A RESOURCE FOR ALBERTANS

Comfort, Hopes and Wishes

……

Making Difficult Health Care Decisions

Provincial Health Ethics Network

The Provincial Health Ethics Network (PHEN) of Alberta is a non-profit organization that provides resources on addressing ethical issues related to health. PHEN does not advocate for or take positions on particular ethical issues; its role is to facilitate thoughtful, informed and reasoned ethical decision-making from all perspectives. PHEN is funded primarily by Alberta Health Services.

Provincial Health Ethics Network
507, 10240 – 124 Street
Edmonton, Alberta T5N 3W6

Phone 780-447-1180 1-800-472-4066
Email info@phen.ab.ca
Web www.phen.ab.ca

This publication was made possible by the generous support of

The Jack McLeod Memorial Fund

With thanks also for the contribution of the Alberta Cancer Board

Contributing Authors

This resource was realized largely through the volunteer efforts of a wonderful group of individuals who generously donated their time, energies and extensive expertise. The Provincial Health Ethics Network (PHEN), as the coordinating body for this project, acknowledges with deep gratitude the significant time and energy donated by the following members of the Alberta Collaborative Initiative on Decision-Making at the End of Life, without whom this project would not have been possible.

Debra Allen	College and Association of Registered Nurses of Alberta
Brenda Ashman	Medicine Hat Regional Hospital
Tracey Bailey	Health Law Institute, University of Alberta
Carol Barwick	Hospice Calgary
Vivian Collacutt	Community Cancer Support Network, Alberta Cancer Board
Brian Farewell	Regional Clinical Ethics Service, Calgary Health Region
Dr. Nancy C. Goddard	Department of Nursing, Red Deer College
Gary Goldsand	Clinical Ethics, Royal Alexandra Hospital
Sharon Hovey	Human Organ Procurement and Exchange Program, Southern Alberta
Christine Kainz	Human Organ Procurement and Exchange Program, Southern Alberta
Karin Kellogg	Health Law Institute, University of Alberta
Dr. Brendan Leier	Clinical Ethics, University of Alberta & Stollery Children's Hospitals
Dr. Kevin Levere	Pediatric Palliative Care, Alberta Children's Hospital
Margaret Lidstone	Human Organ Procurement and Exchange Program, Northern Alberta
Linda Read Paul	Palliative & Hospice Care Services, Calgary Health Region
Nina Preto	W. Maurice Young Centre for Applied Ethics, University of British Colombia
Dr. Barbara Russell	Clinical Ethics, University of Alberta & Stollery Children's Hospitals
Dr. Victoria Seavilleklein	Provincial Health Ethics Network
Dr. Sharron Spicer	Pediatric Palliative and Respite Care, Alberta Children's Hospital
Jane Steblecki	Health Law Institute, University of Alberta
Colleen Torgunrud	Northern Alberta Renal Program, Capital Health
Aydan G. Dunnigan-Vickruck	Office of the Public Guardian, Government of Alberta
Dr. Eric Wasylenko	Regional Clinical Ethics Service, Calgary Health Region
Loretta Young	Southern Alberta Huntington Disease Resource Centre

Special thanks also to the following individuals for their support throughout this project:

Dr. Paul Byrne	John Dossetor Health Ethics Centre & Stollery Children's Hospital
Rev. Dr. D. Neil Elford	Supportive Care Services, Royal Alexandra Hospital
Dawn Friesen	Population Health Strategies, Alberta Health and Wellness
Dennie Hycha	Regional Palliative Care Program, Capital Health

Table of Contents

Introduction

Serious illness or injury can cause great anxiety and uncertainty for both individuals and their families. In addition to the emotional distress that often accompanies poor health, there are often many important and difficult health care decisions to be made.

This document is meant to help guide decision-making by giving clear information about medical treatments and ethical issues that may arise in this difficult time. To help achieve this purpose, any terms that are harder to understand are underlined the first time they appear in each chapter and are defined in the Glossary at the end of the booklet.

