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## Factsheet 2

### Young Onset Dementia - Impact on Children and Teens A factsheet for parents



Dementia is commonly seen as a health and social problem of older people. Nevertheless dementia also can occur under the age of 65. Around one person in a thousand is diagnosed with dementia between the age of 45 and 65 years.

Many people with young onset dementia (YOD) have children who still live at home. Depending on their age, children may have difficulties understanding and accepting the changes in their parent. It is therefore important to support them to learn more about dementia. This knowledge will help them to handle the situation.

Children are very sensitive to changes in their home and family life. If a parent changes their behaviour towards them and if roles change between parents, they will notice it, even at a very young age. They may relate the changes to themselves and develop anxiety. Therefore openness about the situation is essential. Children should be given enough room to ask questions. It is important to keep them informed about what's happening, without putting too much pressure on them.

#### How do children react?

If a parent is diagnosed with young onset dementia, it most commonly evokes a lot of emotion. Fear of loss, anxiety about the future, and grief can be common reactions. Some children may react with feelings of guilt because they believe the dementia to be their fault or themselves to be the cause.

Children can also react with rejection and shame, especially if their parent behaves in an embarrassing way in public. The situation can place excessive demands on the child, which may stretch their patience. They may easily give up repeating things for their parent, and then withdraw from talking with them. Anxiety can be caused by the behaviour of the parent with dementia but also by the fear of loss. Some children feel helpless, as they realize that they can't do anything to change the situation. As a result, feelings of anger can occur – anger about the dementia, towards their parent with dementia or anger at the well parent who isn't able to change the situation.

Some children don't show their feelings openly, even if the dementia is affecting them. They may find it hard to identify their own feelings. Physical symptoms

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like head or tummy aches or difficulties at school can be possible signs of emotional distress.

### Which difficulties can appear?

YOD often has a considerable influence on family life. Children frequently have to face new tasks and shoulder responsibilities, which can put additional pressures on them. As the **relationship** between the child and the parent with dementia changes and roles shift, when children have to care for their parents, the loss of an important role model is implied. This can lead to children feeling unsupported or that they are missing out on their own childhood. On the other hand children may identify with the well parent and suffer from witnessing that parent's grief and burden.

When younger children recognize changes, they often find it difficult to classify them. This is why they tend to blame themselves for being the cause of the dementia or for provoking occasions when the parent with dementia is cross tempered.

Some children may **become afraid of their parent with dementia**, caused by lack of understanding about the way they have changed, whereas others are not fearful and want to help.

Especially for teenagers it can be hard to talk with others about their family situation. They feel too embarrassed to bring friends home like they used to. Furthermore teenagers can have difficulty moving away from the parental home and becoming independent in general. They may feel pressure to take on responsibility for their parents. As a result **social contacts may suffer** and teenagers may find it hard to establish new friendship or romantic relationships.

Caring for a person with dementia may demand a lot of time. Children and teenagers sometimes feel that the whole family revolves around the parent with dementia and no one seems to care about them. Sometimes financial possibilities are more limited than before and more wishes remain unfulfilled, which can be very **frustrating** at all understanding

Children are often very willing to take on care or nursing tasks. And sometimes this may be necessary to maintain the domestic situation. However, this can leave them with (too) **little time and energy** for their own activities and hobbies.

### What to do?

There are no universal rules about how to support children who have a parent with YOD. How they handle the situation depends on each individual. Nevertheless there are some tips that can provide helpful guidance.



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- **Calling dementia by its name**

It is important to try and find time and space to respond to the questions that children have, regardless of their age. This means the well parent needs to be informed and prepared to answer. Giving children the name of the dementia can help them to make sense of the changes which are going on. It is always good to have a name for things one is dealing with. Depending on the age of the children concrete information about dementia can be given. Even at a very young age children are able to understand some basic facts, e.g. that dementia is a disease of the brain and that it is not catching. As young children tend to think 'magically', it can be helpful to put information into a story or to compare changes due to dementia with things the children are familiar with (e.g. that memories are like books on a shelf, which are knocked over by the disease). Choosing age-appropriate language is also very important. Books on dementia that are available for different age groups may also be helpful.



- **Showing interest**

Children often have a very good sense of what is going on and are aware of subtle as well as more noticeable changes. Often they are seeking an explanation for what they are experiencing. However, it is only if parents are aware of this, they can purposefully relieve their children's anxieties. To openly ask about the children's thoughts and feelings can be a very good start for a conversation. It will give them security to know that they can ask questions anytime.

- **Being honest**

Being honest with children is very important. At a younger age they shouldn't be burdened with too many details, however, it is not helpful to foster false hopes. There can be questions occurring from "Why is daddy behaving so strangely?" to "Is mummy going to die?" In any case an honest answer is important.

It is also fine for parents to admit that they don't know everything. The most important thing is that the children feel their parent is there for them, and that the family will be facing the future together. It is not a sign of weakness to ask Alzheimer's Associations, support groups or a psychologist for help. Communicating openly that it is ok to seek for help elsewhere lets children know it is ok for them to seek help, too.

- **Finding the right words**

Younger children often have difficulty naming their feelings. It is important to encourage them and help them put how they feel into words. Helping them to find the right words for expressing those feelings will make it easier for them to talk to others and therefore not feel isolated.

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- **Mediating conflicts**

It is possible that the relationship between child and the parent with dementia will become tense or problematic. The parent with dementia may not understand the child, and may not be able to help them, or be patient with them. If children get angry with the parent with dementia, one should try to explain that problems in the behaviour of a person with YOD don't occur because of a wish to upset the other, or because of selfishness, but rather result from the impact of dementia itself. It is no one's fault.

