Planning your palliative care:
A booklet to help you get ready to leave the hospital

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What is palliative care?

Palliative care is a special area of health care. It focuses on providing the best quality of life for people with advanced illness. The palliative care team will suggest care plans to help:

- relieve pain and symptoms
- support patients and caregivers
- help with planning for the future

It is an area of care that respects all beliefs, cultures, faiths and values.

The goal is to help patients live as actively and comfortably as possible until they die.
Reading this guide will help you and your caregivers prepare for your discharge from the hospital. The transition from hospital to the right environment is different for everyone. It could be to home or to another health care facility.

Your health care team will help you and your caregivers plan a safe discharge. Usually, your team will follow these steps:

Step 1: The health care team learns about your needs.

Step 2: The health care team meets with you and your caregivers to talk about your options.

Step 3: You will prepare for the place you will receive care.

This booklet is based on the experience of many patients, caregivers and healthcare professionals. We hope you find it helpful.
Step 1
Learning about your health care needs

In this step your health care team learns what you need to have a safe and comfortable discharge from the hospital. For example, they will learn if you need help bathing. They will learn if you need help moving around. They will learn if you need someone with you to make sure you are safe and comfortable.

The list below explains each health care team member’s role:

**Nurse**

A nurse provides regular assessments and care. They help you with many daily tasks such as:

- checking your pain and symptoms
- giving you medicines
- taking care of your skin and wounds

They are familiar with your medical needs.

**Social Worker**

A social worker helps you and your caregivers cope with the impact of your illness. They are here to help you with many types of needs. These include emotional, financial and any practical needs. A social worker can give you:

- Individual and family counseling about coping with illness, loss and bereavement (grieving)
- information about practical or financial resources
- information about hospice and palliative care units in the community and help filling out forms
- support with the transition from hospital to home or hospice and palliative care units
- help with talking to your care providers. This includes organizing family meetings with your health care team (read more about family meetings on page 9)
• information about advance care planning, living wills, powers of attorney, and how to decide who makes decisions when you cannot

Physical and Occupational Therapists
These therapists will check to see how well and how safely you move around and function. They also check to see how well you manage your daily activities. This includes getting dressed and taking a bath. They may recommend equipment to help you such as:

• wheelchairs/walkers
• bedside commodes (toilets)
• hospital beds
• bath chairs

Spiritual Care
Spiritual care providers can talk with you. They are there to help you find what you need and what is important to you. You do not need to belong to any specific religion to receive support. Spiritual care includes:

• exploring spiritual meaning in times of illness
• reflecting on how illness has changed your life, family and community
• providing encouragement and comfort
• providing support for loss and grief
• providing a time for prayer, meditation and reflection
• linking spiritual and faith-based activities

Speech and Language Pathologist
A speech and language pathologist is here to help if you have trouble eating, drinking and/or communicating. They can make recommendations to:

• help you swallow better
• eat more comfortably
• communicate more clearly
CCAC Coordinator

The Community Care Access Centre (CCAC) is a governmental agency which organizes the services you need at home. These services can include:

- nursing visits
- caregiver relief
- equipment
- personal support (such as help with bathing)
- physiotherapy and occupational therapy
- social work

The services funded by the government vary from region to region. The CCAC Coordinator in the hospital will tell you what services are available to you in your home.

Palliative Care Doctor and Nurse

A palliative care doctor or nurse will work with your medical team. They are there to help control any symptoms that cause you discomfort or distress. They can also help with:

- giving recommendations about discharge options
- supporting you and your caregivers through your illness
- finding resources such as hospice and palliative care units in the community
- adjusting from hospital care to home or hospice palliative care

Dietitian

A dietitian helps people with nutrition needs due to their illness. They will make recommendations to help you keep the safest and most satisfying diet.
**Respiratory Therapist**
A respiratory therapist may check to see if you need oxygen at home. They will also help you learn about funding available for home oxygen.

If you have a tracheostomy, the respiratory therapist will also find out what your needs are. They will recommend equipment that you will need to manage your tracheostomy at home.