This booklet may be used during a crisis or in advance of one, to help start discussions with loved ones about future health care planning. It may be a resource for individuals facing their own health care decisions or who are in the position of making difficult decisions for family members or others.

This document is not meant to replace conversations that you may have with health care providers, family members, friends, spiritual care advisors, or other trusted individuals. Instead, it is meant to offer information and help to support these important conversations. It is our hope that the information given here will provide a good place to start and will help to identify any additional questions that you may wish to ask.

In the process, we hope that this booklet will help to ease the burden of decision-making and provide comfort in the knowledge that decisions are being made in keeping with your wishes or the wishes of your loved one.

The information contained in this document is not legal advice. The details provided here may change over time and are not meant to replace or override information you may receive from medical and/or legal professionals.

PART I

Planning Ahead

In this part, we discuss ways of thinking ahead about your health care wishes and sharing them with friends and family.

Chapter 1:
Making Choices for the Future

Chapter 2:
Relevant Legal Documents

Chapter 1:

Making Choices for the Future

Health is important to all of us, and medical interventions can have a big impact on our lives. This is why patients and long-term care residents are usually given the chance to agree to or refuse treatments or interventions that are offered. However, sometimes we will be too sick to make these decisions for ourselves. In these situations, it’s very important to have thought in advance about what is important to us in life and about what sorts of treatment we might like to have.

Thinking ahead about our wishes, and talking about them with family and friends, can help to make sure that we are treated how we would want. It can also help to guide the person who may be asked to make decisions for us, namely a substitute decision-maker.

What is advance care planning?

Advance care planning is the process of thinking about your wishes for your future health care and discussing these with friends and family. This can also include discussion about what your goals are in life and what is important to you (what you value). It can also include your feelings about possible medical treatments.

Often these wishes are written down. One of the documents that may be used to record advance care planning information in Alberta is called a personal directive. For more information about planning a personal directive, see Chapter 2.

Advance care planning is usually a process that happens between you and the people you are close to. However, as advance care planning becomes more common in health care, one of your health care providers might start a conversation about it with you and your family. The purpose of this discussion is to make sure that your care plan is clear, that it is recorded for when it is needed, and that it is followed in a thoughtful and respectful way.

→ Advance care planning is important because you don't know when you might suddenly become ill or injured and not be able to make your own decisions.

Why is it important to plan ahead?

Advance care planning is especially important for the elderly and for people who have a terminal illness. Even if you are able to make your own decisions, dealing with a serious illness or injury can be very stressful. As a result, it might be easier for you – and your loved ones – if you have this discussion earlier, when you are well.

Advance care planning is especially important for the elderly and for people who have a terminal illness. Serious illnesses are often unpredictable, so no one knows when the sick person may lose capacity (the ability to make decisions for themselves) or when care plans and goals might change.

Having a long illness may make it possible to predict what kinds of decisions might need to be made. This means that you can ask for additional medical information, such as what the illness will look like in the future. Having conversations about these issues can help to make sure that everyone on the care team is working toward the same care goals and reduce the chance that you or your loved one will be given too much or too little treatment according to these goals.

What sorts of things should I think about?

It can be hard to know where to start when thinking about decision-making in the event of a serious illness or injury. Whether you are planning for yourself or making decisions for someone else, it might be helpful to think about the following sorts of questions:

- Which relationships are important to you?
- Who do you trust to speak on your behalf if you can't speak for yourself?
- How do you normally make important decisions? Who do you normally go to for support?
- What values guide you in making important decisions, for example, about pain and suffering, the value/sanctity of life?
- What are your religious, cultural or spiritual beliefs?
- What are your hopes or fears about various medical treatments?
- What types of treatment would you consider having in certain circumstances?
- What types of treatment would you not consider having in certain circumstances?
- What do you expect the final phase of life to be like?
- Which aspects of life do you value most?
- Which aspects of life would you be willing to give up and still want to go on living?
- Which aspects of life would you miss most if they were gone?

