Early Onset Dementia

Advice for Caregivers

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 Dementia?

- A group of symptoms affecting intellectual and social abilities that interfere with daily functioning
- Affects people's ability to function at work, in social relationships and in their daily activities
- There are different causes: Alzheimer's disease is the most common cause. There are currently half a million Canadians that have Alzheimer's disease or a related dementia and 14% of those are under the age of 65

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 parents
- Be more physically fit and active
- Have heavy financial commitments, such as a mortgage or children in university
- Have a rarer form of dementia

Issues in Early-Onset Dementia (EOD)

- Often occurs at a time of life when roles are affected in regard to family and professional responsibilities
- Most services are designed to help those with dementia who are older and are not planned for younger people and their families
- When dementia begins in middle life, misdiagnosis may be more likely

Why is it Important to Obtain an Accurate Diagnosis as Soon as Possible?

An accurate diagnosis of EOD:

- Can take a very long time, often due to lack of awareness of dementia in people under 65, even among physicians
- Helps friends and family members understand the changes in your relative and will allow them to respond with appropriate understanding and concern
- Leads to obtaining adequate supports and health care services
- Gives an individual with EOD time to plan for the future while he or she can still participate in making decisions

Negotiating with the Workplace:

- Until your relative has a definitive diagnosis make sure that he/she does not quit work until he/she has been fully assessed and can make choices and access employee benefits where available based on a correct diagnosis
- Think of different strategies for accommodating limitations at work before approaching an employer. You know what kind of employer your relative works for, so approach them accordingly.
- Be mindful of risks associated with your relative's type of work and assess if they can continue to work safely
- Make sure that you are aware of potential repercussions of discussing diagnosis. Approach the Employee Assistance Program if this is available to discuss different options

After you have considered these suggestions, and if you choose to talk to your relative's employer here are some tips:

- Find out whether early retirement is an option
- Familiarize yourself with the company benefits and see if employee assistance programs are available
- Explore what benefits are available through the workplace, private insurance and through the Canadian Pension Plan and/or Provincial Disability Support Program

Financial

People with EOD will eventually be unable to work and this loss of income is often a serious concern. Spousal caregivers may also quit their jobs or decrease work hours, which increases financial strain.

- Talk to a financial advisor and to a lawyer to help you plan for your future financial needs
- Put safeguards around excessive spending, gambling and be aware of vulnerabilities to scams
- Younger people with dementia, and caregivers, need to make sure that they are receiving the benefits to which they are entitled

Legal

- A Power of Attorney (POA) is a document that gives a person the right to make financial, property and personal care decisions on behalf of another person.
- Complete a POA as soon as the diagnosis is made to assist you with planning as the disease progresses.
- POAs vary from province to province; consult your provincial Ministry of the Attorney General for information and assistance

Driving

- The possibility of having one's driving license suspended can be extremely upsetting to the patient as driving is associated with independence and autonomy.
- When someone loses his or her license, major changes to his or her routine follow and impacts on family members' routines and roles.
- As difficult as it may be, driving is an issue that needs to be addressed; the earlier this is done the better. Please discuss your concerns with your treating physician(s)

Issues for Couples

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 own 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

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.

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 service s 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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