



DementiaUK
Helping families face dementia

Changing relationships and roles



When someone is diagnosed with dementia, it may have a significant impact on their relationships and roles – with their family, friends and work colleagues.

These changes can be difficult to accept, but it is possible to find ways to adapt so the person with dementia and the people around them can find connection and enjoyment in their roles and relationships.

How might dementia change roles and relationships?

Everyone has their own experience of dementia, and the ways in which it changes roles and relationships will vary. However, these are some of the changes that may occur.

Overprotectiveness

The partner, family member or friend of the person with dementia may not understand the symptoms and changes they see, and worry excessively – especially if they haven't had previous experience of how dementia can affect people. They may struggle to accept the diagnosis, not want to face up to it, or have difficulty coping with the

changes in the person.

They may be concerned about the person's vulnerabilities and changing abilities. This may lead to them becoming overprotective – for example, they might encourage the person to stop driving, working or participating in their usual activities. They may be reluctant to leave them at home alone or let them go out unaccompanied.

This can be overwhelming for the person with dementia, who may not agree that they need to be looked after or resent others for making decisions on their behalf. Their partner, family member or friend may also find it hard if they feel their concerns and opinions are being dismissed.

Changes in family roles

As the person's dementia progresses, the roles of their partner or other family members may change. Their partner may feel that they are now first and foremost their carer, rather than their life partner. Their children may feel their roles have reversed and they are now responsible for looking after the parent who used to look after them.



Partners and family carers may also feel under pressure to make changes to their own lives to accommodate their caring role – such as by reducing their hours at work or stopping altogether, or spending less time socialising.

These situations may lead to resentment, misunderstandings and arguments, particularly in people with certain types of dementia – for example frontotemporal dementia, which can cause changes in personality and behaviour.

It is not uncommon for tensions to run high, and both the person with dementia and their family members may be hostile towards each other at times – such as by speaking unkindly or shouting. This can be hurtful to everyone, and the person who doesn't have dementia may later feel guilty about what they said or did.

Sexual and intimate relationships

Dementia may cause changes in a couple's sexual and intimate relationships. One partner may want to be intimate more than the other, or the person with

dementia may behave in sexually inappropriate ways, such as making sexual advances in public. Please see Sources of support on p10 for information on sex and intimacy when someone has dementia.

Stigma, shame and anxiety

Stigma and embarrassment can also affect relationships – for example, the person’s friends may be unwilling to spend time with them in public in case they behave in a way that attracts attention.

Family and friends may also feel anxious about spending time with the person with dementia. This could be because they are worried about how the person will react to them, don’t know what to say to them, or are uncomfortable with performing caring tasks. It may lead to them withdrawing from the person with dementia or avoiding seeing them, which can be upsetting for them both.

Please see Sources of support on p10 for information on stigma.

Children and teenagers

About 70,800 people in the UK live with young onset dementia (where symptoms develop under the age

of 65), and many are parents of children, teenagers or young adults.

It can be very difficult for young people to accept that their parent has dementia. They may feel:

- distressed to see their parent’s health and abilities deteriorating
- upset if their parent shows less interest in their life, eg talking about school, helping with homework or participating in activities together
- fearful if their parent displays challenging behaviour, eg shouting or swearing
- bored if their parent repeats conversations or asks the same questions again and again
- embarrassed about being seen in public together, eg if the parent’s behaviour is changing or they neglect their physical appearance
- resentful of or exhausted by taking on caring responsibilities

It is important that the young person has an opportunity to talk about their feelings. They may want to confide in their other



parent, another family member or a friend, or they may find it easier to talk to a professional – your GP will be able to give you advice on any counselling or other support available in your area.

Online or face-to-face support groups, such as young carers’ groups, can be a great way for children and teenagers to connect with others in a similar situation.

It is a good idea to inform your child’s school of their parent’s dementia diagnosis. This will allow their teacher and other staff to

support them. For example, they may be able to speak to a school counsellor about their emotions.

The school may also be accommodating of unexpected absences and put measures in place to change the way they communicate with the child’s parents if necessary.

For more information and resources for parents and young people, see Sources of support on p10.



Roles and relationships at work

If the person with dementia works, their relationships with colleagues may be affected. For example, their colleagues may feel that the person is underperforming, is difficult to communicate with, or is behaving in ways that are unusual in the workplace.

Sometimes, the person's difficulties may initially be put down to work-related stress, which can have similar symptoms to young onset dementia. This may lead to delays in getting a diagnosis.

Although it can be difficult, it

is advisable for the person with dementia to tell their employer about their diagnosis. This means that their colleagues and managers will have a better understanding of what is causing the changes in the person's work and working relationships, and can make adjustments to their role and support them to continue to work, if they wish to do so.

