

Explaining dementia to children and young people

Finding out that someone close to you has dementia, and then coping with it from day to day, can be distressing for everyone involved. It can be particularly challenging explaining things to children and young people. This factsheet explains how children and young people can be affected when someone close to them has dementia. It also suggests how parents can talk to their children about the condition and ways to help them feel secure and involved.

Dementia can create some very challenging situations for families and social groups, and it can be hard to know how much to explain to children and young people. It is natural to want to protect children from difficult or confusing situations, but it is important to explain what is going on. There are a number of reasons for this.

- Children and young people are often aware of difficult atmospheres and tensions even when they haven't been told the facts, so it can be reassuring for them to understand what the problem is.
- Although the news may be distressing, children and young people may find it a relief to know that the person's behaviour is part of their dementia and is not directed at them.
- It can be more upsetting for the child or young person to find out later than to cope with the reality of what is happening. If a child is not told, they may find it difficult later to trust what someone close to them says.

- Seeing how people around them cope with difficult situations helps young people learn valuable skills about dealing with tough and distressing situations, and being able to manage painful emotions.

It is important to try to be as honest as you can, by offering clear explanations and plenty of reassurance. Adapt what you say and how you say it to the age and level of understanding of the child or young person.

Also try to get a sense for how much detail they can cope with, and tailor your discussion accordingly. Make sure they feel they can ask questions and that they can share the feelings that the people around them might be experiencing.

How dementia in a close family member or friend can affect children or young people

When a close family member or friend develops dementia, each member of the family may be trying to cope with their own feelings. They might also be managing the practicalities of caring. Adults may be upset, tired or stressed – or simply not at home as much. All of these changes can make a child or young person feel anxious.

Very young children may need reminding why the person with dementia sometimes behaves in an unusual way. Young people may need to talk about their feelings as changes occur. These feelings may include:

- grief and sadness at what is happening to someone they love
- anxiety about what will happen to the person in the future
- fear, irritation or embarrassment – for example at unusual behaviour in front of other people
- boredom, for example with repeatedly hearing the person with dementia repeat the same stories and questions
- guilt for feeling some of the emotions listed above

- confusion about ‘role reversal’ – having to be responsible for someone 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 anymore
- a sense of uselessness or rejection because of an inability to help the person to cope or ‘get better’
- anger or rejection if other family members are under pressure and seem to have less time for them than they had before.

It may help if the child is given time to express their feelings and talk about how these changes are affecting the whole family. Explore ways in which the child or young person can help the person with dementia, and help them feel loved and wanted. It is important that the child understands that this will not cure the dementia, but it will help the person.

You could also suggest that they could explain to their friends the changes that are happening to their relative, which will help their friends to understand too.

Common anxieties

A child or young person may be afraid to talk about their worries. They may know that the adults are already under strain and don’t want to upset them further. Older children and teenagers may feel embarrassed to show their feelings, and may hide their emotions by seeming uninterested or detached. They may need gentle encouragement to talk about their feelings.

Young people sometimes believe that they are responsible for the dementia. These feelings are a common reaction to any unhappy situation, especially if they do not understand it or are not given a clear explanation of why the person has changed. It is important to address their anxieties, use reassurance, provide information and clearly explain the reasons why the person seems different. You may find factsheet 400, **What is dementia?** helpful here.

Another common concern among children and young people is that they, or their parents and other relatives, may develop dementia in the future. Reassure them that this is unlikely. Factsheets 405, Genetics of dementia, and 450, **Risk factors for dementia**, can help you to understand what causes dementia.

Signs of distress

Everyone reacts differently to difficult experiences and shows distress in different ways. This is the case for children and young people, as well as for adults. If you are worried about how the situation is affecting a child or young person, the following signs may be worth keeping an eye 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. They show that the young person may need more support. Make sure they have plenty of time to talk things through. If you're worried, consider talking to the school or the GP.
- **Schoolwork** – Children and young people who are upset find it harder to concentrate and their schoolwork may suffer. If this happens, talk to the appropriate teaching or support staff so that they are aware of the situation and understand the difficulties.
- **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. Try to talk things through in a calm, matter-of-fact way.

- **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. Adopting mature or 'adult' roles and responsibilities can deprive children and young people of opportunities to enjoy childhood and this may cause problems later in life.

What you can do to help

Talk about it

It's important to reassure children and young people that you are there for them, and you are in this situation together. This makes them feel that you also understand the difficulties they face. They need to know that, despite all the pressures, you still love them however preoccupied, sad or frustrated you may seem at times. It will help children and young people if you can make regular time to be with them, and provide opportunities where they can talk about any concerns they might have.

Here are some tips to help you discuss the situation effectively. Discussing means both talking and listening – and listening may be the most valuable part of the conversation.

- Explain the situation as clearly and calmly as possible.
- Try to use simple examples of behavior that might seem strange, such as the person with dementia forgetting where they are or wearing a hat in bed.
- Focus on the things that the person can still do, as well as those that are becoming more difficult.

- Try to be patient. You may need to repeat your explanations on different occasions, depending on the age of the child or young person.
- Encourage the child or young person to ask questions, if they have them.
- Ask how the person's dementia makes the child or young person feel. Listen carefully to what they have to say and try to imagine the situation from their point of view. This will help you find out exactly what might be worrying them.
- Give the child or young person plenty of reassurance and hugs, where appropriate.
- Don't be afraid to use humor, if it feels appropriate. It often helps if you can laugh about the situation together.

If the person with dementia has received an early diagnosis, they may be able to talk about their dementia clearly to a child or young person. The same is true if the person has a form of dementia that does not affect their understanding and communication in the early stages. 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 a good way of reducing fear and maintaining a positive relationship. The person may need support in talking to the child or young person, and it might be helpful if you are present when the conversation takes place.

Involve the child or young person

Try to find ways to involve the child or young person in providing care for the person with dementia, or just allow them to spend time with the person. This will help make the situation seem more normal for them, and will prevent them from feeling left out. However, it's important that they continue with their normal lives so don't give them too much responsibility, or let these tasks take up too much of their time.

- Let them know that simply being with the person with dementia and showing them love and affection is the most important thing that the child or young person 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.
- Take photographs of the child or young person together with the person with dementia, to remind you all that there can be good times, even during the illness.
- Don't leave a child or young person alone in charge, even briefly, unless you are sure that they are happy about this and will be able to cope.
- Make sure that the child or young person knows that you appreciate their help, and show them how they are helping the person with dementia.
- Be aware of things that the person with dementia may find upsetting or confusing, and be prepared to provide reassurance if these occur when a child or young person is present. Talk to the child or young person afterwards if the person does become upset or confused, to help them understand why this happened.

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2016. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society.

Factsheet 515LP

Last reviewed February 2013 by Toby Williamson, Head of Development and Later Life, Mental Health Foundation and Jenny La Fontaine, Senior Lecturer, Association for Dementia Studies, Institute of Health and Society, University of Worcester.

Last reviewed April 2016 by Alzheimer's Society

Next review due: April 2019

This factsheet has also been reviewed by people affected by dementia. A list of sources is available on request.



Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland:
0300 222 11 22

9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

alzheimers.org.uk

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers.



Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499