



## Planning to Live Well

# Explaining to children

*It is very natural to want to protect children and young people from a diagnosis of dementia. Finding the right words to explain dementia and what it means is difficult, especially if you are just coming to terms with a diagnosis. However, it is important to be as honest as you can about the situation*

Of course you will have to adapt your explanations to your child's age and understanding. Try to provide clear explanations and plenty of reassurance. Let them know who they can talk to, that it is ok to ask questions and share feelings. Listen to what they have to say.

### Giving explanations

- It is always hard to take in difficult 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 or getting words mixed up 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.
- There are a number of online resources and books which explain dementia to children and teenagers, call our Helpline or visit [www.alzheimer.ie](http://www.alzheimer.ie) for more information.

### 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.
- Children and teenagers may believe they are somehow responsible for the changes they see in their relative. They need reassurance that this is not so and help understanding dementia.
- Children will 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, however preoccupied you may seem at times.

Try to put aside time to talk to your child on a regular basis without interruption. Young children will need reminding of just why their relative is behaving in such a strange way and all children may need to talk about their own feelings as new problems arise.

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 all react differently to experience and 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 often seem bound up in themselves and may retreat to their own rooms or stay out more than usual. They may find it particularly difficult to cope because of all the other changes and uncertainties in their lives. They will need reassurance that you love them and understand their feelings. Talking things through in a calm way may help them sort out some worries.

### 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. There are a number of online resources, such as dementia apps, which children may like to show to their relative and use with them
- Talk about your relative as they were and show your children photographs and mementos.
- 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.