Dementia UK
Helping families face dementia

Changing relationships and roles

Dementia can have a significant impact on a person's relationships and roles with their family, friends and work colleagues. These changes can be difficult to accept, but it is still possible for the person with dementia and those around them to have meaningful and enjoyable relationships.

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

Overprotectiveness

When someone is diagnosed with dementia, it is natural for their partner, family member or friends to have many concerns. They may not understand the signs and symptoms they see and may worry excessively. They may struggle to accept the diagnosis or have difficulty coping with the changes in the person's personality and behaviour. They may be worried about their vulnerabilities and deteriorating 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 even if they are still capable of doing so. 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. This could put relationships under strain.

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. This can be especially difficult for younger children and teenagers who have a parent with young onset dementia (where symptoms develop before the age of 65).

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 giving up their social activities. 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.

When tensions run high, 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 does not 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, and it can be difficult to know if the person with dementia is able to consent to any sexual activity if their mental capacity changes.

In some cases, the person with dementia may behave in sexually inappropriate ways, such as making sexual advances in public or towards people other than their partner.

Please see Sources of support on p13-14 for information on sex, intimacy and changes in sexual behaviour.

Stigma, shame and anxiety

Relationships can be affected by the stigma and shame that often surrounds dementia. For example, the person's friends may be reluctant to go out 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, do not 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 them, which can be upsetting for them both.

Please see Sources of support on p14 for information on stigma.

Children and teenagers

Over 70,000 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.

Having a parent with dementia can be very difficult. The young person may feel:

- distressed about their parent's health and abilities deteriorating
- upset if their parent lacks interest in aspects of their life like helping with homework, going to school shows or participating in activities together
- embarrassed about being seen in public together or inviting friends over, eg if the parent's behaviour is changing or they neglect their physical appearance

- daunted by challenging behaviour in their parent, eg shouting or swearing
- bored if their parent repeats conversations or asks the same questions again and again
- resentful of or exhausted by taking on caring responsibilities
- frustrated if the person's condition and its impact on family responsibilities and finances means missing out on things like extracurricular activities, days out and holidays
- guilty about continuing, or wanting to continue with, their usual activities, eg going out with friends, going away to university
- left out by their other parent and other adults in their life who may have less time to spend with them because of their caring role

It is important that the young person has opportunities to talk about their feelings. They may want to confide in their other parent, another family member, a friend or a teacher, or they may find it easier to talk to a professional – your GP can advise you of 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 or college 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 on supporting children and adolescents, please see Sources of support on p14.

Roles and relationships at work

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

Sometimes, work colleagues are the first people to notice signs of dementia in a co-worker. However, the person's difficulties may initially be put down to work-related stress or problems at home, which can have similar symptoms to the early signs of dementia.

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 p14 for information on employment and dementia.

If you care for someone with dementia and are also working, this may have an impact on your own relationships at work. For example, if you are finding it hard to focus on your work, need to take time off at short notice or are feeling stressed and anxious about juggling work with caring, colleagues may question what is happening and draw incorrect assumptions about your attitude to work or the people you work with.

For this reason, it is a good idea to tell your manager and colleagues that you are caring for a person with dementia – this will help them be more understanding of the changes they are seeing and offer support if it is needed.

Staying connected

While relationships can become more challenging for a person with dementia, there are some practical steps you can take to help them stay connected to you and others.

- Try to keep conversations open and honest so you can understand each other's perspectives and the person with dementia feels included in any decisions
- If it feels right and the person with dementia agrees, tell family, friends and colleagues about their diagnosis – including how the symptoms may affect their behaviour and personality, and cause

changes in their relationships – 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 with someone else?
- Give friends and family advice on how to support the person so they can keep their interactions enjoyable and positive – for example, you could suggest ways to communicate effectively (see Sources of support on p14 for tips for communicating with a person with dementia)
- Find new ways to enjoy time together, for example by listening to your 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 on the things they are finding difficult and how their dementia might progress

Accepting the changes to your role

Although you may never have expected to become a carer for someone 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 and the particular type the person has been diagnosed with so you have a better understanding of how it affects them
- Accept offers of help from family and friends – be specific about what would be most useful and supportive

- Develop 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 ways to increase awareness of dementia within your family, friendship groups, workplace and local community. This will help to reduce stigma and promote better understanding, which in turn could improve relationships
- Join 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 activities that you could do alone, with the person with dementia or with someone else, eg sport, volunteering, an art class or music group
- Try to maintain your social life and hobbies, perhaps by arranging for the person with dementia to go to a day centre or using a volunteer befriender. This will give you a break and allow you to spend time with other people you are close to and keep up with activities that you enjoy

Changes in care

Many people with dementia eventually need support from home carers or to move into a care home. This may involve further changes to your role and relationship. For example, you may feel guilty that you are no longer able to provide all of the person's care yourself, or lonely if they have moved into residential care.