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 2:

Relevant Legal Documents

In our society, we believe that it's important for people to be able to make their own health care, and other, decisions. As a result, there are various legal documents that protect these rights to decision-making, even if a person loses the capacity to make these decisions. Personal directives, supported decision-making, co-decision-making, specific decision-making, and guardianship orders govern personal decisions, including health care decisions, and make sure that decisions are made in keeping with our wishes, values, and preferences, and/or in our best interests.

Enduring powers of attorney and trusteeship orders govern financial decisions, and similarly make sure that decisions are made in keeping with our wishes, values, and preferences, and/or in our best interests. Finally, wills allow capable people to leave behind instructions that they would like carried out after they have died.

What is a personal directive?

A personal directive (often called an advance directive outside of Alberta) is a document that helps to represent your wishes about various personal matters, including health care. If you lose capacity to make these decisions yourself, this document will be used to guide personal care and treatment decisions for you. (For more about capacity, see Chapter 3.)

A personal directive can be helpful because it lets health care providers know what your wishes are, or who can best represent your wishes, at a time when you can't tell them directly.

With a personal directive, you can do *either* or *both* of the following:

- Name a person or persons (agent(s)) whom you trust to make health care or personal care decisions for you. If you also write down health care preferences, your agent(s) will help to make sure that your preferences are followed.
- Write down your health care preferences. These instructions might be quite specific about what personal care or treatments you may or may not want in certain situations.

→ A personal directive doesn't need a lawyer's involvement. However, there are a few strict rules about how this document must be prepared and witnessed.

In your personal directive, it is also possible to name someone that you want to perform your capacity assessment, if your capacity is in doubt. This person could be your agent or someone else that you trust; they will have to make the assessment in consultation with a medical doctor or psychologist. You can also name anyone whom you would like to be told if your personal directive comes into effect.

Does a personal directive have to be written by a lawyer?

No. Anyone who is 18 years or older and understands the relevant information about a personal directive and its effect can make one in Alberta. However, there are a few strict rules that must be followed to make sure that the document is valid.

To be legally valid, a personal directive must be:

- In writing
- Dated
- Signed by the maker (the person making the personal directive) in the presence of a witness
- If the maker can't physically sign it, the document may be signed by someone else at the maker's direction (request) and in the presence of both the maker and a witness
- Signed by a witness in the presence of the maker

The following people *cannot* sign on behalf of the maker:

- The person named as the agent in the personal directive
- The spouse of the agent named in the personal directive

The following people *cannot* act as a witness:

- The person named as the agent in the personal directive
- The spouse of the agent named in the personal directive
- The spouse of the maker
- The person who signs on behalf of the maker if the maker can't sign
- The spouse of the person who signs on behalf of the maker if the maker can't sign.

What sorts of things should I think about when writing a personal directive?

The kinds of things you should think about when writing a personal directive will depend on what kind of directive you are going to write:

- If you intend, in your personal directive, only to appoint an agent to make decisions on your behalf, then the most important thing to think about is who that person should be. You will want to choose someone who knows you well, who you trust to make decisions for you, and with whom you can have frank conversations, in advance, about what your preferences are. A personal directive appointing an agent is the most simple type of directive, and for many people, it will be good enough. You might want to consider appointing alternate, or back-up, agents just in case your first choice can't or won't act when needed. You can appoint one person to act alone, or two or more people to act together.
- If however, in your personal directive, you would also like to provide directions about the kind of care you would like to receive if you ever lose capacity, then there are a number of things you may want to think about, such as:
    - Your main values and beliefs. These will influence what you write in your directive.
    - Try to learn about the various medical technologies and interventions that are offered to very sick and injured people (although you might not be able to predict all of them). Which treatments would you want or not want in certain situations?