In some jobs, it is a legal requirement for a person to inform their employer of a dementia diagnosis – such as the armed forces, healthcare, and

jobs that involve driving or using heavy machinery.

It is illegal to discriminate against people with dementia at work, so informing the employer about the person's diagnosis ensures that employment law is followed and their rights respected.

Please see Sources of support on p10 for information on employment and dementia.

Staying connected

There are some practical steps you can take to help the person with dementia stay connected to yourself and others.

- Try to keep conversations open and honest so you can understand each other's perspectives
- If it feels right, share news of their diagnosis and how it is affecting them with family, friends and colleagues – including how it might change their relationship with the person – so they have more understanding and can support them
- Consider what you personally miss from your relationship. If the person with dementia was previously your confidante, is there another family member or friend who you could turn to? If you took part in activities together that are no longer possible, can you try a modified version, or continue the activity by yourself?
- Give friends and family advice on how to support the person with dementia so they can keep their interactions enjoyable and positive – for example, you could suggest tips for communicating effectively (see Sources of support on p10 for tips for communicating with a person with dementia)
- Find new ways to enjoy time together, for example by listening to favourite music, watching a film, going for a walk or looking at photos
- Focus on the person's strengths and what they can still do, rather than worrying about the future and the things they are finding difficult

Accepting the changes to your role

Although you may never have expected to become a carer for a family member with dementia, there are ways to find feelings of purpose and worth in your new role. Here are some suggestions.

- Do some research into dementia so you have a better understanding and feel less alarmed or concerned about any changes you see in the person
- Say yes when family and friends offer to help – give them guidance on what would be most useful and supportive
- Develop coping strategies to address specific situations that cause tension – for example, if the person with dementia often forgets to lock the front door, you could stick a reminder inside the door
- Consider engaging in work to increase awareness of dementia within your family, friendship groups and local community. This will help to reduce stigma and promote better

understanding, which in turn could improve relationships

- Join social or support groups, in person or online. It can be helpful to meet other people who have similar experiences and share advice and support
- Look for new activities that you could do alone or with the person with dementia – this could be a new sport, volunteering, an art class or music group
- Try to maintain your social life and hobbies. You may wish to look into ways of taking a break from your caring role such as a day centre or a volunteer befriender so you can still have a life outside the family home

Planning for the future

It is natural to be anxious about having difficult conversations about the person's future – such as managing their finances, arranging care and understanding which medical treatments they may or may not want. But having these discussions with the person early on can help avoid conflicts down the line.



In particular, it is important to discuss making:

- a lasting power of attorney: a process that appoints someone to make decisions on the person’s behalf if they cannot themselves
- an Advance Care Plan which sets out wishes for future care and medical treatment

Having these conversations as a family will allow the person’s wishes to be respected and can help to prevent disagreements and confusion as their condition progresses. Please

see Sources of support on p10 for more information.

You may also wish to discuss other plans – big ones, such as making a Will, and smaller ones, like going on a special holiday or meeting up with relatives that the person sees infrequently.

The key is to keep conversations open and make sure the person with dementia is at the centre of everything you discuss. This will help them feel they have some control over the situation and enable you to work through any areas of disagreement.

Sources of support

To speak to a dementia specialist Admiral Nurse about changing roles and relationships or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email helpline@dementiauk.org

If you prefer, you can book a phone or video call appointment with an Admiral Nurse at dementiauk.org/closer-to-home

Dementia UK resources

Driving and dementia
dementiauk.org/driving-and-dementia

Sex, intimacy and dementia
dementiauk.org/sex-intimacy-and-dementia

Stigma and discrimination
dementiauk.org/dealing-with-stigma

Resources for parents and young people
dementiauk.org/parents
dementiauk.org/young-people

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

Tips for communicating with a person with dementia
dementiauk.org/tips-for-better-communication

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Advance Care Plans
dementiauk.org/advance-care-planning

The emotional impact of a dementia diagnosis
dementiauk.org/emotional-impact-of-the-diagnosis

Coping with feelings of guilt
dementiauk.org/coping-with-feelings-of-guilt

Database of young onset dementia support groups and services
dementiauk.org/young-onset-dementia/find-support



Other resources

Relate relationship counselling
[relate.org.uk](https://www.relate.org.uk)

Carers Trust
[carers.org](https://www.carers.org)

Carers UK
[carersuk.org](https://www.carersuk.org)

YoungMinds – mental health
support for young people
[youngminds.org.uk](https://www.youngminds.org.uk)

DEEP – network of people
with dementia, including
support groups

[dementiavoices.org.uk](https://www.dementiavoices.org.uk)

Dementia Carers Count
[dementiacarers.org.uk](https://www.dementiacarers.org.uk)

tide – together in
dementia everyday
[tide.uk.net](https://www.tide.uk.net)

Young Dementia Network
[youngdementianetwork.org](https://www.youngdementianetwork.org)

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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