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## Dementia - advice for families

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### Summary

- Dementia can be difficult to understand, especially for young people.
  - If dementia is explained clearly and simply, it is easier for young people to understand the causes and issues involved.
  - There are things young people can do to make life easier for the person with dementia and their carers.
  - Give the person with dementia reassurance, let them know that you care about them and don't blame yourself for their behaviour.
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Although the vast majority of people with dementia are elderly, there are often young children and adolescents in the household, or close by, who are strongly affected by the illness of someone they love. It may be their grandparent who is affected by the illness or, in the case of younger-onset dementia, their own parent. At a time when they are trying to cope with growing up, they find that they also have to cope with a family member who is ill.

### Talking to children about dementia

The most important way to help children or grandchildren cope with a family member or someone close to them who has dementia is to talk openly and be willing to listen. They need the opportunity to ask questions and express their feelings without fear of a negative reaction. Remember that young children may not be able to take in too much information at one time. Keep it simple and try to respond to their questions at their own level.

### Talking to adolescents about dementia

Adolescents are often good at expressing themselves and their feelings, but don't be surprised if they don't initiate discussion. Watch for clues in their behaviour that something is on their mind and then try to talk openly.

Some young people may have problems talking with parents because they don't want to worry them, or are afraid of making them sad or being an extra burden. They may prefer to talk to people of their own age or to counsellors.

### Reactions of young people to dementia

Young people will react differently to dementia depending on:

- their age and stage of development
- their personality
- how important the person with dementia is in their lives
- how often they interact with that person.

### Questions young people may ask about dementia

The types of questions young people might ask include:

- What's happening to the person with dementia?
  - Why is it happening?
  - Why can't medicine make them better?
  - Did I do something to make them sick?
  - Will I get it too?
  - Will they die?
  - What can I do to make it better?
  - Who will take care of me?
  - Why is everyone always so sad and angry?
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- Why can't things be the way they were?

### **Emotions young people may feel**

Young people, like adults, may have a range of feelings, including:

- fear
- guilt
- denial
- jealousy
- resentment
- frustration
- anger
- sadness
- tension or stress
- embarrassment
- an overwhelming sense of responsibility
- unwillingness to take responsibility
- despair and hopelessness
- helplessness.

### **Things parents and grandparents can try**

You can help young people to cope with their feelings about dementia if you:

- Let them know that they are cared for and acknowledge that it is tough on them as well.
- Give them permission to say what they really feel – don't be afraid of their feelings (or your own).
- Help them confront and deal with their worst fears. Sometimes, these fears may be unrealistic, but they are certainly very real to the child.
- Try to maintain as much family structure as possible. Continue to do some of the things you used to do as a family, as this will give your children a feeling of security and self-confidence.
- Try to spend some time with them each day. It is important that they continue to have separate time where they are the focus of your attention.
- Make family plans and carry them out. Continue even if there isn't great enthusiasm for your suggestions.
- Use respite care services to give everybody a break.
- Encourage teenagers to get on with their lives and make their own plans.
- Deal with conflicts and problems. Don't ignore them.
- Set aside special times when the family can discuss responsibilities and problems, but try not to make 'helping' the overriding concern.
- Notify the child's teacher or school counsellor that there is a serious illness in the family. Check with the school from time to time to see if the child has experienced any problems.
- Encourage learning about dementia in the school environment. Contact Alzheimer's Australia Vic to find out about appropriate resources.
- Carers need to take care of themselves and reassure children that they will not get sick too.

### **Things young people can try**

If you are a young person wondering what you can do, safe, simple and quiet activities that involve repetition are best for people with dementia. Many people with dementia can remember things from long ago, but not things from a few minutes ago. You might like to look at a family photo album with them or play music that they might remember.

The person may only be able to concentrate for a short time. Stop or change what you're doing if they become anxious or distracted. Even though they may not recognise you, your love and understanding can be a great

comfort. Give them a cuddle, a kiss or stroke their arm. The best help you can give is reassurance and letting them know that you care about them.

Things young people can do to make life easier for the person with dementia include:

- Learn all you can about the disease.
- Be calm and patient.
- Be loving.
- Be involved.
- Be understanding.
- Treat the person with dementia with respect.
- Don't correct what they are saying, even if it is wrong or mixed up.
- Help around the house.
- Explain the situation to friends so they know what to expect.

Remember that all the feelings you have are normal and OK. It is very hard to watch someone you love, and who loves you, forget who you are and lose their independence. You must remember that even if the person becomes angry, cries a lot or does strange things like putting a jumper in the oven, it is because they have a brain disease and cannot help what they are doing. Do not blame yourself for their behaviour.

### **Where to get help**

- Your doctor
- Your local council
- Your local community health centre
- National Dementia Helpline – Dementia Australia. Tel. 1800 100 500
- Carers Victoria Tel. 1800 242 636 (Also known as Carers Advisory and Counselling Service)

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Dementia Australia

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