- Consider what conditions you would want to be kept alive in through the use of life support measures (see the treatments described in Part III).
- Consider carefully what conditions you would not want to be kept alive in through the use of life support measures.
- Remember that you can't predict what sort of illness or injury you may have. You may be injured suddenly in a traumatic accident, or you may develop a temporary or long-term illness or disability. As a result, make sure you think about what your wishes would be about different treatments in many different situations.
- If you name an agent, make sure this person is someone you trust to make important decisions on your behalf, and is someone who knows your wishes, values, and preferences.

It can be very helpful to speak to a range of different people when you're writing your personal directive. If you wish, doctors, lawyers, spiritual advisors, social workers and nurses can all be helpful when you're thinking about which health care treatments to mention in your personal directive. They can also give you more information about various treatments and about different situations when they might be used.

→ When thinking about a personal directive, it's important to think about your values and beliefs.

Talking to friends and family members about your wishes, values and health care goals can also be very helpful. It gives your loved ones more information in case they're involved in guiding decisions about your care or interpreting the wishes in your personal directive. It might also allow them to share their own worries and concerns, which might influence your own preferences.

If you have chosen not to mention specific treatments in your personal directive, but instead to appoint someone you trust, talking to this person can also help them make decisions that you would want.

What sorts of things should I be careful about?

A personal directive that provides directions about the care you want to receive may cause problems if your wishes aren't clear. Try to avoid phrases like 'heroic measures' and 'extraordinary treatment.' These should not be used because it's not clear which treatments they refer to. Medical technology changes and a treatment that might have been 'heroic' when you wrote the personal directive might be common by the time your personal directive may be used.

Also, the same treatment may be used for different purposes (e.g., a breathing tube to help keep a person alive for years or as a short-term measure to allow the body to recover from an injury). While you might want the treatment in one situation, you might not want it in another. If you don't provide enough detail in your personal directive, it might be hard for people to follow your wishes.

Because of these concerns, it's very important to make sure you understand well the treatments that you refer to in your personal directive and when and how they are used. If you are less familiar with the treatments that might be offered, you may choose only to name someone you trust and who knows you well (an agent) to make treatment decisions on your behalf.

When does a personal directive come into effect?

A personal directive comes into effect when the maker (the person who made the personal directive) is incapable of making decisions for themselves about a particular area of their life, such as health care, accommodation or work life. *Capacity* to make health care decisions involves:

- The ability to understand the information related to the current decision
- The ability to appreciate the consequences of making that decision

A personal directive only comes into effect when a capacity assessment has been performed and the person has been found to lack capacity in certain areas of their life. Two people have to be involved in a capacity assessment. One of the two people must be a medical doctor or psychologist, while the other person can either be another health care provider or anyone that the maker has named in their personal directive to the capacity assessor. (For more about capacity, see Chapter 3.)

→ There is a specific form and procedure to follow to declare that a patient or resident has regained capacity.

A written declaration about the maker's loss of capacity will then be made, with copies given to the maker, the agent(s) (if any), and any other person the maker has designated in their personal directive. If an agent or agents have been named, they must make every reasonable effort to notify the maker's nearest relative and their guardian, trustee, or attorney appointed under the *Power of Attorney Act* that the personal directive is in effect.

What happens if a person becomes capable once again?

A person may lose capacity only briefly and be able to make decisions again in a matter of days or months. For example, this might happen if the person is recovering from a stroke or waking up from a coma.

There is a specific form and procedure to follow to declare that a patient or long-term care resident has regained capacity. Once the procedure for declaring that someone has regained capacity has been followed, the personal directive is no longer in effect and the patient or resident will be able to make his or her own health care decisions again.

What if someone isn't incapable but still needs help with decision-making?

Patients or residents can always turn to people they trust to help them understand information, talk about health care options, and make decisions. In some cases, however, it may be helpful to have more formally recognized support. There are two formal ways for people to have help with decision-making:

Supported decision-making

This option is for anyone who is capable but who wants more help with decision-making. For example, if you don't understand or speak English well, have a mild disability or are facing a very complex decision, this option may be helpful for you. To choose this option, you must fill out a form appointing someone you trust to be your official 'supporter'. This means that your supporter will have access to relevant information about your health and health care that would otherwise be protected for privacy reasons. Your supporter can help you to access and understand information, help you make a decision and even help you let others know what your decision is. Even though you have help, you are still the decision-maker.

