

From Admission to Home

A handbook for C3 Oncology patients

Patient Name: _____

An admission to C3 is usually to manage uncontrolled pain and symptoms related to cancer. Stays on C3 typically last less than 1 week.

Because of this, planning for discharge begins shortly after you arrive on the unit. “Discharge” is the time you leave the hospital and return home or go to another place to receive care.

You are an important member of the health care team and play an active role in managing your health. Please use this booklet to keep track of information about your care and any questions or concerns you may have.

The health care team will regularly review the booklet with you and answer your questions and concerns. The information in the booklet will help you manage your care when you are discharged from C3.

It is important that you and your family:

- Take part in your care:
 - Tell us about your values, care needs and goals. We want to make sure that the care you receive fits with your wishes.
 - Ask questions until you understand the information.
 - Practice activities and new skills while you are in the hospital.
 - Tell us about what you need to care for yourself at home.

- Tell us if you have any upcoming tests (such as a CT, MRI or ultrasound) that were booked **before** you were admitted to the hospital.

If these tests are to take place **during** your hospital stay, we will need to contact the booking clerk to change the date.

- Write down information so that you can refer to it. Included in this workbook is a section on ‘What I need to learn during my stay...’

It is important that you and the health care team:

- Establish shared goals together.
- Write the goals in this booklet so they are easy to refer to.

What are shared goals?

Shared goals are goals that are set together between you and the health care team. These goals occur through meaningful discussions. The intent of shared goals is for all members of the team and your family to work towards common aims while you are in hospital. They reflect what is important to you and provide a written plan of care for your C3 stay that is clear, understood and supported by all team members.

Recording my shared goals

Talk with the team about what you:

- 1) know of your illness so they can understand where you are coming from and help to determine your needs.
- 2) want to get out of this hospital stay.

As a team, determine what the shared goals will be.

Our shared goals are:

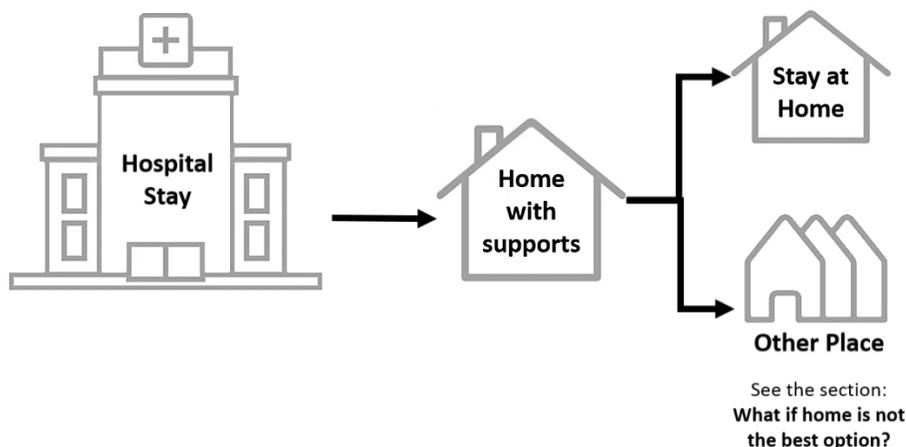
Date: _____

1	
2	
3	
4	

Home First: Putting patients at the center of their health care

Home First is a philosophy put forward by the Ministry of Health and Long-term Care. It is a shift in thinking which focuses on sending patients home first after an acute stay in hospital instead of waiting in the hospital for another place.

Home First provides patients with an appropriate level of care in the comfort of their own home. It includes home care services (such as nursing and personal support as well as access to special equipment), community support (such as adult day programs), and convalescent care beds.



When you go home with home care services, you have time to think about and understand all the options if additional care or placement is needed. Any decisions about major changes in lifestyle should ideally be made from home, not from hospital.

To read more about Home First, visit the Ministry of Health and Long-Term Care website at: <http://www.health.gov.on.ca>

Expected date of discharge

We will begin to talk with you and your family about going home in the first few days of your hospital stay. Starting early allows you and your family as much time as possible to prepare for going home. We will discuss when we think you will go home. We call that the “expected date of discharge”. This date may change. Write down when you expect to go home and update it as it changes.

My expected date of discharge is: _____

Repatriation - for patients who do not live in Hamilton

If you do not live in Hamilton, your health care team will still work from a “Home First Philosophy” to help you get home directly from hospital.

However, we may discuss a process called “Repatriation”. Repatriation is the term used to describe the process of transferring patients to a hospital or health care facility within their own community.

