ADVANCE CARE PLANNING workbook

HUMBER RIVER HOSPITAL

Having a say in your healthcare.

think about it. **talk** about it. **share** it.

ADVANCE CARE PLANNING workbook

None of us know what tomorrow will bring, or can predict what might become of our health. But there is a way to ensure you have a say in healthcare decisions that lie ahead, should there come a time when you are unable to speak for yourself. It's called advance care planning.

What is *Advance Care Planning?*

Advance care planning is a way to help you think about, talk about and share your thoughts and wishes about your future healthcare. It gives you a "voice" in decision making and helps you determine who will communicate for you if you are unable to communicate for yourself. Advance Care Planning should be part of your conversations with your healthcare team.

This workbook is a guide to help you through the process of advance care planning. It includes a number of thought provoking questions to help you explore the values and beliefs that influence your health care decisions.

The workbook has a section with important details about terms relating to various health care treatments. And there are useful tips to consider as you develop and then share your advance care planning decisions with your family and those closest to you, as well as your health care team.

By making your wishes known, your caregivers won't be left wondering what you might have wanted or did not want.

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EVERYONE should have a say in their healthcare. Plan today to ensure that your wishes are known, no matter what the future holds for your family and your health.

There are several ways to make your future healthcare wishes known:

Talk to your family and trusted friends about your values and beliefs. Let them know what care you would be willing to accept or would refuse in various healthcare situations. Talking about the kind of care you do and do not want will help reduce any anxiety that your family and friends may feel. It will also give them the confidence to make decisions for you, if that should become necessary.

You can write an Advance Care Plan. This is a document explaining what you want to happen if you become ill and cannot communicate your wishes about treatment.

In Ontario, there is a document called a Power of Attorney for Personal Care that allows you to name a person(s) who will speak for you if you are unable to speak for yourself. This person is known as an Attorney for Personal Care or Substitute Decision Maker. The Power of Attorney for Personal Care document contains a special section where you can write your Advance Care Plan. Additional information is provided later in this Workbook on page 9.

Once you have completed your Advance Care Plan, you should meet with your physician at Humber River Hospital to discuss your Goals of Care.

It is important for you to communicate and update changes. Over time, your feelings might change about the care choices you've made during advance care planning. That's okay. Changes can be made any time as long as you are able to make health care decisions. Healthcare providers will also consult you directly if your health situation changes.

Who should consider advance care planning?

Everyone. You never know when you may face an unexpected event or illness and will be unable to make your preferences known. It is particularly important for seniors and those managing an existing disease or disability.

When should I consider advance care planning?

Now. It is important to take part in conversations about advance care planning before you become seriously ill. Planning will ensure that if an unexpected event occurs, your treatment wishes are known. This workbook has been created by Humber River Hospital to help guide you through this process.

imagine

1 **imagine** *that, without warning, you are in a serious car crash. You are in a hospital intensive care unit. You are no longer able to communicate with anyone. Your heartbeat and breathing can only continue with artificial life support. Despite the best medical treatment, your physicians believe it is unlikely you will return to your previous quality of life.*

2 **imagine** *your ability to make your own decisions is gone. You live at a residential care facility. You can feed yourself but you no longer know who you are, who your family members are, or what happens from one moment to the next. You will never regain your ability to communicate meaningfully with others. Your condition will likely become worse over time.*

3 **imagine** *you have a progressive chronic illness. Your health care team has told you that you may lose your ability to swallow and breathe on your own.*

THINK about your values & beliefs.

When you plan for your future healthcare, you need to think about your values and beliefs, as well as your personal goals. In order to prepare yourself for advance care planning conversations, write down your thoughts to the following questions:

What is most important to me about my physical or mental well-being?

EXAMPLES

- It is important for me to be able to communicate in some way, even if I cannot speak.
- It is important that my family be comforted.

What makes each day meaningful to me?

EXAMPLES

- Life has meaning when I communicate with my friends and loved ones.
- When I can practice my faith.

What beliefs or values do I think will help my family, trusted friends or health care providers know what is important to me?

EXAMPLES

- I would like to stay home as long as it is not too hard on my family or caregivers.
- Do everything possible to keep me alive until I can say goodbye to family who are coming to see me.

