

Supporting children and young people when a person has dementia

Factsheet 515LP
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When a close family member or friend develops dementia, it is likely that every member of the family will be trying to cope with their own feelings. Children and young people also need time to adjust to the news. It can be particularly hard for them, and they may need some help and support to talk about and understand dementia.

Explaining dementia to children and young people can also feel challenging for the adults and carers who support them. It can be hard to know how much you should tell them about dementia or how best to explain things.

This factsheet explains how you can talk to children and young people when someone close to them has dementia. It covers how they may be affected and suggests ways of supporting them and helping them feel secure and involved.

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Supporting children and young people when a person has dementia

The importance of talking to children and young people about dementia

Finding out that someone close to you has dementia is difficult for everyone. We all need time to adjust and come to terms with our feelings. Children and young people are no different. However, it can be harder for them, as they may not properly understand what dementia is, or they might find it harder to cope with their feelings. They might also be coping with things in their life they find difficult or changes such as moving classes at school, puberty, exams, or university.

It is natural to want to protect children and young people from difficult or confusing situations. However, they are often aware of unusual atmospheres or tensions, even when they haven't been told the facts. There might also be existing issues, problems or difficult relationships within families which can be made worse by dementia.

It can be reassuring for children and young people to understand what the problem is. If they are not told the truth about what is happening sooner, they may find it difficult to trust what someone close to them says later on. It may also be more upsetting for the child or young person to find out about a diagnosis later, than to cope with the reality of what is happening now. Seeing how people around them cope with difficult situations can also help them learn valuable skills about dealing with tough and distressing situations. This can help them to better manage painful emotions.

Offering clear explanations and plenty of reassurance that people can live well with dementia can help children and young people to adjust and manage their feelings. By explaining why the person is behaving differently, you will help them to understand the situation. Children and young people may even find it a relief to know that the person's behaviour is part of their dementia.

If you need more information on dementia to be able to explain things, see factsheet 400, **What is dementia?** To help you talk about living well with dementia see booklet 872, **The dementia guide: Living well after diagnosis.**

How to talk about dementia together

An important part of supporting someone is listening. In fact, listening may be the most valuable part of the conversation, even more so than talking. When you're trying to talk to a child or young person about dementia, ask them to express their feelings. Allow them to talk about how these and how changes are affecting them.

You might also find the following tips helpful:

- Explain what dementia is and what is happening as clearly and calmly as possible at a level that the child or young person can understand. Try to get a sense of how much detail they can cope with.
- Let them know that their feelings are normal and that they can speak to you without being judged.
- Encourage the child or young person to ask any questions they have, and let them know that they can always talk to you. You could also set aside a regular time to talk or do activities together when they can speak with you alone.
- Listen carefully to what they have to say and try to imagine the situation from their point of view. Think about their relationship with the person with dementia. This will help you find out if they are worrying about something specific.
- Acknowledge things that are happening that might seem strange – such as the person with dementia forgetting where they are or not recognising family members.
- Focus on the things that the person with dementia can still do, as well as those that are becoming more difficult.

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- Try to be patient. You may need to repeat your explanations on different occasions, depending on the age and level of understanding of the child or young person.
- Once you've talked to them about the person's diagnosis you can use books, online videos and podcasts to help explain what dementia is. Storytelling is a good way to explain difficult situations and help give an understanding of what the person with dementia may be experiencing. Our YouTube channel is a good resource for this. Go to **www.youtube.com/user/AlzheimersSociety**
- Give the child or young person plenty of reassurance and hugs, where appropriate.
- Don't be afraid to use humour, if it feels appropriate. It often helps if you can laugh together.

Dementia affects everyone individually. Depending on how they are affected by their condition, the person with dementia may be able to talk about this directly with the child or young person. The person may still need support in talking to the child or young person, and it might be helpful if you are there when the conversation takes place. Children and young people often learn by example. Communicate with the person with dementia in a way that you want children and young people to communicate with them.

To find out about other carers' experiences and ideas about talking to children and young people, visit our online community at **alzheimers.org.uk/talkingpoint**

Involving children and young people

If possible, try to find ways of involving the child or young person in the person's care – if they are interested in helping. This might make the situation seem more normal for them, and prevent them from feeling left out. They may find that there are aspects of caring that they find fulfilling and which help them feel more included. This may also help the person with dementia. Children and young people can feel involved by supporting Alzheimer's Society.

