



Explaining to children

Caring for the Carer



Alzheimer National Helpline

1800 341 341

When you are distressed about someone close who has dementia, it is easy to forget just how anxious and bewildered your children may feel. Children need clear explanations and plenty of reassurance in order to cope with the changing situation. Though the facts are distressing, it may come as a relief to know that their relative's strange behaviour is part of an illness and not directed at them.

Of course you will have to adapt your explanations to your child's age and understanding, but always try to be as honest as you can. Once children understand the reasons that change is happening they're more likely to accept it.

Giving explanations

- It can be difficult for children to take in distressing information. Children may need explanations repeated on different occasions so be very patient.
- Encourage children to ask questions and listen to what they have to say so you can find out just what might be worrying them.
- Give them plenty of reassurance and hugs and cuddles where appropriate.
- Practical examples such as your relative forgetting an address, getting words mixed up or wearing a hat in bed can often help you make a point more clearly.
- Don't be afraid to use humour. It often helps if you can laugh together at the situation - not, of course, at the person themselves.
- Focus on the things that the person with dementia can still do as well as those which are becoming more difficult.

Children's fears

- Your child may be frightened to talk to you about their worries or show their feelings in case they upset you further. They may need gentle encouragement and reassurance that it is ok to be upset.
- Young children may believe that they have done something wrong, if for example a relative with dementia begins to lose patience with them or is no longer able to share and enjoy the same quality time together that they used to. For example if a grandparent used to collect the child from scouts and is no longer able to, they may need reassurance that this is because of the dementia rather than anything the child has done.
- Children may need reassurance that it is unlikely that they or any other relative will develop dementia just because they are related to someone with dementia.

Changes for your child

It is important to remember that when someone develops dementia, everyone in the family is affected. Children need to know that you understand the difficulties they face and that you still love them, even on days where you are struggling yourself. Try to put aside time to talk to your child on a regular basis without interruption. Young children may need reminding of why their relative is behaving differently and all children may need to talk about their own feelings as new problems arise.

You may find that children are able to adjust surprisingly well to the changes in a relative who has dementia, particularly in the early stages of a diagnosis. Children are very good at living in the moment, something that people with dementia are often inclined to do.

Difficulties they may wish to discuss might include:

- Grief at what is happening to the person they love and anxieties about that person's future.
- Fear, boredom, irritation or embarrassment at their relative's behaviour, perhaps mixed with guilt for feeling this way.
- Having to assume a responsible role for someone they may remember as being responsible for them.
- Feelings of loss because their relative can no longer communicate with them or because things are not the way they were.
- Anger because other family members are stressed and have far less time for them than before. Expressing feelings Children may react differently to experience and may show distress in different ways.

Expressing feelings

Children may react differently to experience and may show distress in different ways.

- Behaviour that may seem attention-seeking or naughty, nightmares or difficulties in sleeping, or inexplicable aches and pains may suggest that your child is very anxious about the situation and needs even more reassurance.
- School work often tends to suffer as children who are upset find it harder to concentrate. It is a good idea to have a word with your child's teacher or head of year so that everyone at school is aware of the situation and understanding about their difficulties.
- Some children put on an over-cheerful front or appear uninterested although they may be very upset inside. You may need to encourage them to talk about the situation and express their feelings rather than bottle them up.
- Other children may be very sad and weepy and need a great deal of attention over quite a long period. Try to give them some time to themselves each day to talk things over, even if you are very stretched.

Teenage children may find it particularly difficult to cope because of all the other changes and uncertainties in their lives. They may be afraid to bring friends home in case a loved one with dementia behaves strangely. They will need reassurance that you love them and understand their feelings. On the other hand teenagers are often curious and keen to understand how they can help a relative who has been diagnosed with dementia. Talking things through in a calm way may help them to process their feelings about a loved one's dementia diagnosis.

Involving children

Try to find ways of involving your children in the care and stimulation of the person with dementia. But don't give them too much responsibility or let it take up too much of their time. It is very important to encourage your children to continue with their normal lives as much as possible.

- Emphasise that just being with the person for short periods and showing love and affection is the most important thing they can do.
- Try to ensure that time spent with their relative is pleasurable - going for a walk together, playing games, sorting objects or making a scrapbook of past events, for example.
- Talk about your relative as they were and show your children photographs and mementos. People with dementia are often able to talk about older memories and may enjoy talking to children about their childhood experiences.
- Take photographs of the person with your children to remind you all of the good times even during the illness.
- Don't leave your child alone in charge, even for brief spells, unless you are sure they are happy about this and can cope.
- Make sure your child knows that you appreciate their efforts.
- Tell your children how proud the person would be of them if they could understand and express themselves.

For further information and support

Contact Alzheimer National Helpline

Helpline: 1800 341 341

Live Chat via Website: www.alzheimer.ie

Monday to Friday 10am to 5pm

Saturday 10am to 4pm.

Alzheimer Research UK

A website for young people to learn about the brain and dementia which includes sections for young kids, juniors and teens.

Web: kids.alzheimersresearchuk.org/

The Crystal Project - Feathers in my brain book

A children's book aimed at helping children understand dementia.

Web: crystalproject.ie/crystal-project-childrens-book-feathers-in-my-brain/

Factsheet: D3 **First Published:** August 2019. **Revised by:** Mr Ashley Morgan, RPN Helpline Adviser, The Alzheimer Society of Ireland. The Alzheimer Society of Ireland (ASI) has taken great care to ensure the accuracy of the information contained in this factsheet. ASI is not liable for any inaccuracies, errors, omissions or misleading information.