Hospital to Home Guide

Name

Phone Number

Hospital to Home Guide

This guide was developed to assist patients and caregivers in their transition from the hospital to the home for palliative care. It deals with the many important questions and concerns raised when navigating through this challenging transition.

This was designed primarily by patients and caregivers who had already experienced this transition; it contains their lessons and guidance.

They wished they'd had a guide with the important questions to ask, the things to do and the numbers to call. This guide is designed to help you and others like you do exactly that.

Because each situation is unique, not all areas in the guide will apply to every transition. Please refer to those topics that apply to your personal journey.

The guide offers advice, suggestions, and checklists regarding three key areas of the transition period:

1) When you are still in the hospital
2) When you are actually discharged from the hospital
3) When you get home

**Please note* - this document is intended for patients and their caregivers. We will often use the word "you" or "I" to refer to both.*

How to use this guide

Keep this as your go-to document and note-taking support as you move through your transition home.

On the pages in this guide you will see prompts for questions and space to take your own notes.

Patients and caregivers mentioned the importance of having a space where they can write down information as they receive it. This guide is that space for you.

We recommend you keep this guide with you, and when you receive new information, pamphlets, etc. write down the important information again in this guide. For example:

- Write down for yourself the names and numbers you receive for members of your care team
- Cross out sections that don't apply to your case, and
- Add information that does help.

Additional Resources

Use this QR code to visit our online hospital-to-home resource hub, including resources for transportation, service providers, food, financial needs, education, and caregivers.

https://www.isenberglab.com/hospital-to-home-resource-hub

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Your Journey Home

Use this as both a table of contents and a tracker to help you prepare.

	At Hospital	Travel Home	At Home
Your Location			
Milestone Moments	Decision to go home	Discharge and travelling home	The first 48 hours
Your care team	☐ Review your Care Team Map 9 ☐ Fill out important contacts sheet 10		☐ Fill out multiple copies of essential contacts 24
Essential checklists	☐ Getting home from the hospital 14	☐ Before you leave the hospital double check 19	☐ Enjoying your home 22
Ask questions	☐ Questions for your care team 12 ☐ Review support for caregivers 16 ☐ Reflections on going home 15	☐ Review symptoms and prescriptions with your physician 18	☐ Review medication tracking 21 ☐ Review support for caregivers 23

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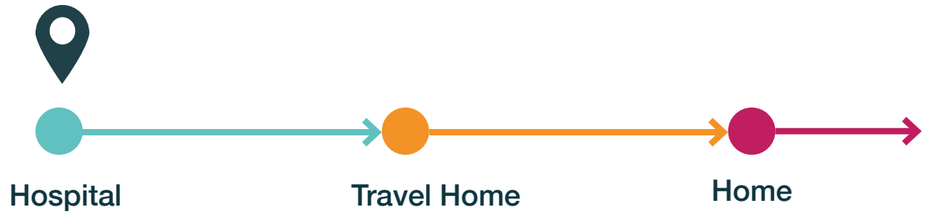
At Hospital



As you meet with different members of your care team at the hospital, it's easy to feel overwhelmed. Take the time you have before going home to help get yourself prepared; learn more about your team, your needs, and the changes that will happen once you are home.

It's normal to be worried or anxious about going home. You can speak with members of your hospital care team, including your social worker, doctor, clinical chaplain or spiritual care provider.

Your care team may have the following people:

Hospital Care Team

Principal medical provider (**most responsible physician, MRP)**
Directs your hospital care team.

Palliative care team Works with you for symptom management and support.

Social worker Provide resources for practical, social, and emotional needs as well as counselling prior to discharge.

Hospital homecare coordinator Will support coordinating your care needs at home including care plans and support services.

Hospital occupational therapist (OT) Will provide mobility guidance, plan supports, and advise you on the equipment needed for your daily routines at home (e.g., dressing, bathing, getting in and out of bed, etc.).

Clinical chaplain/ spiritual care provider Spiritual, religious, and emotional support.

Home Care Team

Palliative care team Oversee your care at home.