Please talk to anyone from your health care team about any issues that are important to you. You may have questions or concerns about many topics such as:

- your symptoms
- what you and your caregivers expect for your future
- your hopes and fears
- your future planning
- grief and bereavement

Your team will help make sure your concerns are addressed.

Write down your questions on the next page.
Make sure you ask all your questions before you leave the hospital.
Write down your concerns or questions here.

You can bring this list to your family meeting or show it to a member of your health care team at any time.
Now that your health care team understands your needs, they will meet with you and your caregivers. At this meeting you will make plans for your discharge from the hospital. This meeting is often called a “family meeting”.

Family meetings are planned in advance. To goal is to provide a dedicated time for you and your caregivers to talk about your questions and concerns with your health care team.

During this meeting, you and the team will help you decide the best place to be cared for. This choice will be based on your needs. It will also be based on the resources available where you live.

Bring your own questions to the family meeting as well.

Take the time to talk about your questions and concerns.

**What do we talk about at a family meeting?**

Family meetings always start by introducing you and your caregivers to the health care team members at the meeting. Then, you will usually discuss the following topics that are explained in more detail below:

1. Your current health.
2. What you need for a safe discharge. This includes who can support you.
3. What type of care you would like.
4. Options for where you can receive care after the hospital.
1. Your current medical condition

The health care team will give you and your caregivers an update about:

- your illness
- your treatments so far
- future treatments to treat your disease and manage your symptoms
- what you can expect to happen in the future

2. What you need for a safe discharge and who can support you

Next, the team will explain what you need for a safe and comfortable discharge. This may include help with:

- bathing
- taking medicines
- preparing meals
- getting back and forth to the bathroom

The health care team will then ask about who is able to help you at home. They will also talk to you about other ways you can get support. This may include through your insurance or other resources you may have.

3. Your personal preferences for care

Your personal preferences for care are often called goals of care. This is a term that means your hopes and expectations for yourself throughout your illness and treatment.

It is important that you talk to your health care team about:

- what is important to you
- what you value
- what you want to accomplish in the future
- how the team can help support you to accomplish this
These are examples of many patients’ wishes:

- I want to stay at home as long as possible
- I want to stay pain free
- I want to remain alert

No matter what your goals are, your team will help you understand what is possible. They will also be there to help you understand what is available to help you meet your goals.

## 4. Options for your care after hospital

Your health care team will explain what options are available to you. Your options are based on your needs, your resources, your goals of care and the support available.

Your options may include:

1. Home
2. Palliative Care Unit or Hospice.

Read the sections below to learn about each option.

### Home

(This includes retirement homes or long-term care facilities)

It may be possible for you to return to your home. It may also be possible to stay at the home of a caregiver who can care for you.

Whether this can be arranged will depend on where you live, your medical needs and what resources you have.

If going home is possible, we can work to arrange a visiting home care team to provide:

- pain and symptom management through nursing and/or doctor visits
- equipment such as a hospital bed and oxygen medicines
• personal care support for help with general hygiene such as bathing and skin care
• other resources you may need to be comfortable and cared for

The services available are different from region to region. You and your team will talk about this in detail for your situation.

**Palliative care units and residential hospices**

You can choose to be cared for in a palliative care unit or hospice. The environment in these places is quieter than a hospital.

In a palliative care unit or hospice you always have expert support and pain and symptom management. The focus of palliative care units is on helping you be as comfortable as possible and improve your quality of life. Staff in a palliative care unit are also there to support both the patients and their caregivers.

Palliative care units are the best choice if you do not want to go back to an acute care hospital for on-going medical care. This type of care includes artificial life support, chemotherapy, blood tests and regular blood transfusions.

Palliative care units and hospices care for you with:

• medical expertise in symptom management
• nursing expertise
• medical and nursing care 24 hours a day
• oxygen
• social workers, volunteers and therapists

The staff in the palliative care units strive to help you meet your goals. For example, if you feel well enough, the staff can help you organize trips outside the palliative care unit. This can include going:

• home for short visits
• home for overnight stays
• to special outings
As well, it is always possible for the staff to help you transfer home if it is a safe choice.

