



DementiaUK
Helping families face dementia

Supporting children and adolescents when a parent has young onset dementia



There are an estimated 70,800 people in the UK living with young onset dementia, where symptoms develop before the age of 65. Many of these people have young or adolescent children who will experience the impact of dementia first hand. This can be very unsettling and upsetting.

As a parent, if you are caring for a partner with young onset dementia it can be a stressful and socially isolating time for you too. The person you would normally turn to for support and conversation may no longer be able to provide it, and you may find you have to take sole responsibility for your children.

Juggling these dual caring responsibilities along with work, finances, the home and wider family life can be very challenging. You may feel torn between your needs and those of your partner and children.

Understanding the ‘dementia journey’

Witnessing changes in a parent can be very upsetting for a child or adolescent, especially if they do not understand what is happening.

Younger people with symptoms of dementia may not recognise the changes in themselves or may be reluctant to seek a diagnosis. This means your child may have noticed changes for some time without there being an explanation and may have been upset or distressed by them.

It can be helpful to describe dementia to them as a journey: as the condition progresses, each stage of the journey is different, and can affect individuals in different ways.

Often, dementia is associated with memory loss, but people with young onset or rare dementias may experience different symptoms, such as changes in:

- behaviour and personality
- language and communication
- movement and coordination
- social and life skills
- vision and spatial awareness

Over time, the symptoms of dementia will become more apparent and the person with dementia may need more help with things such as remembering people and names (including



their own family's); washing and dressing; eating and drinking; and communicating. It is important to be honest with your child about these changes, and to prepare them for the fact that their parent will not get better.

Dementia UK's website contains information, leaflets and short videos to explain the changes dementia brings, see Sources of support on p10.

Supporting your child

Children and adolescents express their emotions in a variety of ways. They may be aware that family relationships are changing,

causing them anxiety, stress and feelings of loss or grief. You may notice changes in their mood, behaviour and emotions – for example, they may become quiet and withdrawn or act out of character; or their schoolwork may be affected. They may also show physical responses such as headaches, nausea and complain of aches and pains.

Children and adolescents need to have their feelings validated and not be judged, so it is important that they know it is okay to talk about their emotions. Otherwise, they may begin to keep their feelings to themselves, and this can

lead to them developing unhealthy coping mechanisms.

Changing family dynamics

Over time, the parent with dementia will become less able to engage with and care for their child. This can lead to a role reversal where the child needs to take on a caring role for their parent which can be psychologically challenging for all.

The parent's behaviour may become irrational at times, and their understanding of everyday life may alter. This could lead to misunderstandings between the parent and child – for example, they may tell the child off for things they have not done or overreact to situations in the home.

Children often develop coping mechanisms to deal with these situations, such as adapting their own behaviour to avoid triggering their parent. They may have to adjust to telling their parent what to do, and how to do things. Older siblings may have to take on additional responsibilities and look after younger children and can

feel resentful about their changing role. This can leave them feeling confused and upset if they feel that their own needs are not being met.

There may be changes in the parent's ability to look after their personal hygiene, or they may behave inappropriately in public, which could cause their child embarrassment, making them reluctant to spend time with them or to bring friends home.

It can be exhausting being a parent with sole responsibility for the family, and you may have less time and attention to dedicate to your children than you would like. Children may worry that they have done something wrong and mistakenly feel they are responsible in some way for the change in the family dynamic.

It is important to help your child understand the impact of caring on your life and theirs and provide them with opportunities to talk and help if they wish.

These tips may help:

- Give your child time to talk about their feelings using an approach that is appropriate for their age



- Talk about your own emotions so they know they are not alone in having difficult feelings; supporting each other as a family can help
- Explain to your child that dementia is causing the changes in their parent
- Try to establish what they understand about the condition. Clarify what dementia is and how it is affecting their parent. There are books, films and resources available to help you do this – please see Sources of support on p10
- Your child may feel scared about the future. Be as open and honest as you can be about the situation – shielding them from the truth may cause misunderstandings later on
- If they find talking difficult, look for other ways they can share their feelings with you, perhaps by writing a note, sending a text or WhatsApp message or recording their feelings or questions in a voice message or notebook
- Encourage your child to share their situation with friends and their friends’ parents so they understand what they are experiencing
- Talking and art therapy sessions can be helpful, particularly with younger children, as a way to

encourage them to express their thoughts and emotions. Your GP, health visitor or children's centre should have information about what is available locally

- Speaking to an independent person like a counsellor or therapist may help a child to explore and express their thoughts without thinking they are upsetting anyone or feeling under pressure to give an answer
- Encourage the child to take part in a group activity or club so they can switch off from what is happening at home and have fun with others of their own age

Recognising themselves as a young carer

Your child may not consider themselves to be a 'carer' but if they provide practical, physical, emotional or personal care such as helping with cleaning and shopping, looking after siblings or helping their parent to get dressed, eat meals or move safely around the home, they are helping in a caring capacity.



Your child has certain legal rights in their caring role. Your local council has a duty to look at what responsibilities your child is taking on and assess if they need extra support, for example by arranging for professional carers to provide help if needed. This support can be linked with a needs assessment for the person with dementia or carer's assessment for the other parent – please see Sources of support on p11.

Being a young carer can have a major impact, particularly on an adolescent's health, social life and self-confidence. Many young carers struggle to juggle their friendships, education and caring responsibilities. They may

feel unable to invite friends to their home due to their parent's symptoms, or start to miss school or be bullied.

See Sources of support on p11 for details of organisations such as Carers UK and Carers Trust that provide information about the needs of young carers and support networks.

