

Alzheimer Society

ALBERTA AND
NORTHWEST TERRITORIES

Tough Conversations For Young Onset Care Partners



Care Partners, these next scenarios are not here to scare you, but we want to make you aware of things that **may** happen. It is important to know that these things do not happen to everyone, but knowing it can, will better prepare you in the case these situations arise.

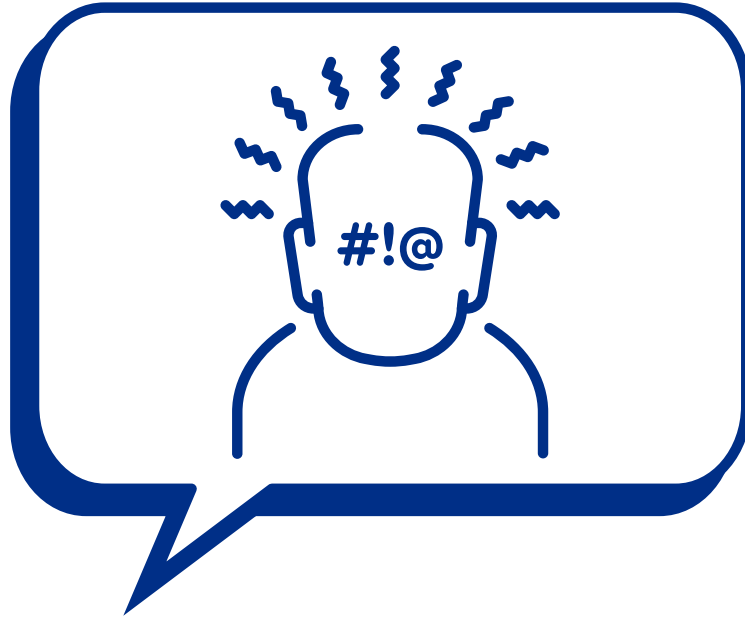
Within each of the situations below, there can be many individual experiences, they can range mild to extreme. Remind yourself that your family member has dementia, and this is the cause of these situations.

LACK OF INHIBITION:

For care partners the lack of inhibition may be embarrassing and frustrating. Lack of inhibition is when the person cannot control what they want to say or do. It may be expressed in different ways including: their speech (use of swear words); when they get dressed; how they spend their money; etc.... It is when their inside voice becomes their outside voice.

Tips:

1. Speak to staff at the Alzheimer Society
2. Monitor funds & make legal changes to accessing funds if needed.

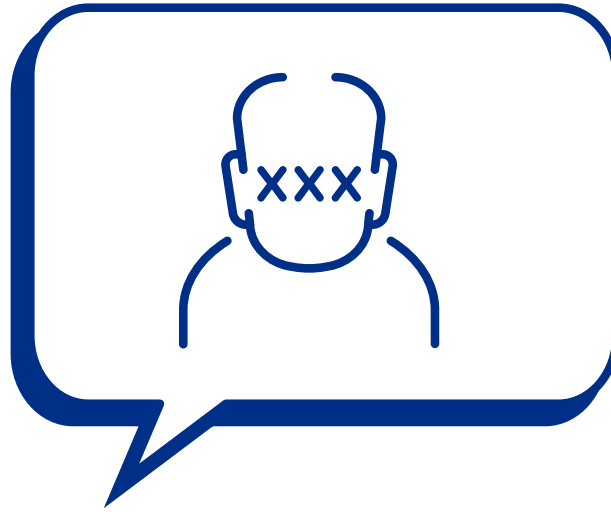


AGGRESSION:

This can be verbal/physical/sexual. It is often shocking, as this may be significant change in who they are as a person. You need to assess the risk to you. You may want to deny this could happen to you, but this is not an uncommon situation.

Tips:

1. Watch for signs of frustration increasing and if you see this, do not challenge and keep some distance until the situation has calmed (see below for safety plan).
2. Create a safety plan for you and any family members. A safety plan should include extra vehicle keys; someplace you can go to (neighbours); access to a telephone; knowing which room you will go to; calling 911.
3. Speak to staff at the Alzheimer Society.
4. Speak to family doctor; you may need a referral to a specialist.