Here are some ideas to help you:

- Let the child or young person know that, if it's possible, simply being with the person with dementia and showing them love and affection is one of the most important things they can do.
- Try to ensure that the time they spend with the person is pleasurable. Activities could include going for a walk together, playing games, sorting objects, listening to music or making a scrapbook of past events.
- Talk about the person's life and interests and show the child or young person photographs and mementos.
- At any stage of the condition, the person can still hug the child or hold their hand, if that feels right. These can all be good ways of reducing fear, reassuring the child, and maintaining a positive relationship.
- Make sure that the child or young person knows that you appreciate their help. Show them how they are helping the person with dementia.
- Children and young people can complete a fundraising challenge, such as a Memory Walk or bake sale. By supporting Alzheimer's Society, they can make a difference for all people affected by dementia. It can give them the opportunity to talk about dementia with their friends in a relaxed and positive way. Dementia Friends information sessions can also be held at their school or college. These sessions give their friends and peers an opportunity to learn more about dementia, and how to make their community more dementia-friendly. For more information, see 'Other useful organisations' on page 12.

It is also a good idea to be aware of things that the person with dementia may find upsetting or confusing. Be prepared to provide reassurance if these happen when a child or young person is present. Talk to the child afterwards if the person does become upset or confused, to help them understand why this happened.

There might also be times you think it would not be best for the child or young person to be left alone with the person with dementia, for instance if they begin to show aggressive or sexual behaviour. Try to explain the reasons for this. Make sure the child knows that this is a symptom of the person's condition, rather than how the person with dementia feels towards them.

Young children may need reminding why the person with dementia sometimes behaves in an unusual way. All children and young people may need to talk about their feelings at different times when their relationship with the person with dementia changes.

How dementia can affect children and young people

Children and young people can respond in a number of different ways when they find out that a person has dementia, and to their new situation. These feelings may include:

- confusion about what dementia is and how to respond to or behave with the person
- grief and sadness about what's happening to someone they love
- fear about what will happen to the person in the future, and whether they will develop dementia too, especially if the person has a rarer type of dementia with a strong genetic link (see factsheet 405, **Genetics of dementia**)
- anxiety, irritation or embarrassment – for example, because the person with dementia behaves unusually in front of other people. Or they might feel labelled at school or in friendship groups simply as the relative of a person with dementia
- boredom – for example, with hearing the person with dementia repeat the same stories and questions
- fear of the person with dementia themselves as well as their behaviour
- confusion and a feeling of instability about 'role reversal' – for example, having to be responsible for their parent who used to be responsible for them
- a feeling of loss if their relative doesn't seem to be the same person that they were, or because it isn't possible to communicate with them in the same way
- a sense of uselessness or rejection because they feel they can't help the person to cope or 'get better'
- stress and confusion around their own future – for example, if a parent has dementia the young person might feel concern about going away to university and 'leaving' the other parent to cope
- rejection – if other family members are under pressure and seem to have less time for them than they had before
- guilt for feeling any of these emotions.

Children and young people may be afraid to talk about their worries. They may see that you and other adults are already under strain and not want to cause any further upset. Older children and teenagers may feel embarrassed to show their feelings or may try to distance themselves from their emotions by becoming uninterested or detached. They may need gentle encouragement to talk about their feelings.

Young people sometimes believe that they are responsible for the way that people around them are acting, including the person with dementia and other family members. This belief is a common reaction to any unhappy or difficult situation, especially if they do not understand it fully. They may also feel this way if they are not given a clear explanation of what dementia is and how it can affect people. For example, if the person with dementia behaves in a way that is out of character, the child or young person may think they have done something wrong to cause the reaction. It can be helpful to reassure the young person and talk about their anxieties, and also provide more information about dementia and why the person seems different.

On particularly difficult days, carers and other adults might be short-tempered or not have time for younger people, or simply may not be at home as much. They may also be finding it difficult to manage the practicalities of caring. Children and young people might interpret this as being their fault, and all of these changes can make a child or young person feel anxious. It is very important to reassure them that they haven't done anything wrong, and that they're not responsible for the way that others are feeling or acting.

Another common worry among children and young people is that dementia is contagious and they might catch dementia. They may also worry that they, or their parents and other relatives, may develop dementia. Reassure them that this is not how people develop dementia. Older children may find our information about dementia and the brain helpful – this includes a series of films. See [alzheimers.org.uk/braintour](https://www.alzheimers.org.uk/braintour)

It might also help to explain that scientific research means that better treatments or even a cure could be found in the future. For more information see factsheets 405, **Genetics of dementia** and 450, **Risk factors for dementia**.

Signs of distress

Everyone reacts differently to difficult experiences and shows distress in a wide range of ways. This is true for children and young people as well as for adults.

The age of the child or young person, as well as their personality and stage of development, will all play a part in how they react. Some children, especially very young children, may not recognise or be able to communicate that they are feeling stress at all. If you are worried about how a situation is affecting a child or young person, the following signs may be useful to look out for:

- **Anxiety-related symptoms** – nightmares, difficulty sleeping, attention-seeking or ‘naughty’ behaviour, as well as unexplained aches and pains, are all signs of anxiety. Loss of appetite, feeling or being sick, or constantly feeling tired can also be signs.
- **A deterioration in their schoolwork** – children and young people who are upset find it harder to concentrate and their schoolwork may suffer.
- **Appearing unaffected** – if a child or young person appears uninterested in the situation, or seems unusually cheerful, they may be bottling things up or putting on a brave face. You may need to encourage them to talk about the situation and to express their feelings.
- **Being sad and weepy** – some children and young people respond by feeling very upset and may need a great deal of attention over a long period of time. Even if you are feeling under a lot of pressure, try to give them some time each day to talk things over.
- **Retreating from the situation** – older children and teenagers can often seem preoccupied with their own lives and may retreat to their own rooms or stay out more than usual. They may find the situation particularly hard to handle because of all the other changes and uncertainties in their lives. Teenagers may feel embarrassed to talk about their feelings, but they still need to know that you love them and that you want to understand what they are going through. They may need some time before they are ready to talk about how they feel.