Co-decision-making

This option is for anyone who isn't capable of making decisions on their own but who could make decisions if they had good support from a trusted person. With co-decision-making, decisions are made by the person and their co-decision-maker together. To choose this option, an application must be made to the Court. The patient or resident must be able to consent to the co-decision-making order and to the person appointed as their co-decision-maker.

What happens if a person is incapable and they don't have an agent appointed in a personal directive?

In some cases, a person won't be capable enough to make decisions with either a supporter or a co-decision-maker, and they will need someone to make decisions for them. If they don't have an agent appointed in a personal directive, a substitute decision-maker may be chosen for them either on a temporary basis, for a particular decision, or on longer-term basis.

Specific decision-maker

If a decision-maker is needed on a temporary basis, in order to make a decision about health care or a temporary admission to or discharge from a residential facility, then a health care provider can appoint a specific decision-maker to make the decision. A specific decision-maker is chosen from the following list of family members, in the order shown below. Where there are two or more relatives in the same level of the hierarchy, the elder or eldest relative takes precedence and whole blood takes precedence over half-blood:

- spouse or adult interdependent partner
- adult son or daughter
- father or mother
- adult brother or sister
- grandfather or grandmother
- adult grandson or granddaughter
- adult uncle or aunt
- adult nephew or niece

There are certain decisions a specific decision-maker may not consent to. As well, there are certain requirements for someone to step in and act as a specific decision-maker; for example, they must have been in contact with the adult in the previous 12 months and have knowledge of the adult's wishes, or values and beliefs.

It is important to consider whether you are comfortable with the people in this list making decisions for you. If you aren't, then this may be a good reason to draft a personal directive and specify who you would want to make such decisions for you.

Guardianship order

If a substitute decision-maker is needed on an on-going basis and there is no agent appointed in a personal directive, then an application may be made to the Court for a guardianship order.

A guardianship order appoints a person or persons as guardian(s) to make personal decisions for an adult who lacks the capacity to make these decisions. Guardianship orders are concerned with personal matters, including health care, but not with finances (which are considered in a trusteeship order). However, a guardian can access the incapable person's assets if they need to pay for personal and health care expenses.

Guardianship can either be public or private.

Private guardianship means the court names a private individual (such as a friend or family member) to make certain specified personal decisions on behalf of an incapable person. The court may appoint any adult in this role whom the court believes will:

- Act in the best interests of the incapable person, and
- Be suitable and able to act as guardian for the incapable person.

If there is no appropriate private person to fill this role, then guardianship will be public. *Public guardianship* means the court appoints the Public Guardian to make certain specified decisions for the incapable person. The Public Guardian is a government official who reports to the Provincial Solicitor General's Department.

If you have a guardian, can you make any decisions yourself?

Perhaps. Guardianship orders aim to give guardians only the authority necessary for the guardian to make or help make reasonable judgments relating to the personal matters of the incapable person. If the adult has decision-specific capacity, a guardianship order would only let the guardian make those kinds of decisions that the adult can't make for him or herself. All other decisions would still be made by the adult.

What documents address financial matters?

Thinking ahead about your health care may also make you think about other things, such as your financial situation. Enduring powers of attorney and trusteeship orders both address financial matters, rather than personal matters such as health.

A *power of attorney* is a document prepared by a capable person (called a donor) that appoints another capable person (called an attorney) to make financial decisions on their behalf.
If a power of attorney is 'enduring,' it will come into effect (or stay in effect) even if the donor becomes incapable. If the power of attorney is not enduring (or no power of attorney is prepared) and the donor becomes incapable, then family members or others must ask the court to appoint a trustee to take care of the donor's property and financial matters (see below).