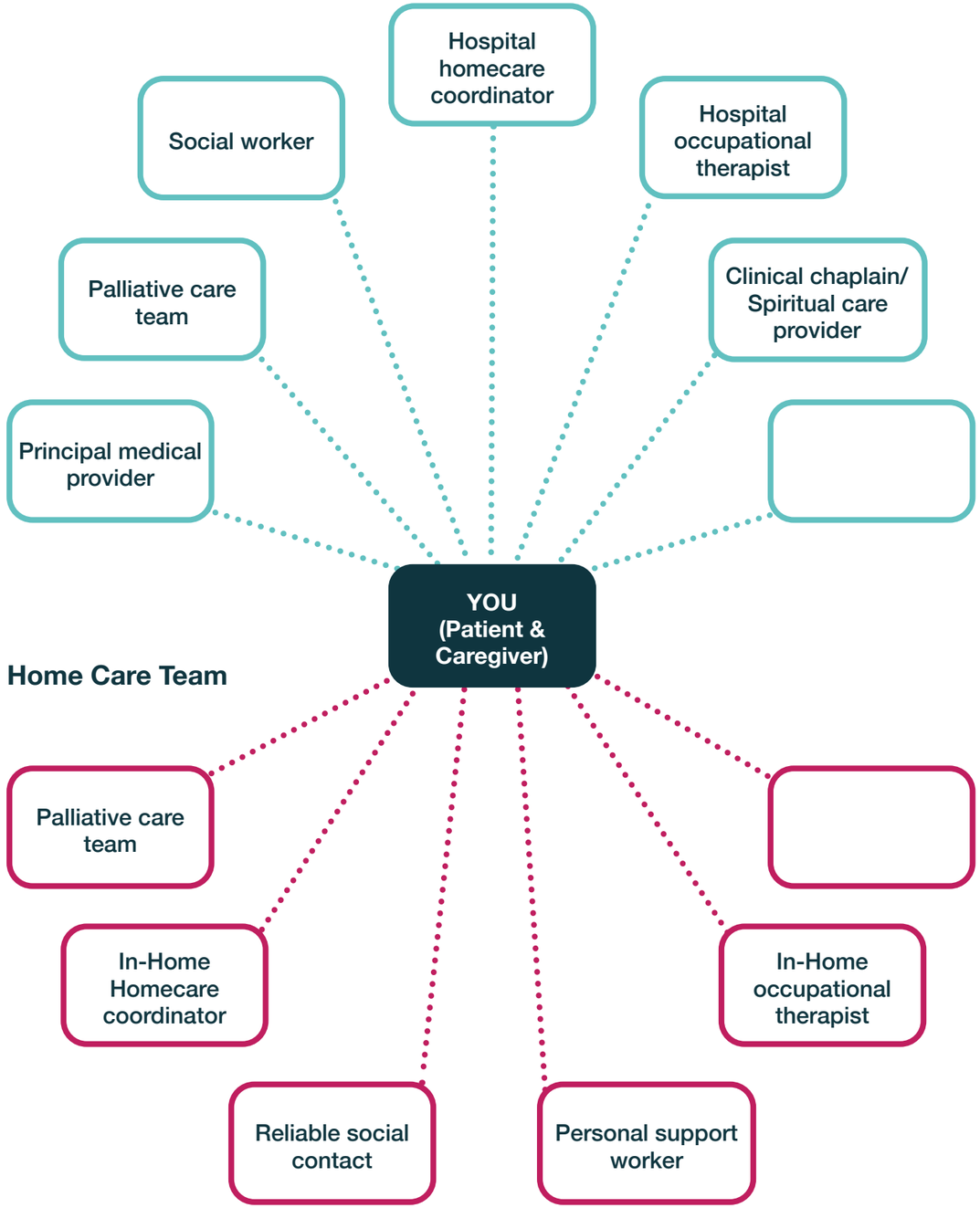
In-Home homecare coordinator Assist with care plans, support services, and coordinating care at home with other health care providers.

Reliable social contact Someone from your personal circle that you can rely on to speak to or ask for small favours and errands.

Personal support worker (PSW) Either government-funded or privately hired for assistance with daily care, mobility, routine activities and respite care.

In-Home occupational therapist (OT) May meet with you in your home to help advise on activities and equipment to help you in your daily routine (e.g., dressing, bathing, getting in and out of bed, etc.).

Hospital Care Team



Important contacts

Fill out this list of services to access the support you need once home.

Nursing Service
The nursing service is the first place to call for help during the transition home, and once at home.

☐ This is the name and number for my **Nursing Service.**

_____

_____

Homecare Coordinator
This person from Ontario Health atHome coordinates care needs at home, including personal support workers, and nurses. Workers are supported by the government, and there is no charge for their services. Due to staff shortages in the healthcare system, additional supports will need to be paid for with personal funds or private insurance.

Based on your needs, your homecare coordinator will connect with you in the first two weeks after getting home.

You can contact them 8 am to 8 pm, every day of the week.

Ontario Health atHome is the new name for government-funded home and community care services. Previous and now discontinued names for Ontario Health atHome include HCCSS, LHIN, and CCAC (Home and Community Care Support Services, Local Health Integration Network, and Community Care Access Centre).

☐ This is the phone number for my **Homecare Coordinator.**

_____

_____

Reliable Social Contact
This person is someone you can rely upon to call and speak with, or ask for small favours and errands. Be sure to call and confirm that they can help support you at home.