While this can be a difficult stage, professional care may lead to improvements in your relationship. Having someone take over the caring tasks that you or the person with dementia find stressful or upsetting may reduce tension between you, and the extra support may free up time to spend enjoying each other's company.

It may also give you time to invest in your relationships with other family members and friends, which may have been difficult to maintain when all your time was spent on caring.

If the person with dementia needs to move into a care home, you may wish to look for a placement close to your own home so you can visit often. If this is not possible, consider how easy it will be to visit – for example, what are the visiting times, and is it accessible by public transport if you do not drive? You can also ask the care home how they can help you stay connected with the person, for instance by supporting them to make phone or video calls.

It is also important to consider the impact on children or teenagers who live at home. Having a parent leaving the family home and moving into residential care can be very distressing, so take the time to explain why this is happening and support them through this difficult transition. Ideally, look for a care home that is welcoming to children and teenagers, with an environment and atmosphere that they will feel comfortable visiting.

Please see Sources of support on p13 for information on choosing home care or a care home, including for people with young onset dementia.

Planning for the future

When someone develops dementia, you may need to have difficult conversations about their 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 – with them and other family members.

In particular, it is important to discuss making:

- a lasting power of attorney (LPA): a legal document that appoints someone to make decisions on the person’s behalf if they lose the mental capacity to do so themselves
- an advance care plan which sets out their 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 p13-14 for more information.

Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, 'Dementia: what next?' Hosted by dementia specialist Admiral Nurses, they cover topics like types of dementia, symptoms, financial and legal issues and planning for the future. Sign up at
› **dementiauk.org/dementia-what-next**
To speak to an Admiral Nurse on our free Helpline , call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email › **helpline@dementiauk.org**
If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit › **dementiauk.org/book**

Dementia UK resources

Advance care plans

› dementiauk.org/advance-care-planning

Changes in sexual behaviour

› dementiauk.org/changes-in-sexual-behaviour

Choosing a care home for a person with dementia

› dementiauk.org/considering-a-care-home

Choosing a care home for a person with young onset dementia

› dementiauk.org/young-onset-dementia-choosing-a-care-home

Coping with feelings of guilt

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

Driving and dementia

› dementiauk.org/driving

Employment and young onset dementia

› dementiauk.org/employment

Finding help and support at home

› dementiauk.org/finding-help-and-support-at-home

Find young onset dementia support groups and services

› dementiauk.org/young-onset-dementia/find-support

Lasting power of attorney

› dementiauk.org/lasting-power

Looking after yourself as a carer

› dementiauk.org/looking-after-yourself

Sex, intimacy and dementia

› dementiauk.org/sex-intimacy-and-dementia

Stigma and discrimination

› dementiauk.org/dealing-with-stigma

Supporting children and adolescents when a parent has young onset dementia

› dementiauk.org/supporting-children-and-adolescents-when-a-parent-has-young-onset-dementia

The emotional impact of a dementia diagnosis

› dementiauk.org/emotional-impact

Things to try when someone stops recognising you

› dementiauk.org/when-someone-doesnt-recognise-you

Tips for communicating with a person with dementia

› dementiauk.org/tips-for-communication

Other resources

The Befriending Network

› befriending.co.uk

Carers Trust

› carers.org

Carers UK

› carersuk.org

DEEP – network of people with dementia, including support groups

› dementiavoices.org.uk

Dementia Carers Count

› dementiacarers.org.uk

Relate relationship counselling

› relate.org.uk

Support for young carers: Carers UK

› carersuk.org/help-and-advice/practical-support/support-for-young-carers

tide – together in dementia everyday

› tide.uk.net

Young Dementia Network – an online community of people with young onset dementia, their families and friends, and professionals in the field, hosted by Dementia UK

› youngdementianetwork.org

YoungMinds – mental health support for young people

› youngminds.org.uk

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline:
0800 888 6678 or **helpline@dementiauk.org**

Book a virtual appointment:
dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan **the QR code**

Thank you.

Dementia UK
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