What are my wishes for organ and tissue donation when I die?

EXAMPLES

- I have signed a donor card which is in my wallet or I have registered with beadonor.ca.
- I do not wish to donate organ and/or tissue when I die.

When I think about death, what do I worry about?

EXAMPLES

- I worry that I will be in pain.
- I worry that my family will not know what to do.

When I am nearing death, are there things I would wish for (or would not wish for)?

EXAMPLES

- I would like music, prayer, religious or spiritual rituals/readings in my own language.
- I do not want music or flowers in my room.

When I am nearing death and cannot speak or be understood, are there things I would like my friends and family to know?

EXAMPLES

- I love you.
- I forgive you.

It is important to know that the choices you make now may not be ideal if you become very ill. Your healthcare team will consider your wishes, but will not offer you treatment that is of no benefit.

Write down how you feel about health care treatments. Definitions are found under the heading "Health Care Treatments" on the following page.

HEALTH CARE TREATMENTS

Cardiopulmonary resuscitation (CPR) refers to medical procedures used to try to restart a person's heart and breathing when the heart and/or lungs unexpectedly stop working. CPR can range from breathing and pumping on the chest to electric shocks that try to restart the heart and machines that breathe for the individual.

Dialysis is a medical procedure that cleans your blood when your kidneys no longer can.

A **feeding tube** is a way to feed someone who can no longer swallow food. It is a small plastic tube that carries liquid food. The tube is inserted through the nose, or directly into the stomach or intestines.

An **intensive care unit (ICU)/critical care unit (CCU)** is a unit in a hospital where people are critically ill and treated with the anticipation of recovery. Here, patients may be cared for by using a **ventilator** - a machine that helps people breathe when they cannot breathe on their own. A machine is attached to a tube that is placed down the windpipe. Alternatively, patients may be cared for by using **BiPAP**. This is a breathing machine that helps get more air into and out of the lungs. The machine delivers the air to the patient through a mask. Also, a patient in ICU/CCU may be given a **vasopressor** - a special intravenous medication to raise a low blood pressure.

An **intravenous line (IV)** is a way to give a person fluids or medicine. A hollow narrow tube, is placed in a vein in the hand, arm or another location.

A **tracheostomy** is a surgical procedure to create an opening into your windpipe through your neck.

A **transfusion** is when a person is given blood or blood products through an intravenous line.

For information relating to treatments and the roles of health care team members, contact the Patient & Family Resource Centre (PFRC) at Humber River Hospital pfrc@hrh.ca or online at www.hrh.ca/findhealthinformation

The physician gives you medical care to help manage your signs and symptoms.

The nurse helps with the delivery of your physical and medical care.

The social worker helps guide you and your family through the social, emotional and practical aspects of your illness.

The dietitian specializes in food and nutrition and works closely with the health care team to meet your nutritional needs.

The hospital chaplain is available to meet with you and your family as you reflect upon the spiritual questions related to your illness.

The bioethicist helps you make difficult choices by exploring your values, cultural and religious traditions. Legal and social considerations may also be reviewed.

The pharmacist is available to answer questions about medications, their benefits, side effects and instructions for usage.

The physiotherapist and the **occupational therapist** provide instruction related to maintaining the highest quality of life and level of independence that is possible.

The respiratory therapist specializes in activities related to breathing and mechanical support of breathing ie.: use of a ventilator or the BiPAP machine.

The speech language pathologist (SLP) specializes in managing swallowing difficulties to reduce your risk of choking. The SLP can also help you communicate to improve your quality of life.

TALK about it, with family or friends and with your healthcare team.

Discussing your treatment wishes with loved ones may be an uncomfortable conversation, but it will help reduce pressure and stress during an already challenging time.

The best people to talk with are your family members or trusted friends. The people with whom you choose to have these conversations should know you well.

Talking about your health and future healthcare may be hard. It may bring up questions, concerns and uncomfortable feelings. You do not have to talk about your decisions all at once. Give yourself time to make your decisions and to make sure your wishes are understood.

Remember, your health care team is an excellent source of information regarding your health and future health care choices. They can talk to you about what treatments may be beneficial or harmful to your health.