☐ This is the name and number for my **Reliable Social Contact.**

_____

_____

Personal Support Worker
The personal support worker will provide assistance with daily care, mobility, routine activities, and respite care. They can be government-funded, or privately hired.

☐ This is the phone number for my **Personal Support Worker Agency.**

_____

_____

Community Doctor/Nurse Practitioner
This person leads your palliative care team and will be your primary medical contact at home. They will contact you after your discharge based on your clinical needs. Call them as you need.

☐ This is the phone number for my **Community Doctor/Nurse Practitioner.**

_____

_____

☐ This is the **pharmacy** where I will pick up my prescriptions.

_____

_____

Questions to answer when reviewing this guide.

Use the next four pages to talk through some of the key questions patients and caregivers recommend asking while at the hospital. In some cases, other healthcare workers (like Occupational Therapists) can provide further information for these questions.

I'm nervous about leaving the hospital. How can I know we're ready?

Do I need any training or resources for moving in and out of bed, using the bathroom, etc. with less pain and effort?

Do I need a wheelchair, ramp, bathroom railings, or other home improvements? How will I pay for them?

What kinds of home-based healthcare workers are provided through the healthcare system? Are they free, or is there a cost?

What services can I rely upon to help me with my needs? Who in my social circle could be a good contact?

Are there other services that I may be eligible for or afford, that I should know about?

Getting home from the hospital

These checklist items and questions will help you get ready to go home.

My plan for getting home is to:

- ☐ I will travel by: _____
- ☐ I have confirmed the equipment I need
- ☐ I have a way to enter my home

Questions about travel

- Who will I contact for a ride home?
- How much will it cost? Can insurance help cover the cost?
- What will be the easiest way to enter my home?

Questions on travel equipment

- Do you need equipment to get home? Mobility devices? Walker?
- Who do you call for them? Are there ways costs can be covered?
- Do you need to arrange oxygen for traveling home? (If yes, go to QR code (p. 4)

Things to think about

Take some time by yourself to reflect on the questions below as you prepare to go home.

How are you physically different now going home than before you went to the hospital? How are you energy levels compared to before you were in the hospital? What are you unable to do now compared to when you went to the hospital?

Imagine a previously routine day. What changes will you need to make at home? How will you have to navigate your home differently now? Where might you need to adjust your home layout to give you enough space? How might you adjust your routine based on your energy level?

How can you make sure you still enjoy your favourite things at home? Plan visits from friends and family? Move seating to the bedroom? Bring art or photos to keep close by? Move your bed to a different floor? A set up for video-calls?

Caregiver support

Caring for a loved one at home is a meaningful commitment, and may require changes to your daily life and self care needs. While the patient is still at the hospital, we recommend the following:

1. **Care**
   Take some time for yourself while you have hospital care to support your loved one/patient. Consider a movie with friends, a quiet coffee, or a long walk.

2. **Review**
   Review this guidebook, and take some time to prepare for the upcoming journey.

3. **Support**
   Check and see about what supports are available to you while at the hospital, including support groups and workshops.

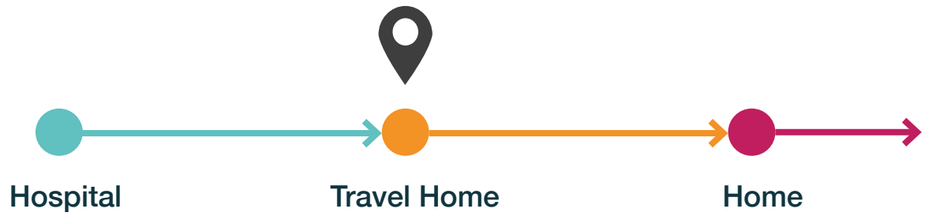
4. **Resources**
   Use the QR code below to access additional resources to help you prepare as a caregiver.

Available Resources

Hospice Palliative Care Ontario Caregiver Support Modules
Canadian Virtual Hospice Caregiver Modules
Canadian Hospice Palliative Care Association Caregiver Guide
The Ontario Caregiver Organization

https://www.isenberglab.com/hospital-to-home-resource-hub

Travel Home



Discharge and travelling home can feel like an overwhelming moment. You are ready for it.

Use the following checklists to:

- Help you review what to expect once you are home, and
- Double check that you have everything you need to go home.

Speaking with your doctor before discharge

When you speak with your doctor before discharge, review these questions about your symptoms and medications.

☐ These are some **potential symptoms** I may experience:

_____

_____

☐ **If my symptoms change or I feel worse**, before 911 **I will call:**

_____

_____

☐ **I know how to administer the medications** I am prescribed.

_____

_____

☐ This is the name, number, and address for **my pharmacy.**

_____

_____

☐ This is the number and address for the **my pharmacy for injectibles:**

_____

_____

☐ I have a way, or a person, to **pick up my medication**.