A *trusteeship order* is a document issued by the court. This document appoints a person to make decisions about property and financial matters for an adult who can't make reasonable judgments to do with matters relating to his or her estate

Trusteeship can be private or public. Private trusteeship means that the court names an individual (such as a friend, family member or business associate) to make property and financial decisions. The court may appoint any adult in this role whom it believes will:

- act in the best interests of the incapable person,
- not be put into a position where their interests will conflict with the incapable person's interests, and
- be suitable and able to act as trustee for the incapable person.

If there is no appropriate private person to fill this role, then trusteeship will be public. Public trusteeship means the court appoints the Public Trustee to make these decisions. The Public Trustee is a government official.

How will the adult's capacity be assessed before such steps are taken?

For guardianship, trusteeship orders and co-decision-making, a specific process must be followed to assess an adult's capacity. Details about that assessment are then presented in court. An adult has a right to refuse to participate in a capacity assessment, except in rare cases when an assessment is ordered by the court. For specific decision-making, a health care provider will assess the adult's capacity although a more formal capacity assessment may be requested.

How can I leave instructions to be followed after my death?

A will is a document prepared by a capable adult that contains instructions about what they want to happen after they die. It addresses property and financial matters, as well as funeral or memorial arrangements. It might also include the person's preference about burial or cremation.

A will comes into effect when a person dies.

An executor (male adult) or executrix (female adult) is the person named in the will who is responsible for carrying out (or 'executing') the instructions in the will on behalf of the deceased person.

All adults should consider writing a will to make sure that their property is disposed of according to their wishes. Other wishes, such as those regarding funeral arrangements, don't have to be followed, but they can serve to let your executor or executrix know what your preferences are. You should review your will from time to time and update it if necessary. Reviewing your will may be particularly important after certain life events, such as getting married or having a child.

In fact, if you get married, you will have to draft a new will since any previous will you have will no longer be valid.

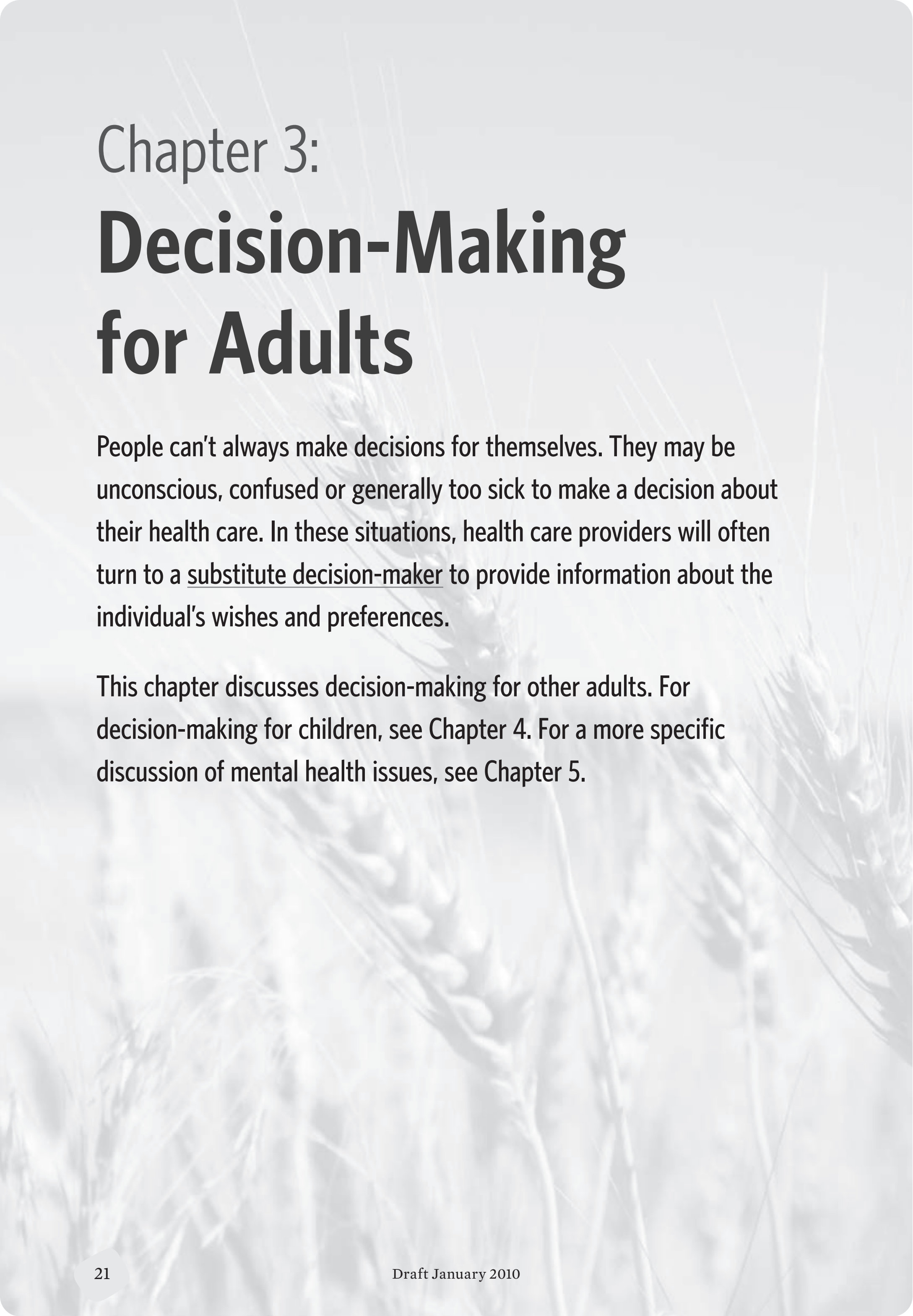
TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