You may be required to pay a fee (co-payment) directly to the palliative care facility that you choose. The cost is the same as the cost to stay at a long-term care facility.

Depending on your financial situation, these fees may be reduced or waived. Ask your social worker for more information about costs.

Choosing the right place for you

After talking and thinking about all the topics, you and the health care team will help you choose the right place:

- Your needs
- Your goals and wishes
- People who can support you
- Other resources

= The best place for you to stay

Read the next section to learn about how you can prepare.
Step 3
Preparing for the place you will receive care

Read the section below that applies to you.

You will learn what to expect and how to prepare for the place you will be going to receive care.

I am going home. What should I expect?

Before you leave the hospital there are resources you may need to have in place. Everybody’s needs are different so please review this list. You may need only 1 or 2 items, or you may need more.

If you have questions about your supports when you go home, please ask your nurse, social worker or doctor.

Your health care team will arrange these resources for you before you leave the hospital:

- **CCAC services**
  The Community Care Access Centre (CCAC) will talk to you about setting up care in your home. This includes nursing and personal support, such as help with bathing. Make sure you have met with a CCAC Coordinator in the hospital before you go home. Each community has different resources. The type and amount of services may change based on your needs and existing resources.

- **Home palliative care team**
  Your health care team will help you access a home-based team to visit you at home. This team will help you with pain and symptom control. This team may include your family doctor or another health care provider who specializes in home palliative care. This team and the staff from CCAC are your home-based health care team. Feel free to talk to them about any issues that are important to you.
Prescriptions for all medicine you take by mouth
Before you leave the hospital your doctor will give you a prescription for all medicine you take by mouth, such as pills, liquids and syrups. You may fill the prescriptions in the hospital before you leave, or at a pharmacy closer to your home.

Prescriptions for all medicine given by injection
Medicines given through a needle are supplied by a central pharmacy that works with CCAC. Your health care team will fax this prescription to the central pharmacy before you leave the hospital. These medicines will then be delivered to your home. This will usually be done the day before you go home.

Health and safety equipment
You may need to rent or buy equipment to keep you safe and comfortable at home, such as a hospital bed. The CCAC may provide the equipment you need. If not, they can provide information about how to rent or purchase equipment.

Any equipment you will need should be delivered to your home before you leave hospital. If CCAC is providing the equipment then the CCAC coordinator will organize the delivery to your home. A family member must be present to accept the equipment.

Oxygen
If you need oxygen, it will be arranged for you by a respiratory therapist. This will also be delivered to your home before you arrive.

Hospice referral
You may benefit from a referral to a community hospice agency. This is a group of people with are experts in helping people and their families cope with the challenges of advanced illness. Hospices often send volunteers to a patient’s home to provide:

- caregiver relief
- support to patients and their caregivers
- support children in the family
- bereavement support in the future
**Backup application to a palliative care unit or residential hospice**

If you are going home, you may want to send a back-up application to a palliative care unit or residential hospice. The unit or hospice keeps your application on file. This will allow you to have a shorter wait time if your needs or goals of care change. Your social worker in the hospital will help you with this back-up application.

**Any follow up appointments with your doctors, and necessary treatments, if applicable.**

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### Other things to consider:

The CCAC offers you many services. But, you may need other services or resources to make sure you are safe at home. You will need to arrange for these services yourself.

Your health care team will explain services you will need. Please feel free to ask your social worker. You can also check the resource section of this guide for more information on these services.

**More support at home**

You may need more support than the CCAC can provide for you. This may include more hours and visits from nurses and personal support workers to help with:

- household chores
- preparing meals
- daily care such as bathing

**Equipment not provided by CCAC**

Some equipment may not be provided by CCAC. Your occupational therapist and physiotherapist will recommend the right equipment for you. They will also teach you how to get this equipment.

