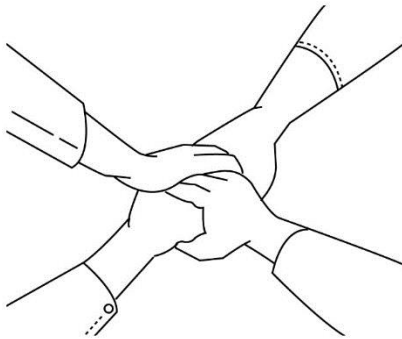


Making your wishes known

Goals of care

Making decisions about your care when facing a serious health condition



At Hamilton Health Sciences, we want to make sure that the care you receive fits with your wishes. In order to do that, we want to understand your goals of care. Goals of care are decisions about the care you want now or in the near future and about where you want to have that care. They are based on your understanding of your present health condition, options available for treatment, and benefits and risks of those treatments.

These decisions are made by you or, if you are not able, your substitute decision maker (SDM).

The information in this booklet can help you:

- Make difficult decisions that you or your family may experience about the goals of your care.
- Understand how your health care team can help.

Many patients who are admitted to hospital have an advanced illness. Often admission to hospital is a sign that there has been a change in your health. The team may be concerned that there is a chance that your heart may stop during this admission or in the near future.

It can be upsetting to think about the end of our life. Technological and medical advancements can make it seem like we can fix any health problem you might have, however everyone will face the end of their life.

Even though most of us would prefer to think that we will be well until we die quickly surrounded by our family, most people will spend some time in poor health before they die. Thinking about the care we might want at end of life can be easier if you are able to do this at a time when you are well and it is not a crisis.

Meet with your health care team

The health care team may include doctors, specialists, nurses, social workers, physiotherapist, occupational therapist or chaplains.

They will meet with you and your family to discuss:

- your health,
- what to expect in the future, and
- the next steps in your care.

The health care team will support you and your loved ones to make decisions about your care. It is important that you ask them any questions you may have.

It is also important that you ask those who may have to make decisions on your behalf to come with you to meetings. This will help them have a good understanding of your decisions that are discussed with your health care team.

Understand your health

What is your understanding of your illness now and how that illness will change or progress over time?

Think about:

- How long have you had the illness?
- Has your ability to care for yourself gotten more difficult recently?
- Have your trips to the hospital or “crisis” in your health become more frequent and closer together?
- What have your doctors told you about what to expect in the future with your illness?
- What are your treatment options?

Think about what is right for you

Decisions about your care should reflect your personal values and respect your beliefs about what is important.

You may want to consider:

- What makes life meaningful? What would a good day look like?
- Do I want everything done to prolong my life even if I do not have a good quality of life? What outcomes are unacceptable to you? What are you willing to sacrifice and not?
- Do I have cultural or religious values that influence the decisions made about my care?
- What fears or worries do you I have about the possibility of my health changing or the possibility of dying?
- Do I have questions or concerns about the dying process? What would be important to me if I was nearing death?

Examples of patient wishes:

- No matter what happens, I want us to stay at home, no more hospitals.
- I'm worried about being a burden on my family.
- What I fear most is pain and not being able to breath.
- I would like to be alert and aware as long as possible.
- I just hope I have time to finish my memoirs.
- If I live to see my daughter married, I'll die happy.
- When death comes, I want my family around me.
- I don't want my wife to have to quit her job to take care of me.
- My wish is never to be hooked up to machines.
- It's important to me to live as long as possible, and to go out fighting.

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

Learn about the different medical procedures that can be offered

Some procedures may improve your quality of life; others may only prolong life/delay dying.

Death delaying/life prolonging medical procedures can include many different things, such as CardioPulmonary Resuscitation (CPR), ventilation (machine that breathes for you), tube feeds or Total Parental Nutrition (TPN) feeds, dialysis, chemotherapy, radiation, blood transfusions, and many others.

Ask if the treatments proposed will:

- reverse or “fix” the illness
- improve your quality of life
- delay dying

Questions to consider:

- Would I want _____ if it prolonged my dying by a few hours or days only?
- Would I want _____ if I would not be able to return to doing the things that are important to me, such as visiting with family and friends, participating in my hobbies, being independent in caring for myself?
- Would I want _____ if it increased my pain and suffering at the end of life?

Remember, even if you decide against specific medical interventions there are still many things we can do to help you to be comfortable in your last days and hours of life.

What is CPR?

CPR is used to try to restart someone's heart and/or breathing after it has stopped. CPR involves someone placing their hands on the chest and pushing down over and over again, and giving oxygen/air through the person's mouth. This helps to pump oxygen throughout the body until the team is able to restart the heart, if that is possible. Other things that can happen are:

- Applying an electrical shock over the heart (cardiac defibrillation) to try to restart the heart
- Putting a breathing tube in and connecting to a machine called a ventilator
- Transferring the patient to the ICU/CCU if the team is able to restart the heart

How can I know if CPR will work for me or my family member?

