

‘We need the right information at the right time’ - individual with young onset dementia

This Guidance is 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 discussion with the person with dementia and their family and should be used flexibly to adapt to individual needs and circumstances. People affected by young onset dementia were instrumental in creating this resource and they have identified what they felt were important.

It is designed to be used as a prompt to aid the support that workers offer but is not intended to tell people what is needed. People affected by young onset dementia should have the opportunity to feel empowered by the prompts on this guidance and it should be utilised in a versatile way with the individual.

Resources such as young onset specific films, books and blogs are available at www.youngdementiauk.org/resources

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, as it might be difficult for them to call you, i.e every six months
- Each individual's situation is different, and 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 requires to be addressed first
- Offer a copy of the 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

Content

We have split the content into colour co-ordinated areas

Emotional / Psychological	- counselling, fears, concerns
Practical	- eg DVLA
Legal	- POA, Wills
Financial	- mortgages, loss of earnings, benefits, pension arrangements
Health & Wellbeing	- team of professionals/roles and responsibilities; information about the type of dementia; living well

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
<p>Emotional - Counselling – grief/loss of what is being taken away. Diagnosis is a life changing moment</p> <p>Emotional support for family / carers</p>		<p>Emotional – Connecting with others in a similar situation – Young Dementia Network / Local Groups / National Events</p>	<p>Emotional – Communication – pictures, Boogie Boards and communication technology may be more beneficial to use to communicate as opposed to verbal/written word.</p> <p>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</p>
<p>Emotional – support with the shock of the diagnosis, how to move forward - feeling like you have an identity / occupation / need</p>		<p>Emotional - Maintaining relationships – with partner / children / family / friends / colleagues</p>	
<p>Practical - Employment – Support to stay in employment for the family member and the person with a diagnosis, by making reasonable adjustments / working with the employer.</p>	<p>Practical – Talking to children and young people about the diagnosis – signpost to videos / books / young carers support groups</p>	<p>Practical – Where is the local, age-appropriate support</p>	<p>Practical – How to access a Blue Badge / taxi vouchers</p>
<p>Practical - Support for people who are at risk of losing job due to being performance managed as a result of their symptoms</p>			

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Practical - Support for people who have lost their jobs as a result of their symptoms but prior to diagnosis.			
Practical - DVLA (what to expect / the local driving assessment centre / the process / that you have to notify them as soon as you get a diagnosis). Individuals may not have to give up driving	Practical - Family issues – signpost and support to relevant organisations Practical - Consider the individual diagnosed may have elderly parents / spouse / other caring responsibilities	Practical – Are there any courses for the person who is diagnosed or the family members to attend?	Practical – How to access a bus pass
	Practical - Family member registering with local emergency care services	Practical – Tell your electricity, gas, water company that you live with a person who is terminally ill. You will be a priority if there is a power cut	Practical – If required, where can individuals get support with housing
	Practical – Talking to other family members	Practical - support with adaptations to housing and equipment.	Practical – If required, where can individuals find age appropriate respite and overnight care, time away and holidays as a family
	Legal – Discuss Lasting Power of Attorney or signpost Legal – Discuss Wills or signpost Legal – Advance statements / decisions	Practical - Provide education for family and carers in practical techniques to manage symptoms.	
	Financial – benefits (Personal Independent Payments)		

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	where to access support to fill in the forms? Citizens Advice / local council		
	Financial - Seeking independent financial advice may be important for some		
	Health and well-being – Clinical trials and research open to the individual	Health and well-being - signposting to relevant national websites/ organisations and explain what each one does – offer the clinic leaflet	
	Health and well-being – clinical decisions re: treatment, clinical advanced planning eg Unified DNR – needs early consideration due to potential changes in capacity.	Health and well-being – how to stay active / importance of this / living well groups (national)	
		Health and well-being – Links / facts about young onset dementia / types of dementia	



The UK Network of
Dementia Voices

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

For more information about the Network visit www.youngdementiauk.org/young-dementia-network or email network@youngdementiauk.org