Repatriation occurs when patients from outside of Hamilton no longer need the specialized care of the Juravinski Hospital, but still need continued hospital care. To do this, the team will arrange for you to be transferred to your home hospital – the hospital in the city where you live.

You will be transferred to a hospital that is able to provide the care you need.

Repatriation does not change or cancel your follow-up appointments with your oncology team.

What if home is not the best option in the long term?

Sometimes home is not the safest or best option for a patient in the long term. However, when you are waiting for supportive care in another environment, you may still need to return home even for a short time.

Based on your current medical situation and the care you will likely need in the future, the health care team may discuss other options such as:

- **Rehabilitation (rehab):**
 - There are rehab programs at the Juravinski Hospital. Patients stay at these programs for up to 3 weeks, but can leave earlier if their goals are achieved.
 - There is a longer rehab program at St. Peter's called Restorative Care. This program is for patients who need a slower paced rehab.
- **Convalescent care:**
 - There are 3 places for Convalescent Care in Hamilton – St. Joseph's Villa, Dundurn Place and Shalom Village. When applying for Convalescent Care, patients will be placed where the first bed becomes available.
- **Retirement home:**
 - Retirement homes are paid for privately. Patients will return home to decide which home is right for them. You can get a list of retirement homes from the LHIN Care Coordinator.
- **Long-term care home (Nursing Home):**
 - Patients will return home to wait for a bed at long term care home. This process is managed by the LHIN (home care).
 - In some situations, patients can apply for a transitional care bed to wait for a long-term care bed. The LHIN will decide if a patient meets the criteria for a transitional care bed.

- **Hospice care:**
 - There are 2 hospices in Hamilton – Bob Kemp Hospice and Emmanuel House.
 - Patients will return home to wait for a hospice bed. Application can be completed from hospital or at home. Hospice applications are managed by the LHIN (home care).

- **Palliative Care at St. Peter’s Hospital**
 - Palliative care in hospital setting. The healthcare team includes physiotherapists, occupational therapists, a recreational therapist, social workers, dieticians, nurses and palliative care physicians.

What I need to learn during my stay...

1. Wounds, catheters, PICC lines, PORTs and drains

Sometimes you will go home with a wound (from surgery, an accident or illness), a line or a drain. Ask your health care team:

- What things should you watch for?
- How to care for it?
- Who should I call if I have a problem?
- Is anyone going to help me care for this?

My questions and notes about my wounds, lines and drains:

2. Medications

It is very important to take your medication correctly when you go home from the hospital. While you are in the hospital, it is a good time to review all of the medications you take with your health care team. Review the medications that have been prescribed by a doctor, those you have bought at the pharmacy, and vitamins, supplements and herbs you take.

Medication changes:

While you are in the hospital some of your medications may have changed. Ask your health care team if:

- Any medications have been stopped.
- Any doses of medications have been increased or decreased and why.
- Any medications started and why.

Make sure you understand the following about all of your medication, both the new medications and the ones you were on:

- Why you are taking the medication.
- When you should take the medication.
- Any important side effects you should watch for.
- Who to call if you experience those side effects.

Other medication concerns:

- Do you have any problems paying for your medications?
Please discuss with your health care team. There may be help to pay for some of the costs of your medications.
- Do you have problems knowing when to take your medications or remembering if you took them? If you do, most pharmacies will organize your medications in a bubble pack for no extra charge. You can ask the pharmacy to do this and/or ask your doctor to write an order for it on the prescription.

Do you have enough of your medications, including the ones you were on before you came to hospital, until your next doctor's appointment? If not, please make sure you ask the doctor to give you a prescription before you leave the hospital.

My questions and notes about medications:

3. Symptoms and management

Why was I admitted to C3? _____

What are my most common symptoms (such as pain, shortness of breath, constipation and fever)?

Symptom	What can I do when they occur?	When do I seek medical help?	Where should I go if I need help? (family doctor, JCC, RESSCU, or ED)*

RESSCU – Rapid Evaluation and Symptom Support Cancer Unit

ED – Emergency Department

*Contact numbers can be found at the back page of this handout.

My questions and notes about my symptoms:

4. Follow-up appointments and tests

You may be sent home with follow-up appointments and/or tests. This will be discussed with you on day of discharge.