_____

_____

Double check: Before leaving the hospital

This is a final once-over checklist to confirm you've got your basics covered. Some of these items may not apply to you. If any box is unchecked, discuss with your healthcare team for support.

☐ I have a way to **travel home.** (I know who to contact for a ride. I know the cost of the trip and my insurance-covered options).

☐ I have **packed all my belongings.** (I have my health card, dentures, glasses, hearing aids, etc).

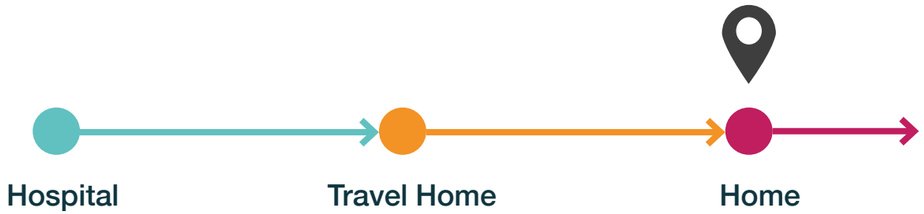
☐ I have **arranged for transportation home.** (I know what equipment I need and have a plan to get them).

☐ I have a way to **get into my house** and into the room where I will be staying. (I have a plan for using stairs, and going down narrow hallways, etc).

☐ I know where I want the **bed set up at home.** (I have a plan for settling into my house).

☐ I have **food** for when I get home. (I know what I'll eat at home. I have a plan for getting the immediate supplies I need for going home).

At Home



Every patient and caregiver described the challenge of the first 48 hours of adjusting to life at home. So know that you are not alone. The work done in previous sections has helped you best prepare for this transition.

As you meet with many new people and healthcare professionals, refer back to your Care Team Map (pg 9) and orient yourself to who they are, what services they provide and how that fits into your care plan.

This section also includes some helpful pieces of information as you settle into life at home, including contact sheets (pg 26-27) and medication tracking.

Medication and keeping track

These items and questions are based on what other patients and caregivers have found helpful for managing care at home.

☐ I have a way to **get my medication.**

☐ I know **how to administer my medication.**

Consider what might be the best way for you to track your medical needs and physical changes. Pick a system that works for you, your needs, and your preferences.

Some examples used by other patients and caregivers include:

- A whiteboard near the bed with all informationand meetings tracked
- A notebook always kept bedside
- A shared Google Doc to help multiple caregivers stay up-to-date

☐ I have a **system to track my medical status and needs.**

☐ I know **the equipment** I need to do well at home.

Enjoying your time at home

These items and questions are based on what other patients and caregivers have identified as valuable additions to their home experience.

Does my home layout allow for people to come and sit with me?
Can I schedule visits in advance?

☐ I have a way for **friends and family to visit and support me.**

Do I need any training or guidance on:

- moving in and out of bed
- using the bathroom

Are there home improvements, like a hospital bed or bathroom railings that could help?
If so, ask your homecare coordinator for a referral to an occupational therapist.

☐ I can **easily move around my home.**

Caregiver Support

Continue to find ways to have breaks and support for your caregivers. There are many resources available to you that can help provide small breaks and supports that fit your needs and circumstances.

Below is the QR code for the Hospital-to-Home Resource Hub.

Other caregivers who have gone through this transition also encouraged caregivers to begin learning about and preparing for death.

Available Resources

Hospice Palliative Care Ontario Caregiver Support Modules
Canadian Virtual Hospice Caregiver Modules
Canadian Hospice Palliative Care Association Caregiver Guide
The Ontario Caregiver Organization

https://www.isenberglab.com/hospital-to-home-resource-hub

Make copies of your most important phone numbers

Use the next set of pages to write out all the important phone numbers and emergency information you need. Place a copy on your fridge, a copy by your bedside table, and keep a third copy wherever makes the most sense for you.

Have friends and family also take a photo of the most important numbers to have a copy on their phones.

Nursing service _____

Phone number: _____

Homecare Coordinator _____

Phone number: _____

Personal support worker _____

Phone number: _____

Community doctor/nurse practitioner _____

Phone number: _____

Pharmacy _____

Phone number: _____

Reliable social contact _____

Phone number: _____

Nursing service _____

Phone number: _____

Homecare Coordinator _____

Phone number: _____

Personal support worker _____

Phone number: _____

Community doctor/nurse practitioner _____

Phone number: _____

Pharmacy _____

Phone number: _____

Reliable social contact _____

Phone number: _____

Nursing service _____

Phone number: _____

Homecare Coordinator _____

Phone number: _____

Personal support worker _____

Phone number: _____

Community doctor/nurse practitioner _____

Phone number: _____

Pharmacy _____

Phone number: _____

Reliable social contact _____

Phone number: _____

Acknowledgements
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