be considered for day to day living	What can wait but needs to be considered or offered when the need arises
Emotional – counselling – grief / loss of what is being taken away. A dementia diagnosis is a life-changing moment	Practical – talking to children and young people about the diagnosis – signpost to videos / books / young carers support groups	Emotional – connecting with others in a similar situation – Young Dementia Network / local groups / national events	Emotional – communication – pictures, Boogie Boards and communication technology may be more beneficial to use to communicate as opposed to verbal / written word
Emotional – support for family members / carers	Practical – family issues – signpost and support to relevant organisations	Emotional – maintaining relationships – with partner / children / family / friends / colleagues	Emotional – looking after mental health / self-esteem / confidence / social isolation and offer activities which can help reduce the impact of longer-term mental health issues
Emotional – support with the shock of the diagnosis, how to move forward - feeling like you have an identity / occupation / are needed	Practical – consider the individual diagnosed may have elderly parents / spouse / other caring responsibilities	Practical – advise where to find local, age-appropriate support	Practical – how to access a Blue Badge / taxi vouchers
Practical – employment – support to stay in employment for the person with a diagnosis and the family member, by making reasonable adjustments / working with the employer	Practical – family member registering with local emergency care services	Practical – are there any courses for the person who is diagnosed or the family members to attend?	Practical – how to access a free bus pass
Practical – support for people who have lost their job as a result of their symptoms prior to diagnosis	Practical – talking to other family members	Practical – advise that electricity, gas and water company are told that you live with a person who has a disability. You will be a priority if there is an issue	Practical – if required, where can individuals get support with housing matters

What needs to be thought about straight away	What needs to be thought about in the short-term	What needs to be considered for day to day living	What can wait but needs to be considered or offered when the need arises
Practical – DVLA / car insurance company – be aware you must notify them as soon as you get a diagnosis. What to expect / the process / local driving assessment centre. Individuals may not have to give up driving	Legal – discuss Lasting Power of Attorney, Wills, Advance statements / decisions or signpost	Practical – support with adaptations to housing and equipment	Practical – if required, where individuals can find home care, age-appropriate respite and overnight care, time away and holidays as a family
	Financial – benefits (Personal Independent Payments) where to access support to fill in the forms? Citizens Advice / local council	Practical – provide education for family and carers in practical techniques to manage symptoms	
	Financial – seeking independent financial advice may be important for some	Health and well-being – signposting to relevant national websites / organisations and explain what each one does – offer the Young Dementia Network Memory Clinic leaflet	
	Health and well-being – clinical trials and research open to the individual	Health and well-being – how to stay active / importance of this / living well groups (both local and national)	
	Health and well-being – clinical decisions re: treatment, clinical advanced planning eg DNR – needs early consideration due to potential changes in capacity	Health and well-being – links / facts about young onset dementia / types of dementia	



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The Young Dementia Network is hosted by Dementia UK.

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