

Early Onset Dementia

Advice for Couples



NICE

National Initiative for the Care of the Elderly

Initiative nationale pour le soin des personnes âgées

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Ensemble pour le bien-être des aînés

www.nicenet.ca

What is Early-Onset Dementia?

- Early-onset dementia (EOD) is a term used for people who develop dementia under the age of 65
- In the early-onset group, the most common diagnosis is Alzheimer's disease and the second most common is frontotemporal dementia (FTD)
- These dementias have been known to develop between ages 30 and 40, but this is uncommon. It is usually an adult in their 50s who develops an EOD

Younger People with Dementia are more likely to:

- Be employed at the time of diagnosis
- Have dependent children or adolescents
- Be more physically active
- Have heavy financial commitments, such as a mortgage or children in university
- Have a rarer form of dementia

Issues for Couples Living with EOD

The changes in intimacy related to the onset of the EOD are distressing to many couples. EOD may cause an increase in sexual activity or the opposite may occur and sexual desire dissipates. Changing roles from spouse to caregiver may impact on emotional intimacy and physical desire. Try to:

- Find new activities that you both are comfortable with and can enjoy together.
- Find different ways to experience intimacy

- Consider what you are comfortable with and if you become uncomfortable redefine the rules and set new boundaries
- Don't be afraid to seek professional help (e.g. treating physician and health care team)

Families with Children

Parents diagnosed with EOD often have young or dependent children at home. It is important that children understand EOD, how it affects their family and what changes to expect in the parent diagnosed with EOD.

- Each child is different and will react in his or her particular way
- Children are often aware of changes to family dynamics even when they have not been told the facts, so it is reassuring for them to be given the facts
- Although the truth will be distressing, children may feel relief knowing that the changes in their parent's behaviour or personality is caused by an illness
- Seeing how you respond to the diagnosis helps young people develop skills necessary to cope with difficult situations, and manage painful emotions
- Adapt the information to be age appropriate so that children understand what is happening, but are not given more information than they are able to cope with
- Reassure children that you are still there for them, and that you understand the difficulties they face. They need to feel stability amidst difficult changes.¹

Reducing Caregiver Stress:

- **Learn about the disease:** Lack of information about the disease can add to caregiver stress. It may be easier for you to accept changes in your partner's personality and behaviour when you recognize that they can be attributed to neurological changes associated with EOD.
- **Be realistic about the disease and your expectations about yourself:** Have reasonable expectations about how much you can do and about what is important to you. There are no 'right' answers and you may need to try different things before you and your loved one come to terms with the diagnosis and how you are both managing.
- **Accept your feelings:** You may go from feeling at ease to feeling tremendous anger at your relative or the disease, to feeling happy to sad, embarrassed, afraid or confused. Remember, this range of feelings is normal and most caregivers experience them; do not judge yourself too harshly.
- **Confide in Others:** Discuss the diagnosis with close friends and family members to allow them insight to the challenges you face. Sharing your feelings with someone you trust will allow you a safe place to unburden yourself emotionally.

¹ Alzheimer's Society, United Kingdom, (2011). "Dementia and children or young people". Retrieved from http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=138

Monitor your mood and watch for symptoms of caregiver stress:

- Denial
- Anger
- Social withdrawal
- Sleeplessness
- Irritability
- Health problems
- Thoughts that life is not worth living
(Seek help immediately)

If you have any of these symptoms for more than a couple of weeks speak to your doctor.

Helpful websites

Alzheimer's Society of Canada

Updates on research, treatment, tips on providing care, information on programs and services at the local chapters.

www.alzheimer.ca

The Association for Frontotemporal Dementias

This is a place for families to turn for accurate information and support related to frontotemporal degeneration.

www.aftd.org

For more information on NICE or any of the
NICE tools, please visit www.nicenet.ca

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UNIVERSITY OF
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FACTOR-INWENTASH
FACULTY OF SOCIAL WORK

National Initiative for the Care of the Elderly
263 McCaul Street, Room 328, Toronto, Ontario M5T 1W7
Tel: 416-978-0545 • Website: www.nicenet.ca