- **Informing others**

It can be helpful for other people, who are closely involved with the children to have some awareness of the circumstances. To understand the child's behaviour and to have sympathy if they are sometimes upset, withdrawn or find it hard to concentrate teachers, coaches and other people close to the family, need knowledge about what is happening in the family. Teenagers should be asked to give their consent for the parent to inform teachers and others. This can prevent problems at school and help teenagers to keep up sporting and creative leisure activities. These are especially important as they can provide children with welcome 'down time' and are often a welcome diversion from daily routines.

- **Providing a secure place**

Every child can benefit from having a place where they feel undisturbed, comfortable and safe. In this place they can have a haven away from dementia, where they can concentrate on other things like homework or a chat with friends over the phone. This could be their own room, or a relative's, friend's or neighbour's house.

- **Every child is different**

All in all it is important to recognise that every child has to find their own way of dealing with the situation. Parents' concern that children will suffer from the situation is realistic and some upset and disturbance in family life is unavoidable, but can be made easier if the child knows the family are working together to manage the situation. It is not wrong to give children tasks they can handle, because this gives them a feeling of 'being needed'. This might be a good way for some children to forget about their anger and grief. They can for example have a nice walk with their parent with dementia on a regular basis, to give the well parent some time for housework or likewise. It may be hard for the well parent to find time or energy to give the children attention, and in this case, it may be helpful for some to have someone in a position of trust in their social environment who they can talk with, who will listen and help them to find solutions to their problems.



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## Concerning genetics

The diagnosis of YOD can be very scary, but when there are children in the family, there is an added concern about potential hereditary risk.

Although researchers are uncovering more about the genetics of dementia, they are still far from a perfect understanding of YOD. In the majority of cases dementia seems to occur by chance and it is not inherited. However, in about 20 to 50 % of cases there is at least one other close relative who has also had a diagnosis of dementia. In around 10% of those cases there is a pattern of inheritance which means that the children have a 50% chance of inheriting dementia.

For Fronto Temporal Dementia (FTD), it is known that in some families there are changes (known as mutations) in genes that increase the chance of the dementia being inherited. Where there is more than one person in a family with FTD but there is no known evidence of a genetic mutation, it is hard to know if there is a risk of inheritance. However, in this situation, genetic consultation and investigation would usually be possible.

In young onset Alzheimer's disease heredity plays a more important role than in late onset AD (where it is less than 1 %) although it is still very rare (about 10%). It may be possible to have genetic screening, if a risk of heredity is suspected. However, genetic testing has to be based on consultation with a medical expert.

YOD is an adult-onset disorder. Any risk to the children is not in the short term. Therefore the decision about genetic testing can usually wait until the child is old enough to decide for him or herself. In some countries genetic screening of an adult disease is possible only at adulthood.

## Support and information

If the parent without dementia has a good knowledge of the disease, questions from the children can be answered confidently. Another option is to make them aware of websites which focus on dementia and are made for children. Furthermore there are a lot of children's and teen's books, which deal with dementia.

If a parent is concerned for the child's emotional welfare, there may be the option of going to family therapy or child therapy. This might not be an option for every child, but sometimes talking about feelings and problems to a neutral counsellor can be very helpful.

Local Alzheimer's Associations can offer good advice. They might also know about projects and other services in the local environment.



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### Further information can be found here:

- Website for children and teens with an FTD parent:  
[www.aftdchildrenandteens.org](http://www.aftdchildrenandteens.org)
- When Dementia is in the House – information for parents and teens (also available in French):  
<http://lifeandminds.ca/whendementiaisinthehouse/>
- Dementia explained – for Young kids, Juniors and Teens:  
<https://kids.alzheimersresearchuk.org/>
- Telling children – information for parents with dementia:  
[www.youngdementiauk.org/telling-children](http://www.youngdementiauk.org/telling-children)



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### **RHAPSODY - Research to Assess Policies and Strategies for Dementia in the Young**

The main goal of RHAPSODY is to improve care for people with YOD by supporting their carers. The project will develop a web-based, interactive learning programme which is tailored to the needs of this particular group of people.

A multi-disciplinary consortium of eight partner institutions from six countries – France, Germany, the Netherlands, Portugal, Sweden and the United Kingdom are joining their efforts. The research teams represent academia, industry as well as a patient and carer advocacy organization.

RHAPSODY is an **EU Joint Programme Neurodegenerative Disease Research (JPND) project**. The project is supported through the following funding organisations under the aegis of JPND: France, The French National Research Agency (ANR); Germany, Federal Ministry of Education and Research (BMBF, FKZ: 01ED1404B); Netherlands, The Netherlands Organization for Health Research and Development (ZonMW); Portugal, Fundação para a Ciência e a Tecnologia (FCT); Sweden, Swedish Research Council (SRC); United Kingdom, Economic and Social Research Council (ESRC).

JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases. [www.jpnd.eu](http://www.jpnd.eu)



**RHAPSODY**  
Research and courage for dementia in the young



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This factsheet was reviewed by Tobias Bartschinski, social care manager, Munich; Angelika Fuls, family carer of a husband with young onset FTD, Berlin; Ellen Nickel, psychologist, Berlin; Elisabeth H. Philipp-Metzen, PhD, gerontologist, Münster; Anja Schneider, MD, Bonn

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