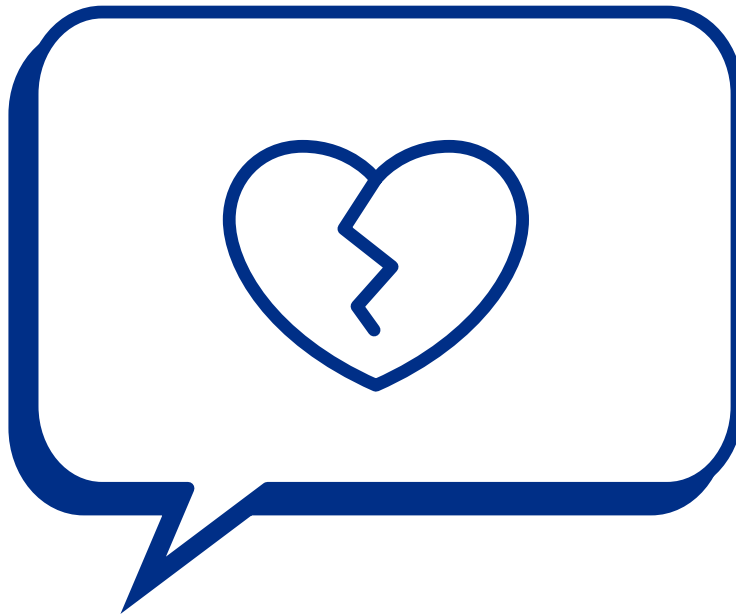
SEXUAL CONCERNS:

The following are some of the concerns that may occur:

- The person living with dementia may feel and increased desire for sexual activity.
- The person living with dementia may masturbate in inappropriate environment.
- The person living with dementia may want to watch porn in inappropriate environment.
- The person living with dementia may have an affair or try to initiate one.
- The person living with dementia may think their life partner is having an affair.
- Care partner may not want to have sexual activity with partner due to changes in cognition and relationship (relationship roles may change).
- Care partner may want to have sexual activity with partner but unsure if they should due to a change in a person's ability to understand.

Tips:

1. Speak to staff at the Alzheimer Society.
2. Speak to family doctor or specialist.
3. Speak to a counsellor



INTIMATE RELATIONSHIP CHALLENGES:

Care partners and people living with dementia may feel a profound sense of loneliness. People living with dementia may start a new relationship to help with the feeling of loneliness. Spouse care partners may feel a loss of relationship and may want to enter into a new relationship while still supporting their spouse who is living with dementia.

Tips:

1. As a spouse care partner, you are not a “bad” person for feeling lonely and wanting/needing a fulfilling relationship.
2. Acknowledge that for the person living with dementia, it is their way of filling the loneliness.
3. Speak to staff at the Alzheimer Society
4. Speak to a counsellor
5. Moving forward with your life while caring for your spouse is difficult. Find your own way to navigate relationship changes and moving forward in your life.



MENSTRUATION:

This may be especially difficult if you are supporting females or people living with dementia when they are still menstruating or have menopause. Male care partners may need to learn more about these body changes and how to help support them.

Tips:

1. Speak to family doctor for assistance in devices/treatment.
2. Speak to staff at the Alzheimer Society.
3. Ask family and friends for assistance.



CHILDREN:

If you have children who are not yet adults (under 18) or otherwise depend on an adult, you will want to look for extra support. It is difficult for children to fully understand dementia and for them to be a “helping care partner”. There are not a lot of resources for children when a parent has dementia. As a care partner you may struggle how to discuss the diagnosis & changes; how to help them live with the changes; having friends over; sharing with the school; struggling with the stigma of the disease; etc.. Sometimes there is an expectation from the health system, for them to be a helping partner.

Children over the age of 18, will be expected by the health system to lend a helping hand even if they have a busy life. To some degree they are better prepared than younger children to help out, but they are also in a different phase of their life where they are in post secondary school; learning about adulthood; starting a career, finding life partners' and having their own family. All these things make being an available care partner more difficult. Adult children often want to assist but are often pulled in different directions. Some adult children are uncomfortable with the situation with their parent and may avoid helping.

For all children the change in relationship roles can be a challenge. →

Tips:

1. Speak to staff at the Alzheimer Society to help brainstorm ideas and how to advocate for your family.
2. Seek out resources at the school/post secondary such as mental health teams.
3. Ask family, friends and neighbours for assistance.
4. Check in with them to see how things are going as they help care for their parent.
5. Try to find time and help them have a childhood/young adulthood.

It is important to remember that everyone's life is different; relationship is different; how we experience our world is different. Your journey is your journey.

For further resources and support, please reach out to your local Alzheimer Society office or visit our website's Young Onset page: alzheimer.ca/en/about-dementia/other-types-dementia/young-onset-dementia



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