

Understanding the Illness

When the person you are caring for is experiencing a new, debilitating chronic or life-limiting illness, understanding the illness can help you and the person you are caring for to cope.

LEARN ABOUT THE ILLNESS/CONDITION

- Ask doctors or nurses for information about the illness/condition that the person you are caring for has.
- Many illnesses/diagnoses have associations or societies that you can go to for information
- Many disease specific organizations have in person, online resources, or support groups to help patients/caregivers (i.e. Heart and Stroke, Alzheimer's, Cancer, and many more)

ASK QUESTIONS TO DOCTORS ABOUT WHAT YOU MIGHT EXPECT

- **Prognosis** is a word used to describe how an illness/condition commonly progresses. While medical professionals can't know what that looks like for each individual person, it can help you understand the common experiences others have had with the illness/condition.
- What are the main **symptoms** i.e. pain or swelling that the person you are caring for might expect to get?
- Ask when or for what reasons you or the person you are caring should **re-connect with the doctor?**

TIME - Estimates of time are usually not exact but can help you in trying to plan. Some questions are:

- What can we expect if the illness/condition progresses?
- What effect may this illness/condition have on quality of life?
- What effect might this illness/condition have on life expectancy?

MEDICATION - The person you are caring for may require new or different medication as the illness/condition progresses. Some questions are:

- What are side effects of any new medication?
- How might each medication or foods affect each other?
- Is the medication covered? (i.e. Ontario Works (OW), OHIP, Trillium, Ontario Drug Benefit (ODB), etc.)

PHYSICAL OR INTELLECTUAL CHANGES - Are there any changes we should prepare for? i.e. general weakness, vision impairment, loss of ability to walk or care for self, confusion, cognitively not able to manage, etc.

- Transportation
 - Could it affect ability to drive, use public transit, necessitate accompaniment to medical appointments, or limit daily activities?
- Mobility Devices
 - Will the illness/condition affect their ability to walk or manage their own care now or in the future?
 - What if we need a mobility aid (i.e. walker, wheelchair, cane)? Who helps with this?
 - Are there any adjustments that we could consider to make to home safer and more comfortable?
- Changes in Mood
 - Be aware that regardless of diagnosis, **it is normal to feel sad, angry, or withdrawn** when you are dealing with a significant illness/condition. If the feelings do not go away or affect functioning, it may be a sign that treatment may be necessary.

WHEN TO SEEK HELP

Connect with the care team or support network of the person you are caring for to express any concerns.

Resources - Click on the links & logos below

- Ontario Caregiver Help Line 1-833-416-2273 (CARE)
- Look for societies or support groups that are specific to the diagnosis of the person you are caring for. Look for Canadian and/or Ontario websites and content.