SHARE your plans. WRITE them down.

Filling out your Advance Care Plan form and discussing your Goals of Care ensures that your wishes are known to your loved ones and your health care team.

Writing an Advance Care Plan

What is an Advance Care Plan?

An Advance Care Plan is the document where you write your wishes about the healthcare and treatment you want to receive should you become unable to speak or otherwise communicate your wishes. In Ontario, anyone can write an Advance Care Plan. There is a form on pages 13 and 14 where you may document your wishes. You may choose instead to create your own plan or use a form provided by a legal professional or use the Government of Ontario Power of Attorney Kit. Or you may choose to make a recording or video of your wishes.

What is a Substitute Decision Maker?

In addition to writing an Advance Care Plan, you should also name a Substitute Decision Maker to speak for you when you are unable to speak for yourself. The Substitute Decisions Act, 1992, allows you to give another person(s), called a Substitute Decision Maker, the power to make healthcare decisions for you, should you ever be unable to make them yourself.

How do I decide on my Substitute Decision Maker?

You should consider the person who you feel is best able and willing to carry out your wishes, if you are unable to speak for yourself. Your parents, spouse, children and their spouses, or family friends could all serve as a Substitute Decision Maker. You can have more than one Substitute Decision Maker, in the event one cannot be reached in case of emergency. The Substitute Decision Makers can be listed in order, and you can decide if they must reach a consensus, or can act alone.

What is a Power of Attorney for Personal Care Document?

The Government of Ontario has made available a document called a Power of Attorney for Personal Care. You can use this document to name a person(s) to be your Substitute Decision Maker (Attorney for Personal Care). There is also space in the document to include your Advance Care Plan should you wish to write it there. Contact the Office of the Public Guardian and Trustee of the Ontario Ministry of the Attorney General for instructions in completing this document by calling 1-800-366-0335 or on line at *www.attorneygeneral.jus.gov.on.ca* (click on "Public Guardian and Trustee"). You may also consult with your lawyer to complete a Power of Attorney document.

I have someone who is my Continuing Power of Attorney for Property and helps me with my banking. Isn't that the same thing?

No, a Continuing Power of Attorney for Property is not the same thing as being a Substitute Decision Maker and does not enable the person to make health care decisions on your behalf. A Continuing Power of Attorney for Property addresses financial issues only.

Who can help me complete my Advance Care Plan?

It is strongly recommended you talk to your physician, nurse and health care team before completing an Advance Care Plan. This will ensure your instructions are clear and easily understood by those who provide treatment.

Where should I keep my Advance Care Plan?

Make several copies of your Advance Care Plan. Keep two or three copies at home. If you have an Emergency Response information kit, place a copy in there so that emergency workers can find it. Give a copy to your Substitute Decision Maker and your family physician. Bring a copy with you when being admitted to hospital.

How often should I change the content of my Advance Care Plan?

Review the content of your Advance Care Plan once a year, or when your health condition changes. This makes sure it is still what you want now and in the future. Your health care provider may suggest changes to be considered. Following any changes, destroy the original/copies of the previous Advance Care Plan and inform the Substitute Decision Maker.

Is this legally binding?

The wishes you express in your Advance Care Plan are binding on your Substitute Decision Maker and health care providers (unless your wishes are not consistent with accepted health care practices) and will be honoured by the courts.

Preparing for a "Goals of Care" Discussion

Your health care team will approach you and, if you wish, your family and trusted friends, to talk about your goals of care and future health care treatment. The following are times when these discussions may occur:

- At your request or the request of your Substitute Decision Maker
- When your condition changes significantly
- When you are admitted to hospital

They will talk to you about your health, your current condition, the care that would and would not help you and what you can expect from that care and treatment.

When having these discussions with your healthcare team, you need to:

- Provide a copy of your Advance Care Plan if you have prepared one. Your Advance Care Plan will guide and inform your advance care planning conversations with your health care team.
- Be sure to ask questions about anything that will help you make your decisions.
- Take time to think about your choices. You may need to have several discussions before coming to a decision.