**Medicine not covered by CCAC**

Your pharmacist will tell you if a medicine is not covered. They will help you with other coverage if it is available. If you have a private insurance plan, they may cover costs of these medicines.
Write down these important phone numbers:

Local CCAC office: 

Home palliative care doctor: 

Home palliative care nurse: 

Palliative care doctor in the hospital: 

Hospital social worker: 

Admitting doctor in hospital: 

If you have to come back to hospital:

1. Tell the nurse and doctor that you have been seen by the palliative care team on your previous admission.

2. Bring your medicines with you.
This is what will happen next:

1. Your social worker and/or your palliative care nurse or doctor will give you information about the hospices and palliative care units available to you. They will also explain any important information about fees and policies.

2. You and/or your family members or caregivers can visit any of the units to talk with staff and see the facilities.

3. Your application(s) will be made from hospital by your health care team.

4. You will wait in the hospital for the first bed to come available at one of your chosen facilities. If you are able, you can also wait at home. CCAC may be able to provide more services at home for you while you wait for admission.
Below is a list of hospices and palliative care units.

You can also use this web link to view palliative care units on a map. It also provides direct links to each facility’s website: http://Goo.gl/maps/aeRh

### Residential Hospices

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<tr>
<th>Residential Hospices</th>
<th>Address</th>
<th>Phone</th>
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<tbody>
<tr>
<td>Carpenter House</td>
<td>2250 Parkway Dr, Burlington</td>
<td>905 631 9994</td>
</tr>
<tr>
<td>Casey House (HIV/AIDS)</td>
<td>9 Huntley St (Jarvis/Bloor)</td>
<td>416 962 7600</td>
</tr>
<tr>
<td>Dorothy Ley Hospice</td>
<td>220 Sherway Dr</td>
<td>416 626 0116</td>
</tr>
<tr>
<td></td>
<td>(Queensway/West Mall)</td>
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</tr>
<tr>
<td>Hill House Hospice</td>
<td>36 Wright St, Richmond Hill</td>
<td>905 737 9308</td>
</tr>
<tr>
<td>Ian Anderson House</td>
<td>430 Winston Churchill Blvd, Oakville</td>
<td>905 337 8004</td>
</tr>
<tr>
<td>Kensington Gardens</td>
<td>38 Major St (Spadina/College)</td>
<td>416 963 9640</td>
</tr>
<tr>
<td></td>
<td>ext. 1426</td>
<td></td>
</tr>
<tr>
<td>Perram House</td>
<td>4 Wellesley Pl (Wellesley/Jarvis)</td>
<td>416 925 9866</td>
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### Hospital-based Palliative Care Units

#### Toronto Central

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<thead>
<tr>
<th>Hospital-based Palliative Care Units</th>
<th>Address</th>
<th>Phone</th>
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<tbody>
<tr>
<td>Baycrest</td>
<td>3560 Bathurst St (south of Hwy 401)</td>
<td>416 785 2500</td>
</tr>
<tr>
<td>Bridgepoint Health</td>
<td>14 St.Matthews Rd (Broadview/Gerrard)</td>
<td>416 461 8251</td>
</tr>
<tr>
<td>St.Michael’s</td>
<td>30 Bond St (Yonge/Queen)</td>
<td>416 864 5226</td>
</tr>
<tr>
<td>Sunnybrook</td>
<td>2075 Bayview Ave (Bayview/Lawrence)</td>
<td>416 480 6182</td>
</tr>
<tr>
<td>Toronto Grace</td>
<td>650 Church St (Church/Bloor)</td>
<td>416 925 2251</td>
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#### Toronto East

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<thead>
<tr>
<th>Hospital-based Palliative Care Units</th>
<th>Address</th>
<th>Phone</th>
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</thead>
<tbody>
<tr>
<td>Providence</td>
<td>3276 St.Clair Ave East (Warden/St.Clair)</td>
<td>416 285 3666</td>
</tr>
<tr>
<td>Scarborough General</td>
<td>3050 Lawrence Ave East (McCowan/Lawrence)</td>
<td>416 438 2911</td>
</tr>
<tr>
<td>Toronto East General</td>
<td>825 Coxwell Ave (Coxwell/Danforth)</td>
<td>416 469 6580</td>
</tr>
</tbody>
</table>
Community hospices

Community hospices are non-profit organizations. They train volunteers to help you in your home. Volunteers help patients and families with:

- personal care
- respite care
- emotional support
- spiritual support
- funeral planning
- bereavement support
- financial planning
- legal planning

These services are provided free of charge.