There are many factors that influence whether CPR might succeed including your health, age, reason your heart has stopped, and whether there is someone right there who can begin CPR when the heart stops beating.

CPR was originally developed to help people whose heart stopped suddenly and unexpectedly, such as with drowning or a heart attack. These people were often healthy before suffering an unexpected event.

Its use has since been expanded to anyone whose heart stops. People who have serious illness often have a decline in their health over time. The heart stops because the person is actually dying of their illness and is expected as a natural result of the illness. CPR is almost always unsuccessful in these cases.

Less than 1 out of 5 people who are given CPR survive and are well enough to leave the hospital. The rate is much lower for people with serious illness, such as cancer, advanced lung disease, heart failure, end stage kidney failure, dementia and people over 75 years of age.

What are the outcomes of CPR?

Like any medical procedure, there are risks associated with CPR. Some risks are associated with the procedure itself, such as bruised or broken ribs and collapsed lungs. Other problems are a result of the loss of oxygen to the brain while the heart is stopped, such as difficulty with speech, memory, attention, and ability to take care of yourself.

Many patients who survive CPR are not able to function as well as they did before CPR.

Only one out of 4 people who survive CPR are able to go home and live independently. This includes people who were well before suffering a cardiac arrest. Half of the people who survive CPR will need so much help to care for themselves that they will not be able to return home.

In the rare cases when the team is able to restart the heart in a patient with advanced illness, the person may be in a coma and dependent on the ventilator to breathe. They still have the illness that caused their heart to stop. After days or weeks, when it is clear the person will not wake up or be able to breathe on their own, their family is then faced with the difficult decision to turn off the ventilator and allow the person to die.

What happens if I decide against having CPR at the end of life?

Many people worry that if they decide against having CPR that the health care team will “give up” on them. This is not true. The decision to have CPR only influences what happens when your heart stops and you stop breathing. Many people who have decided they would not want CPR are still receiving treatment for their disease.

Decide who will be your substitute decision maker

What is the role of a Substitute Decision Maker (SDM)?

Sometimes people who are ill become unable to make health care decisions for themselves. If that happens, your Substitute Decision Maker (SDM) or Power of Attorney (POA) for personal care may be needed to make decisions about your health care. It is important that your SDM or POA understands your wishes and values. Talk with him or her about your views.

What are the requirements to be an SDM?

To provide consent on behalf of an incapable patient, the SDM or POA must be:

- capable with respect to the treatment proposed
- at least 16 years old, unless he/she is the incapable patient's parent
- not prohibited by court order or separation agreement from having access to the patient or decision-making power on behalf of the patient
- willing and available to take on the responsibility for giving or refusing consent.

Meaning of "available" – a person is available if it is possible, within a time that is reasonable in the circumstances, to communicate with the person and obtain a consent or refusal. (Health Care Consent Act 1996, c. 2, Sched. A, s. 20 (11)).

What is the difference between a SDM and POA for personal care?

A POA is a legal document which authorizes a person to act on your behalf for decisions about your personal care, should you become incapable. Not everyone has a POA.

However, everyone has a substitute decision maker. If there is not a court appointed SDM, and the patient does not have a POA for personal care, then an SDM is determined using a prescribed ranking order as listed below:

- a legally appointed guardian
- the person named in a POA for Personal Care (not POA for Property)
- a representative appointed by the Consent and Capacity Board
- a spouse or partner
- a child or parent
- a parent with right of access only
- a brother or sister
- any other relative by blood or marriage
- a Public Guardian and Trustee

Personal care decisions include decisions about your health care and medical treatment, diet, housing, clothing, hygiene and safety.

Please ask your health care provider for the patient education material on "Making decisions for Others – Role of the Substitute Decision Maker" if you have further question about this role.

Talk to your family and SDM about your wishes

It is important that your SDM understand what you want and don't want for your health so that they can share this with the health care team if they need to step in and talk for you.

For more information

- Advance Care Planning Workbook
 - <http://www.makingmywishesknown.ca/>
- For more information about making decisions about end of life care and the role of a Substitute Decision Maker, talk to a member of your health care team, and also ask for a copy of the Hamilton Health Sciences educational pamphlet:
 - Making Decisions for Others – Your Role as a Substitute Decision Maker
- For more information about palliative care and resources in the region ask for a copy of the Hamilton Health Sciences educational pamphlet:
 - Palliative Care at Hamilton Health Sciences and surrounding communities
- Powers of Attorney Kit:
 - Allows you to name powers of attorney for personal care and property
 - <https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/poa.pdf>
- For information about medical assistance in dying, talk to a member of your health care team, and also ask for a copy of the Hamilton Health Sciences educational pamphlet:
 - Medical Assistance in Dying – FAQ for Patients and Families
- Health Care Consent Act of Ontario and the Substitute Decisions Act of Ontario, visit the Consent and Capacity Board website :
www.ccboard.on.ca