Your health care team will work with you to decide which of the following goals of care best describe your wishes for your future healthcare.

goals of care

Cardiopulmonary Resuscitation

Goals of care are directed at your receiving any appropriate investigations/interventions that can be offered to treat and control your condition including attempted resuscitation (trying to restart the heart after it has stopped beating).

Medical Care

Goals of care are directed at your receiving any appropriate investigations/interventions that can be offered to treat and control your condition **excluding** attempted resuscitation (trying to restart the heart after it has stopped beating) and **excluding** the option of intensive care/critical care unit admission.

Comfort Care

Goals of care are directed at your receiving interventions which are directed at maximal comfort, symptom control and maintenance of quality of life **excluding** attempted resuscitation (trying to restart the heart after it has stopped beating).

You can also include any specific instructions or wishes you feel are important for your health care team to know.

At Humber River Hospital, once you and your health care team have agreed upon your goals of care, the physician will enter these goals of care into your computerized chart. An example of Goals of Care Orders is included on the opposite page.

Remember, you can request changes to your goals of care at any time. Simply tell your health care team you want to have further discussions about your goals of care. Your health care team will also review your goals of care whenever your condition significantly changes.

HUMBER RIVER HOSPITAL

All Programs

Goals of Care Order

Addressograph

NOTE: BOXES MUST BE CHECKED ☑ TO BE EFFECTIVE

Is there an existing Health Care Directive? ☐ Yes ☐ No

Cardiopulmonary Resuscitation

Patient will receive any appropriate investigations/interventions that can be offered including:

☐ Full resuscitation and treatment

or

Only the following interventions will be provided (check all that apply):

☐ chest compressions ☐ intubation/ventilation
☐ defibrillation ☐ vasopressors
☐ BiPAP

☐ **Medical Care**

Patient will receive any appropriate investigations/interventions that can be offered **excluding** attempted resuscitation and **excluding** the option of Critical Care Unit admission.

☐ **Comfort Care**

Patient will receive interventions which are directed at maximal comfort and symptom control and maintenance of quality of life **excluding** attempted resuscitation.

Specific Instructions: Document details of the patient specific instructions or wishes and/or details of discussion with the individuals indicated below. (Refer to date/time of Progress Note entry if more space required.)

_____

_____

_____

Indicate all individuals who participated in Goals of Care discussion(s):

☐ Patient Print name: _____
☐ Substitute Decision Maker Print name: _____
☐ Family Member(s) Print name(s): _____
☐ Health Care Provider(s) Print name(s): _____

Physician's Name (Print)	Physician's Signature	Time	Date (day/month/year)

Transcribing Nurse's Name (Print)	Transcribing Nurse's Signature	Time	Date (day/month/year)

☐ Telephone Order

Review: The Goals of Care were reviewed with the patient and /or Substitute Decision Maker and no change to the form is required

Physician's Name (Print)	Physician's Signature	Time	Date (day/month/year)

Physician's Name (Print)	Physician's Signature	Time	Date (day/month/year)

If the review results in any changes to the patient's Goals of Care, a new form must be completed. The Physician shall draw a line diagonally across this form and insert the time, date, signature and the words "See new order form". This form shall be filed immediately behind the new Goals of Care Order form in the chart's Advance Care Plans tab.

PROVIDE COPY OF COMPLETED FORM TO PATIENT OR SUBSTITUTE DECISION MAKER

ADVANCE CARE PLANNING checklist

Complete this checklist to ensure you have included these important steps in your advance care planning.

think about it.

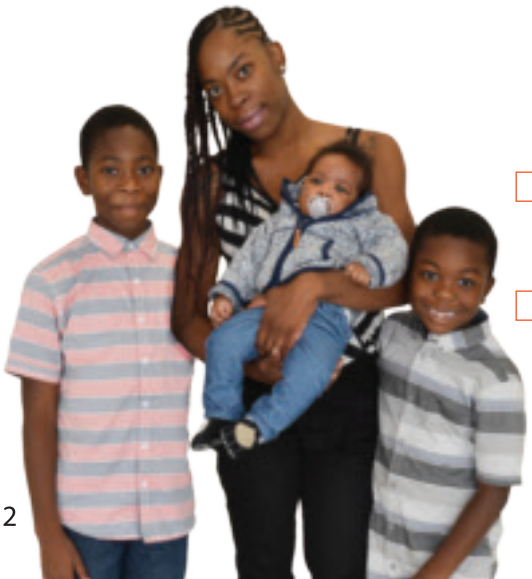
- ☐ I have thought about my values, beliefs and personal goals as I plan for my future healthcare.
- ☐ I have written down my thoughts to the questions on page 5 in the workbook.
- ☐ I have written down my thoughts about the health care treatments on page 6.

talk about it.

