

Explaining Dementia to children

The degree of impact on children and teens will depend on:

- *Who has the illness – parent, grandparent, aunt etc.*
- *How close the relationship is*
- *Where the person lives e.g. in their home, independently or in an old age home*

When you are distressed about someone close who has dementia it is easy to forget just how anxious 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 explanation to your child's age and understanding but always try to be as honest as you can. It is more upsetting for a child to find out later that they cannot trust what you say than to cope with the truth, however unpleasant, with your support.



Giving explanations

It is always hard to take in distressing information. Depending on their age, children might need to have explanations repeated on different occasions. You may have to be very patient.

- Encourage children to ask questions. Listen to what they have to say so you can find out just what might be worrying them.
- Give plenty of reassurance and hugs and cuddles where appropriate.

- Practical examples of behaviour, which seems strange, such as the person forgetting an address, getting words mixed up or wearing a hat in bed, may help you to make a point more clearly.
- Don't be afraid to use humour. It often helps if you can all laugh together at the situation. (Make sure they do not laugh at the person with dementia but rather with them)
- Focus on the things that the person can still do as well as those that are becoming more difficult.

Children's fears

- Your child may be afraid to talk to you about their worries or show their feelings because they know you are under strain and they don't want to upset you further. They may need gentle encouragement to talk.
- Your child may be confused about how the person got the disease.
- Young children may believe that they are responsible for the illness because they have been naughty or have had bad thoughts. These feelings are a common reaction to any unhappy situation which may arise in a family.
- Older children may worry that the dementia is a punishment for something the person did in the past.
- Children of all ages will need reassurance that this is not the reason for the person becoming ill.
- You may also need to reassure older children that the disease is not contagious and that it is unlikely that you, or they, will develop dementia just because a relative has the illness.

Changes for your child

When someone in the family develops dementia everyone is affected. Children need to know that you understand the difficulties they face and that you still love them, however preoccupied or even snappy you may seem at times.

Try to put aside time to talk to your child on a regular basis without interruption. Young children may need reminding why their relative is behaving in a strange way.

All children will probably need to talk about their feelings as new problems arise. They might wish to discuss, for example:

- Their feelings of grief and sadness at what is happening to the person they love and anxieties about the future.
- Being afraid, irritated or embarrassed by the person's behaviour and bored by hearing stories and questions repeated over and over again. These emotions might be mixed with guilt for feeling this way.
- Having to assume responsibility for someone they may remember as being responsible for them.
- Feelings of loss . because their relative does not seem to be the same person as they were or because they can no longer communicate easily with them.
- Feelings of anger . because other family members are under pressure and have far less time for them than before.
- Guilt for feeling angry.

Expressing feelings

Children all react differently and show distress in different ways. Here are some things to look out for:

- Some children have nightmares or difficulties in sleeping, may seem attention seeking or naughty, or complain of aches and pains (eg. headaches, stomach pains) that cannot be explained. This could suggest that they are very anxious about the situation and need more support.
- Schoolwork often tends to suffer as children who are upset find it harder to concentrate. Have a word with your child's teacher or head of department so that staff at the school are aware of the situation and understand the difficulties.
- Some children put on an over-cheerful front or appear to be uninterested although inside they may be very upset. You may need to encourage them to talk about the situation and express their feelings rather than bottle them up.
- Other children may be sad and weepy and need a great deal of attention over quite a long period. Even though you may feel under a lot of pressure yourself, try to give them some time each day to talk things over.
- Teenage children often seem bound up in themselves and may retreat from the situation to their own rooms or stay out more than usual. They may find the situation particularly hard to handle because of all the uncertainties in their lives.
- Embarrassment is a very powerful emotion for most teenagers. They will need reassurance that you love them and understand their feelings. Talking things through in a calm, matter-of-fact way may help them sort out some of their worries.

Involving children

- Try to find ways to involve 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 children to continue with their normal lives.
- Emphasize that just being with the person with dementia and showing love and affection is the most important thing they can do.
- Try to ensure that time spent with the person is pleasurable . going for a walk together, playing games, sorting objects or making a scrapbook of past events are ideas for shared activities, which you might suggest.
- Talk about the person as they were and show the children photographs.
- Take photographs of the children and the person together to remind you all of the good times even during the illness.
- Don't leave children alone in charge, even for brief spells, unless you are sure in your own mind that they are happy about this and will be able to cope.
- Make sure that your children know that you appreciate their efforts.

Notes:

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