My questions and notes about appointments and/or tests:

5. Home Care

If your health care team feels you need help after you go home, a LHIN* (home care) Care Co-ordinator will meet you to discuss a care plan at home that is best appropriate for you. Examples of care of home care include:

- Nursing
- Personal support such as bathing and getting dressed
- Physiotherapy
- Occupational therapy
- Speech-language therapy
- Social work
- Nutritional counselling
- Medical supplies and equipment
- Information about and referral to additional health and social services in your community

* Local Health Integrated Network, formerly CCAC

My questions and notes about home care:

Making sure the C3 team knows my wishes and values

Talking about goals of your care

We want to make sure that the care you receive fits with your wishes. To do this, early in your stay we need you to share information about yourself, your goals of care and planning for the future. This is necessary so that we can provide care that is right for you. It is especially important for patients who have been given difficult medical updates since arriving to hospital.

No matter what stage of health or wellness you are at, questions to think about are:

- What makes life meaningful for me?
- What is important to me as I think about the future?
- What do I want/not want in terms of treatment? Do I want everything done to prolong my life even if it is of reduced quality? What outcomes are unacceptable to me? What am I willing to sacrifice and not?
- What fears or worries do I have about the possibility of my health changing or the possibility of dying?
- What do I want for the end of my life whenever that time comes?

Talking about Advanced Care Planning

Having these discussions is a part of “Advanced Care Planning”. This can include appointing a Power of Attorney who would make decisions on your behalf if you are unable to make decisions for yourself, completing a Will that will be followed after you pass away, and talking to your loved ones about what your wishes are if you were to come to the end of your life.

We understand these discussions can be very hard and emotional. It is never too early to think about these questions and have your wishes known about advanced care planning.

We encourage you to talk with the social worker or another member of your team if you have questions about advanced care planning. We want to help provide the information you need to make decision that are right for you.

Do I have to make these decisions alone?

No. You may find it helpful to talk to others about your care wishes and to have them with you during the goals of care discussion so they are aware of and can support you in your decision making.

This may include:

- your spouse or partner
- other family members or friends or other people who are meaningful in your life
- someone in your faith group
- your health care team

If you would like more information about advanced care planning, please ask to speak with a social worker.

What is palliative care?

Palliative care is a way of providing health care that focuses on improving the quality of life for you and your family when you are faced with an illness that may not be cured. The aim of palliative care is to prevent and provide relief from symptoms, and address other matters, such as physical, spiritual, emotional, social, and practical problems that can happen when someone is experiencing a serious illness.

The team on C3 want to provide you with the best quality of care. In some situations, a specialized team called the Palliative Care Consult Team may provide expert advice on managing your pain and symptoms.

Palliative care:

- Helps you to feel as well as you can by managing your symptoms, such as pain, shortness of breath and fatigue and weakness.
- Helps you and your family to understand your illness, treatment choices, and how those choices might affect your health.
- Supports your right to make decisions about your health care which respects your wishes and choices.
- Supports the wishes of you and your family to be in the setting of your choice (home, hospice, hospital, long term care).
- May help you and your family avoid unnecessary hospital visits by helping you and your family to know what to expect in the future and have plans to address changes in your health.

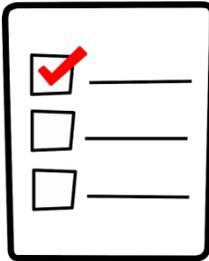
Resources

Go to the Hamilton Health Sciences, Patient Education website library www.hhsc.ca/pedl and search for the topics below:

- Welcome to C3
- Making Your Wishes Known – Goals of Care
- Palliative Care

Before you go home checklist

Check off when you can answer yes:



A graphic of a checklist box with three items. The first item has a red checkmark, and the other two have empty checkboxes.

- All of my (including my family's) questions have been answered
- I know the next steps in my health care
- I understand how to take my medications
- I have enough medication or prescriptions until my next doctor's appointment
- I know when my follow-up appointments are
- I know who to contact if I have problems when I am home

Contact numbers

When to call the JCC at 905-387-9495

Appointment change

If you need to change your appointment, call the JCC from Monday to Friday, between 9:00 am and 4:00 pm and press 1.

Urgent problems – Monday to Friday, from 9:00 am to 4:00 pm

If you have an urgent problem as listed below and need to speak with your doctor, call the JCC by 4:00 pm. Please have your chart number ready. Urgent problems are any changes in your condition, such as:

- fever of 38.0°C (100.0°F) or higher
- chills
- bleeding
- severe vomiting
- difficulty breathing
- pain

Urgent Care/RESSCU (Rapid Evaluation and Symptom Support Cancer Unit)

When you feel you cannot manage your symptoms, call your Primary Team for a referral before your symptoms get worse.

RESSCU hours: Monday to Friday 8:30 am to 6:00 pm.

The Nurse Practitioner is available from 9:00 am to 5:00 pm.