

## Families and carers as partners in dementia care

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### What is a carer?

- A carer is someone who is responsible for looking after another person, for example, a person who has a disability, or is ill or very young. [British]. Collins English Dictionary.
- The majority of care for people with dementia is undertaken by their family carers.
- Many family carers report that this results in high levels of stress, depressive symptoms and social isolation

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### understand the significance of family carers and social networks in planning and providing care

Dementia has physical, psychological, social and economic impacts, not only for people living with dementia, but also for their carers, families and society at large.

In 2019, informal carers (most commonly family members and friends) spent on average 5 hours per day providing care for people living with dementia. This can be overwhelming. Physical, emotional and financial pressures can cause great stress to families and carers. (World Health Organisation WHO).

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### Valuing carers

Through your communication you can show carers that you respect their knowledge and that you want to listen to their views. Working together, you will have more satisfaction and be of more comfort to the carer.

Carers can be such a valuable source of information. In particular, family or friends can fill you in on information from a person's past: this may be the critical piece of the puzzle in coming to understand a person's behaviour and their needs so much better.

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### Understand the word....“carer”

- The label 'carer' also seems to imply that the person has willingly chosen this role, whereas what often happens is that people fall into the role without choosing it as such. They start by helping out and end up becoming indispensable. Chris Carling explains this well in her book, But then something happened:
- "I never consciously chose the role of carer. Rather I fell into it, almost by accident, starting by helping out as my parents got older, the way in families you do, and then helping some more, and more as their minds became muddled. And suddenly, or so it seemed, I was the responsible adult in the family." More information please see Social Care Institute of Excellence
- [HTTP://www.healthtalk.org/peoples-experiences/nerves-brain/carers-people-dementia/topics](http://www.healthtalk.org/peoples-experiences/nerves-brain/carers-people-dementia/topics)

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### Supporting carers to maintain their health and interests

asking the carer, 'What do you think?' or 'How does this feel?' or 'How does it look to you?' and listen to what they say. You can learn much from carers, and they can learn a lot from you too.

Remember.....it is vital that carers keep themselves well. Ask them what you can do to help them do that.

A story from Hannah who tells us what it has been like caring for someone during lockdown.  
<https://www.youtube.com/watch?v=428418426>

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## Caring and cultural differences

Dementia does not discriminate and will affect people from all cultures and backgrounds. Issues of diversity may have an impact on how people experience dementia, including the acceptance of the condition within their family or community. A person's background and culture are important to them as an individual so is an important consideration for the delivery of person-centred care.

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## Complex relationships

The relationship the carer has with the person with dementia may be complex and involve a lot of personal things that we don't know about. We need to remember that families have had a lifetime of experience together before they have contact with the care system.

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## Be aware of the impact on younger carers and their concerns

- Many younger people have caring responsibilities for someone with dementia. This may be for a grandparent or for a parent who may have young onset dementia.
- It is important that staff consider the impact of caring responsibilities on the whole family and understand the needs and concerns that younger carers or members of a household with caring responsibilities, may have.

<https://vimeo.com/335371304>

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## Be able to communicate compassionately, effectively and in a timely manner

- care partners
- Effective communication with carers is just as important as with people living with dementia.
- The skills staff can employ are similar to those they would use when communicating with a person with dementia.

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## Work closely with families.

- Find out what carers think and feel.
- Interpret complex situations accurately.
- Negotiate, mediate and intervene sensitively and appropriately.

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## Living well with dementia

<p>Carers will have to make a range of difficult decisions as they support a person with dementia,</p>	<p>particularly as dementia progresses and the person is no longer able to make those decisions for themselves</p>
<p>This can be stressful for the carer and people can experience a range of feelings such as worry or guilt about whether they are doing the right thing.</p>	<p>Support from health and care professionals through this process can be vital.</p>

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## Be helpful and kind to carers


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- What is available locally to people with dementia and their carers varies from location to location.
- Therefore, you will need to work with staff in your service to identify what is available locally for the client group you serve. The local Council, NHS Trusts and charities may have on-line or written information available or you may need to undertake you own research to identify relevant local services.

## Darnell's story

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- <https://vimeo.com/334921229>
- Spoken word poet Denneil Dunbar shares a poem with us that he has written about his mother, who has a diagnosis of dementia.
- Dementia UK.  
Helpline. 0800 888 6678.



## Thank you for listening.

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