- **Getting overly involved in a person's care** – it is understandable that children and teenagers may want to get involved in caring for someone they love. However, it is important that it doesn't interfere with their own development or studies. Adopting mature or 'adult' roles and responsibilities can deprive children and young people of opportunities to enjoy childhood.

How to support children and young people

Children and young people need reassurance. They want to know that you are there for them and that you are all in this situation together. This helps them feel that you understand the difficulties they face. They need to know that they are still loved however preoccupied, sad or frustrated the adults around them may be at times. When children and young people learn about dementia, they feel more comfortable talking about it. Alzheimer's Society is creating a dementia-friendly generation, supporting young people to understand dementia and make a positive impact for people affected by dementia.

The following can help:

- Let the child know that their feelings are normal and that they can speak to you about them without being judged.
- With the right support, people can live well with dementia. It can be reassuring to tell children and young people this, and explain that they can be part of this support.
- Help them learn more about dementia using dementia organisation websites aimed specifically at children, such as Dementia In My Family (see 'Other useful organisations' on page 12).
- Talking therapies can be helpful. Speaking to an independent professional might help the child or young person explore their feelings without worrying that they may be upsetting a member of their family.
- Try to help the child express themselves in a way that works best for them. This might be through arts therapies like painting, music or drama.
- Take photographs of the child or young person together with the person with dementia, to remind you all that there can be good times.

- Suggest that they explain their relative's changes to their friends, which will help their friends to understand too.
- Letting the child's school know what is happening can help so that they are aware of the situation and understand the types of difficulties the child may be facing. The school should also keep you informed of any changes they have noticed, and they may be able to arrange counselling or other support too.
- Children at school and young people at university may also be able to get extra support or adjustments around their exams.
- Let them know that they can speak anonymously to someone on a helpline – such as Alzheimer's Society support line or Childline. Online discussion forums might also be helpful for teenagers.
- They can learn more about dementia at school, college, university, or work by becoming a Dementia Friend. Alzheimer's Society's Dementia Friends is the biggest ever initiative changing the way people think, act and talk about dementia. It helps young people understand how to support people affected by dementia. You can request a Dementia Friends information session online at dementiafriends.org.uk/webrequestinfosession
- If you want to support them at home, you could help them to fundraise through fun events and follow Alzheimer's Society on social media.

If you or the child or young person would like more support and information, you can call Alzheimer's Society on **0333 150 3456**. Or you can visit our online community at alzheimers.org.uk/talkingpoint

Other useful organisations

Alzheimer's Society Youth engagement team

youngpeople@alzheimers.org.uk
alzheimers.org.uk/youngpeople

Alzheimer's Society provides resources for schools, youth groups and universities to support people affected by dementia.

Childline

0800 11 11
www.childline.org.uk

Childline is a free, private and confidential service where children and young people can talk about any worries or concerns they might have. They offer support over the phone and online.

Dementia Explained

www.kids.alzheimersresearchuk.org

Dementia Explained is Alzheimer's Research's website for children and younger people. It offers age-appropriate information about dementia across three age ranges.

Dementia Friends

www.dementiafriends.org.uk

Alzheimer's Society's Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.

Dementia In My Family

www.dementiainmyfamily.org.au

Dementia In My Family is a website that has age-appropriate information about dementia separated by ages, from pre-school to 16+.

Dementia UK

www.dementiauk.org

Dementia UK have resources for talking to children about dementia, including videos for children on their YouTube channel.

The Dragon Story

www.gloriousopportunity.org/thedragonstory.php

The Dragon Story is a four-minute cartoon for five- to nine-year-olds explaining dementia and how it can affect family members.

Young Minds

0808 802 5544 (parents helpline, Monday–Friday 9.30am–4pm)

www.youngminds.org.uk

Young Minds is a charity dedicated to improving and supporting the mental health of children and young people.

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Professor Pat Sikes, Professor in Qualitative Inquiry and Rikki Lorenti, Admiral Nurse Clinical Lead & Hospital Clinical Lead for Dementia

This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email publications@alzheimers.org.uk

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on **0330 333 0804** or go to alzheimers.org.uk/donate

We are Alzheimer's Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

For support and advice, call us on **0333 150 3456** or visit alzheimers.org.uk



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