- ☐ I have discussed my health care treatment wishes with my family members and/or trusted friends.
- ☐ I have discussed my health care treatment wishes with my Substitute Decision Maker.
- ☐ I have discussed my health care treatment wishes with my physician(s) and other members of the health care team.

share it.

- ☐ I have completed an Advance Care Plan.
- ☐ I have made copies of my Advance Care Plan to share with others including:
  - two or three copies kept at home
  - one or more copies for family members
  - one copy for my Substitute Decision Maker
  - one copy for my family physician
  - one copy for my physician and the health care team at my hospital.
- ☐ For Humber River Hospital patients, I have met with my physician to complete my Goals of Care.
- ☐ For Humber River Hospital patients, if requested, I have received a copy of the Goals of Care Orders. I will bring them with me when I come to the hospital and I will share them with family/trusted friends, my Substitute Decision Maker and my family physician.



My Advance Care Plan

You may write your wishes here for your future healthcare. This will help guide your Substitute Decision Maker and family, should you be unable to speak or otherwise communicate your wishes.

First Name: Last Name:

Date of Birth:

Address:

Telephone Number: Cell Phone Number:

Email Address:

I have discussed my wishes for future healthcare with my Substitute Decision Maker, who is identified in a separate legal document, and may be contacted as follows:

Name: Relationship:

Telephone Number: Mobile Number:

Email Address:

I have also discussed my wishes with the following people:

Name	Relationship	Contact Information

Here are my wishes for care:

My other planning documents:

In addition to this Advance Care Plan, I have also completed the following documents:

- ☐ Power of Attorney for Personal Care — Location: _____
- ☐ Continuing Power of Attorney for Property — Location: _____
- ☐ Others i.e.: organ donation, specific bequest, etc.

  Name of Document: _____ Location: _____

Resources to Assist with Advance Care Planning

Patient & Family Resource Centre (PFRC), Humber River Hospital

Telephone Number: (416) 242-1000 Ext. 81200
Fax Number: (416) 242-1047
Website Address: **www.hrh.ca/findhealthinformation**
Email Address: pfrc@hrh.ca
Hours: Monday - Friday, 8:00 a.m. - 7:00 p.m.
Location: Level 0 in front of the Food Court

For electronic, print and audiovisual collection on health and wellness matters, contact the Patient & Family Resource Centre at Humber River Hospital. The PFRC will provide information in a language that you can understand. As well, the PFRC can connect you to community resources, including those listed below.

Advocacy Centre for the Elderly (ACE)

Telephone Number: (416) 598-2656 • Toll-Free 1-855-598-2656
Website Address: **www.advocacycentreelderly.org**

Alzheimer Society of Ontario (ASO)

Telephone Number: (416) 967-5900 • Toll-Free 1-800-879-4226 (in Ontario only)
Website Address: **www.alzheimer.ca**

Office of the Public Guardian and Trustee

Telephone Number: Toronto (416) 314-2800 • Toll-Free 1-800-366-0335
Website Address: **www.attorneygeneral.jus.gov.on.ca** *(Click on "Public Guardian and Trustee")*

Speak Up

Website Address: **www.advancecareplanning.ca**

Cardiopulmonary Resuscitation (CPR) Decision Aids

Website Address: **www.advancecareplanning.ca/resource/cpr-decision-aids/**

Trillium Gift of Life Network

Telephone Number: Toronto (416) 363-4001 • Toll-Free 1-800-263-2833
Website Address: **www.giftoflife.on.ca**

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SPECIAL THANKS TO:
Winnipeg Regional Health Authority
Alberta Health Services, Calgary Zone
Fraser Health

www.hrh.ca