



When you need extra care, should you receive it at home or in a facility?


A decision aid to prepare you to discuss the options

This decision aid is for you if:

- you are living with an advanced illness that cannot be cured.
- you would like to plan where you would receive extra care when you need it.
- you want to share your views with others.

What are the care options when you need extra care?

When an illness advances, care focuses on easing symptoms and promoting quality of life. This is called hospice or palliative care. Your health care team can work with you to assess your needs, recommend equipment, and arrange care-giving help. Care can be provided at home or in facilities such as hospitals, nursing homes or hospices. Types of palliative care services are listed below.

Types of Palliative Services	Care at Home 	Care in a Facility 
Visiting health professionals: <ul style="list-style-type: none"> • Nurse • Physiotherapist, occupational therapist, social worker, dietician 	Up to 40 hours a week As needed	24 hours a day As needed
Personal care and support: <ul style="list-style-type: none"> • Personal support workers, health care aids, attendants 	Up to 15 hours a week	24 hours a day
Homemaking: <ul style="list-style-type: none"> • Home care workers 	Up to 15 hours a week	24 hours a day
Community support services: <ul style="list-style-type: none"> • Non-profit groups, private companies, service clubs, charitable and volunteer organizations, friends, relatives 	As available	As available

How can I find out more about the services available in my community?

- Your health care team
- The CCAC-Community Care Access Center (www.ccac-ont.ca)
- The toll free Hospice Palliative Care Information Line (1-877-203-INFO)
- The Canadian Cancer Society (1-888-939-3333) (www.info@cis.cancer.ca)

Working through the steps of this decision aid may help you decide.

- Step 1: How are you feeling right now?
- Step 2: Which reasons to choose each option matter most to you?
- Step 3: What else do you need to prepare for decision-making?
- Step 4: What are the next steps?

Step 1: How are you feeling right now?

Your Daily Activities

Adapted PPS tool (Karnofsky, 1949)

Check how you have been on average in the past week.

Moving About	<input type="checkbox"/> I am able to move about as usual	<input type="checkbox"/> I move about less than usual	<input type="checkbox"/> I am mainly sitting	<input type="checkbox"/> I am mainly in bed	<input type="checkbox"/> I am in bed all of the time		
Activity	<input type="checkbox"/> I am able to do my usual activities such as job, hobbies, housework	<input type="checkbox"/> I am able to do my usual activities <i>with effort</i>	<input type="checkbox"/> I am unable to do my usual work	<input type="checkbox"/> I am unable to do my usual hobbies or housework	<input type="checkbox"/> I am unable to do any work	<input type="checkbox"/> I am unable to do most activity	<input type="checkbox"/> I am unable to do any activity
Self Care	<input type="checkbox"/> I am able to do all my personal care such as washing, dressing, going to the bathroom	<input type="checkbox"/> I need occasional help with my care	<input type="checkbox"/> I need a lot of help with my care	<input type="checkbox"/> Someone else provides most of my care	<input type="checkbox"/> Someone else provides all of my care		
Eating & Drinking	<input type="checkbox"/> I am able to eat and drink as usual	<input type="checkbox"/> I eat and drink less than usual	<input type="checkbox"/> I eat small amounts of food and sips of fluids	<input type="checkbox"/> I am not able to eat or drink			
Alertness	<input type="checkbox"/> I am alert as usual	<input type="checkbox"/> I am less alert than usual	<input type="checkbox"/> I am drowsy most of the time	<input type="checkbox"/> I sleep all of the time			

Your Symptoms

ESAS (Bruera, 1991)

Please circle the number that best describes how you felt on average in the past week.

Check symptoms that worsened this past week.

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain	<input type="checkbox"/>
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness	<input type="checkbox"/>
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea	<input type="checkbox"/>
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression	<input type="checkbox"/>
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety	<input type="checkbox"/>
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness	<input type="checkbox"/>
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite	<input type="checkbox"/>
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing	<input type="checkbox"/>
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath	<input type="checkbox"/>

Step 2: Which of the reasons for each option matter most to you?

Think about the future when you will need extra care. Where would you want to receive this care? Common reasons to choose either care at home or in a facility are below. Check ✓ how much each reason matters to you on a scale from '0' to '5'. '0' means it is **not** important to you. '5' means it is **very** important to you.



Reasons to choose... **Care at home**

**Not
Important**

**Very
Important**

How important is it for you to have more privacy at home?

① ① ② ③ ④ ⑤

How important is it for you to have more control over your daily routines and timing of your care?

① ① ② ③ ④ ⑤

How important is it for you to be close to family, personal belongings, pets and friends?

① ① ② ③ ④ ⑤

List other reasons to choose care at home:

① ① ② ③ ④ ⑤



Reasons to choose... **Care in a facility**

**Not
Important**

**Very
Important**

How important is it for you to have staff available 24 hours a day?

① ① ② ③ ④ ⑤

How important is it for you to have staff manage most of your personal care?

① ① ② ③ ④ ⑤

How important is it for you to free up your family from giving personal care and medications?

① ① ② ③ ④ ⑤

How important is it for you for you to have staff around for safety and security?

① ① ② ③ ④ ⑤

List other reasons to choose care in a facility:

① ① ② ③ ④ ⑤

Now, think about which option has the reasons that are most important to you.

Which option do you prefer? Check one.

Care at home.

Care in a facility. Please specify: _____

I am not sure.

Step 3: What else do you need to prepare for decision-making?



Support

Who else is involved in this decision?

Who is the person?	Name:	Name:	Name:
Which option does this person prefer?			
Is this person pressuring you?	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
How can this person support you in decision making?			
I prefer to...	<input type="checkbox"/> share the decision with:	<input type="checkbox"/> decide myself after hearing the views of:	<input type="checkbox"/> have someone else decide for me. Who?



Knowledge

Do you know enough about the **reasons to choose** each option?

Yes No



Values

Are you clear about which reasons to choose each option **matter most** to you?

Yes No



Support

Do you have enough **support** and **advice** to make a decision?

Yes No



Certainty

Do you **feel sure** about the best choice for you?

Yes No

Step 4: What are the next steps?

Check what you need to do before you make this choice.

- Nothing, I am ready to make my plan.
- I need to discuss the options with _____
- I need to learn more about my options.
- Other. Please specify _____