How school can help support the child

It is important that your child's teacher, along with the leaders of any sports or activity clubs they attend, are made aware of the situation at home so allowances can be made, and support provided, if needed. This will help them understand if your child behaves in ways that are out of character and respond in a caring manner. They may also be able to connect your child with others in a similar situation, which can ease feelings of isolation.

Some schools include dementia on their curriculum. If this is not the case in your child's school, it might be useful to ask a teacher to have a short session about dementia,

particularly if other children have a relative with the condition. The Dementia UK animated film and/or young people's films could be used as an introduction to initiate a discussion – please see Sources of support on p10 for more information.

For younger children, there are illustrated books available about dementia that can help them to understand the condition in an age-appropriate way. You can find suggestions on the 'Dementia books for children' page of our website – see Sources of support on p10.

Making memories

Try to make time to help your child create memories that they can cherish of time spent with their parent, especially in the early stages of dementia.

If possible, arrange days out, a holiday or a short break so the whole family can enjoy time together and create lasting memories – opportunities for travel and outings may become restricted as the parent's dementia progresses, so it is important to

make the most of shared family time while you can.

At a later stage, the parent and child could perhaps go for a walk to a local park, do small jobs in the garden or look at photo albums or watch family videos together.

Although it can be difficult, especially as their parent's dementia becomes more advanced and time-consuming, spending time with your child so they feel special and loved can be beneficial for both you and your child. Planning things to look forward to can help lift everyone's spirits in difficult times.

Do not be afraid to ask family and friends to help with looking after the person with dementia so your child can get away from the home environment and have some one-to-one time with you, where your focus is on them. You could also ask people to sit with the person with dementia so you can attend special events like school plays and sports days.

If your child is older, encourage and support them to plan for their own future without feeling guilty,

especially if this involves leaving home for university or work. If they do move away, keep them up to date about the situation at home and share any changes in their parent's abilities and symptoms so that when they visit, they are prepared for what to expect.

It is sensible to consider what would happen if you become unwell, or need to go away for a few days, perhaps for work, to look after a relative or just to take a break. Having a contingency plan in place with family and friends ready to step in to provide support at home is useful, especially in case of an emergency.

Loss and grief

Dementia is a life-limiting condition and anticipatory loss can happen long before the person dies. The child may grieve for their parent as their health and abilities decline over time.

In time, their parent may have to move into residential care or a nursing home. This will have a significant impact on your child and their home life, and they may need extra support to come to terms

with the change. Or they may feel a sense of relief that the situation at home has altered, and their caring responsibilities have reduced.

Losing a parent is a traumatic event and children can react to grief and bereavement in different ways, depending on their personality and age. The child's school should be made aware and professional psychological support may be required to help the child to adjust.

It is important for the child to feel loved, and for those around them to show compassion and understanding. Family birthdays and occasions such as Christmas Day, Mother's Day and Father's Day may trigger grief long after the parent has died. It helps to talk openly about the parent to allow the child's positive memories to live on, and keep photos and mementoes around the house to remember the person by.

Genetic forms of dementia

Younger people with dementia are more likely to have a familial or inherited form such as young onset frontotemporal dementia,

Alzheimer's disease and some rare dementias.

Genetic testing is available for people aged over 18 but a detailed background medical history needs to be established first, and counselling spanning several months will also be required. Deciding whether to proceed with genetic testing is a very personal decision and everyone will have their own reasons for deciding for or against proceeding with it.

If a person does have a genetic mutation, it means that their children will have a 50% chance of inheriting the faulty gene and developing dementia in the future. A diagnosis of a genetically inherited form of dementia in a parent will therefore have repercussions, including worry and distress about how the child could be affected in the future. Please see Sources of support on p10 for details of our leaflet on genetic forms of dementia. The charity Rare Dementia Support provides information and groups for people with genetic forms of dementia: visit raredementiasupport.org

Sources of support

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

To book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/book-an-appointment

Dementia UK resources

Young onset dementia web section

dementiauk.org/young-onset-dementia

Young onset dementia: different symptoms

dementiauk.org/different-symptoms

Dementia books for children web page

dementiauk.org/dementia-books-for-children

Film resources for young people/adolescents

dementiauk.org/young-people-stories

Understanding genetic forms of dementia

dementiauk.org/genetic-forms-of-dementia

Grief, bereavement and loss
dementiauk.org/grief

Information about dementia for children

dementiauk.org/get-support/resources/children

Resources for parents

dementiauk.org/get-support/resources/parents

Young Dementia Network

An online community of people living with young onset dementia, their family and friends, and professionals, hosted by Dementia UK
youngdementianetwork.org

Other resources

**British Association for
Counselling and Psychotherapy**
bacp.co.uk

Carers Trust
carers.org/about-us/about-young-carers

Carers UK
carersuk.org/help-and-advice/practical-support/arranging-care-and-support-for-someone/support-for-young-carers

**Childhood Bereavement
Network**
childhoodbereavementnetwork.org.uk

Child Bereavement UK
childbereavementuk.org

Dementia Carers Count
dementiacarers.org.uk

Kooth
Online mental wellbeing
community for children and
young adults
kooth.com



NHS – Every Mind Matters
Expert advice and practical tips
around mental wellbeing
nhs.uk/every-mind-matters

Rare Dementia Support
raredementiasupport.org
tide
tide.uk.net

Winston's Wish
winstonswish.org

Young Carers Alliance
carers.org/young-carers-alliance

Young Minds
youngminds.org.uk/find-help/looking-after-yourself/young-carers

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email feedback@dementiauk.org

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We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.



To donate: call **0300 365 5500**,
visit dementiauk.org/donate-to-support
or scan the QR code.
Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.
Helpline: **0800 888 6678** or helpline@dementiauk.org
Virtual clinics: dementiauk.org/book-an-appointment



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