



Gofal Cymdeithasol **Cymru**  
Social Care **Wales**

# Supporting the friends and family of people with dementia

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Around every person with a diagnosis of dementia, there will be others affected by dementia.

## **An introduction to supporting the friends and family of people with dementia**

We have focused mainly on person-centred care in this section, but we are seeing a shift in how we support people by recognising the importance of people around the individual.

This is called relationship-centred care and it acknowledges the value of relationships with family, friends, the wider community and paid staff who influence the experience of living with dementia.

## **People affected by dementia**

Around every person with a diagnosis of dementia, there will be others affected by dementia.

According to an Alzheimer's Research UK report, more than 24 million people across the UK know a family member or friend living with dementia, and 700,000 people will be caring for the person living with dementia.

A dementia diagnosis will affect the whole family:

- it's challenging. Carers will have to manage difficult changes in their loved ones' behaviour and personality, including aggression in some cases. Caring full-time can leave family members feeling socially isolated and having to meet hidden costs
- it's rewarding. Caring is often a very rewarding experience that can strengthen family bonds through the close and intimate relationship shared
- it can change family relationships. Changes in behaviour and personality can cause family carers to treat their loved one in a different, more childlike way. Carers' relationships with siblings can also become strained as the amount of care increases

- it can affect mental and physical health: the negative health consequences of looking after a family member with dementia are well documented.

(Dementia in the Family, Alzheimer's Research UK, 2017)

## Having a break from routine

It's also important to recognise that people living with dementia may also need for a break from their everyday routine and environment.

Research by The Older People's Commissioner for Wales found that seeing their loved one stressed or worried impacted on their quality of life and that a break either together or apart could make a difference.

(Rethinking Respite, The Older People's Commissioner for Wales, 2018)

The Social Services and Well-being (Wales) Act places a focus on well-being of both people who need care and support, and carers who need support.

## Supporting carers

Often it's the little things that matter to carers.

A listening ear, words of reassurance, acknowledgement of feelings, and the opportunity for support to do things that matter to them.

In an Alzheimer's Society survey, family carers listed what they wanted most from home care support:

- enabling people with dementia to live an active and engaged life
- help to live and stay in their own home for as long as possible
- help to live as near normal a life as possible
- support in socialising with people and staying involved in their community
- regular Support groups / respite for carers

Support. Stay. Save (Alzheimer's Society, 2012)

The message is clear: if we are to support people with dementia to live well, we must also support their family and friends.

## Case studies about supporting carers to help you improve your practice

[Video - An Admiral Nurse's tips for looking after yourself as a carer](#)

[Video - An Admiral Nurse gives her advice about how carers can look after their relationship with the person they're supporting](#)

## Useful resources

Find out more about supporting carers

The [Wales Dementia helpline](#) 0808 808 2235 or text HELP followed by your question to 81066

Admiral Nurse Dementia Helpline 0800 888 6678 or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org). A free helpline to speak to specialist dementia nurses, available 9am - 9pm, Monday to Friday and 9am – 5pm on Saturday and Sunday.

[Carers Wales](#)

[Sources of support and advice for carers of people living with dementia or for someone with dementia](#)

[Advice, information and support if you care for someone with dementia](#)

[Online training courses for caring for someone with dementia](#)

[Culture Dementia UK \(support for Black, Asian and minority ethnic people\)](#)

[Dementia – discussing and planning support after diagnosis. A quick guide for people with dementia and their family and carers](#)

Use [Dewis](#) to find local support groups for carers affected by dementia

[Talking Point](#) (an online community for anyone affected by dementia)

## Research links

Improve your practice by accessing the latest research findings.

[Perceptions and experiences of children and young people with a parent with dementia. \(Alzheimer's Society\)](#)

[What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination \(2015\)](#)

## We want your feedback

Help us to improve the Dementia resource for care professionals by telling us what you think about it in our short [four question survey](#).