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.

<table>
<thead>
<tr>
<th>Types of Palliative Services</th>
<th>Care at Home</th>
<th>Care in a Facility</th>
</tr>
</thead>
</table>

**Visiting health professionals:**
- Nurse: Up to 40 hours a week. 24 hours a day.
- Physiotherapist, occupational therapist, social worker, dietician: As needed.

**Personal care and support:**
- Personal support workers, health care aids, attendants: Up to 15 hours a week. 24 hours a day.

**Homemaking:**
- Home care workers: Up to 15 hours a week. 24 hours a day.

**Community support services:**
- 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**

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

#### Moving About
- I am able to move about as usual
- I move about less than usual
- I am mainly sitting
- I am mainly in bed
- I am in bed all of the time

#### Activity
- I am able to do my usual activities such as job, hobbies, housework
- I am able to do my usual activities with effort
- I am unable to do my usual work
- I am unable to do my usual hobbies or housework
- I am unable to do any work
- I am unable to do most activity
- I am unable to do any activity

#### Self Care
- I am able to do all my personal care such as washing, dressing, going to the bathroom
- I need occasional help with my care
- I need a lot of help with my care
- Someone else provides most of my care
- Someone else provides all of my care

#### Eating & Drinking
- I am able to eat and drink as usual
- I eat and drink less than usual
- I eat small amounts of food and sips of fluids
- I am not able to eat or drink

#### Alertness
- I am alert as usual
- I am less alert than usual
- I am drowsy most of the time
- I sleep all of the time

### Your Symptoms

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

<table>
<thead>
<tr>
<th>Symptom</th>
<th>-score</th>
<th>Worst possible symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td>No pain</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Not tired</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Not nauseated</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Not depressed</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Not anxious</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Not drowsy</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Best appetite</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>Best feeling of wellbeing</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
<tr>
<td>No shortness of breath</td>
<td>0</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
</tr>
</tbody>
</table>
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.

<table>
<thead>
<tr>
<th>Reasons to choose…</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care at home</td>
<td>① ② ③ ④ ⑤</td>
<td></td>
</tr>
<tr>
<td></td>
<td>① ② ③ ④ ⑤</td>
<td></td>
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<tr>
<td></td>
<td>① ② ③ ④ ⑤</td>
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<td>① ② ③ ④ ⑤</td>
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<tr>
<td></td>
<td>① ② ③ ④ ⑤</td>
<td></td>
</tr>
</tbody>
</table>

List other reasons to choose care at home:

<table>
<thead>
<tr>
<th>Reasons to choose…</th>
<th>Not Important</th>
<th>Very Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care in a facility</td>
<td>① ② ③ ④ ⑤</td>
<td></td>
</tr>
<tr>
<td></td>
<td>① ② ③ ④ ⑤</td>
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<tr>
<td></td>
<td>① ② ③ ④ ⑤</td>
<td></td>
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</tbody>
</table>

List other reasons to choose care in a facility:

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?

<table>
<thead>
<tr>
<th>Who is the person?</th>
<th>Name:</th>
<th>Name:</th>
<th>Name:</th>
</tr>
</thead>
</table>

Which option does this person prefer?

<table>
<thead>
<tr>
<th>Is this person pressuring you?</th>
<th>□ Yes</th>
<th>□ No</th>
</tr>
</thead>
<tbody>
<tr>
<td>How can this person support you in decision making?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

I prefer to…

<table>
<thead>
<tr>
<th>□ share the decision with:</th>
<th>□ decide myself after hearing the views of:</th>
<th>□ have someone else decide for me. Who?</th>
</tr>
</thead>
</table>

#### 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 ____________________________

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