There are many community hospices located all around Ontario. Ask your social worker to help you find the community hospice nearest to you. You can also call the Ontario Hospice Association (see below). They can help you find the community hospice that is right for you.

Hospice Association of Ontario
40 Wynford Drive, Suite 313
Don Mills, Ontario, M3C 1J5

Telephone: 416 510 3880
Fax: 416 510 3882
Private nursing and home-making agencies

You can hire private agencies for more home support on top of what the CCAC gives you.

Private agencies provide nursing services. Some also offer other professional services such as:

- occupational therapy
- physiotherapy
- speech language therapy
- massage therapy

Some also provide a variety of home and personal support services including:

- cleaning
- shopping
- personal care
- help with preparing meals

Please ask your social worker for more information.

Helpful websites

<table>
<thead>
<tr>
<th>Website Name</th>
<th>Address (URL)</th>
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<tbody>
<tr>
<td>Canadian Virtual Hospice</td>
<td><a href="http://www.virtualhospice.ca">www.virtualhospice.ca</a></td>
</tr>
<tr>
<td>Health and Community Services in your area</td>
<td><a href="http://www.310ccac.ca">www.310ccac.ca</a></td>
</tr>
<tr>
<td>Hospice LifeLine and Hospice Association of Ontario</td>
<td><a href="http://www.hospicelifeline.com">www.hospicelifeline.com</a></td>
</tr>
<tr>
<td>Hospice Palliative Care Ontario</td>
<td>hpc.ca</td>
</tr>
<tr>
<td>Max and Beatrice Wolfe Children’s Centre</td>
<td><a href="http://www.mountsinai.on.ca/temmy_latner/patients/childrens_grief">www.mountsinai.on.ca/temmy_latner/patients/childrens_grief</a></td>
</tr>
<tr>
<td>Toronto Palliative Care Network</td>
<td><a href="http://www.tpcn.ca">www.tpcn.ca</a></td>
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Income support programs for you or your caregiver

If you are unable to work due to illness, you may be eligible for financial help from one or more of the sources listed below.

These sources can help you with basic needs like:

- food
- shelter
- the cost of medicines

Contact each of the programs below in the order that they are listed. Talk to your social worker for more information.

<table>
<thead>
<tr>
<th>Your place of employment</th>
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<tr>
<td>Contact</td>
<td>Your manager or Human Resources department.</td>
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<table>
<thead>
<tr>
<th>Employment Insurance (EI), Compassionate Care Benefits (for a family member/caregiver), or Sickness Benefits</th>
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<tbody>
<tr>
<td>Contact</td>
<td>Service Canada</td>
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<tr>
<td></td>
<td>1 800 206 7218</td>
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<tr>
<td></td>
<td><a href="http://www.servicecanada.gc.ca">www.servicecanada.gc.ca</a></td>
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<tr>
<th>Canada Pension Plan (CPP) Disability Benefits</th>
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<tr>
<td>Contact</td>
<td>Service Canada</td>
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<tr>
<td></td>
<td>1 800 277 9914</td>
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<td></td>
<td><a href="http://www.servicecanada.gc.ca">www.servicecanada.gc.ca</a></td>
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<th>Ontario Works (OW)</th>
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<tr>
<td>Contact</td>
<td>Ontario Works</td>
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<tr>
<td></td>
<td><a href="http://www.mcss.gov.on.ca/en/mcss/programs/social/ow">www.mcss.gov.on.ca/en/mcss/programs/social/ow</a></td>
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<td>Contact</td>
<td>Ontario Disability Support Program</td>
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