PART II

Deciding for Others

This part discusses situations where people may have to make health care decisions for others and gives some guidance about how to carry out this difficult task.



Chapter 3:

Decision-Making for Adults

People can't always make decisions for themselves. They may be unconscious, confused or generally too sick to make a decision about their health care. In these situations, health care providers will often turn to a substitute decision-maker to provide information about the individual's wishes and preferences.

This chapter discusses decision-making for other adults. For decision-making for children, see Chapter 4. For a more specific discussion of mental health issues, see Chapter 5.

What is a substitute decision-maker?

A substitute decision-maker is someone who makes personal decisions (which may include health care decisions) for another person who can't make decisions for him or herself. (The term 'surrogate decision-maker' is also used; this means the same thing).

→ Making an unusual choice is not the same as lacking decision-making capacity. It's important to understand the context and the consequences before reacting to a decision your loved one makes.

It is ideal if the substitute decision-maker knows the patient or long-term care resident's wishes, values and preferences and is able to share them with the health care team. This allows the patient or resident to still have a say in the decisions that are made, even if they cannot participate at the time. This process is easier if the person has done some advance care planning, especially if the substitute decision-maker was involved in these conversations.

Who should be a substitute decision-maker?

A substitute decision-maker should ideally be someone who is close to the incapable person and has his or her well-being most at heart.

Legally in Alberta, a substitute decision-maker could be:

- An agent named in the patient or resident's personal directive (see Chapter 2)
- A guardian appointed by the court (see Chapter 2)
- A co-decision-maker consented to by the adult and appointed by the court
- A family member (nearest relative), appointed as a specific decision-maker by a health care provider, in cases where no agent or guardian exists

When is a substitute decision-maker needed?

A substitute decision-maker is needed when a patient or resident doesn't have the capacity to make a health care decision for him or herself.

In health care, capacity to make health care decisions means being:

- Able to understand and appreciate the relevant information about a particular treatment
- Able to understand and appreciate the consequences of having a particular treatment or refusing it

Sometimes the word 'competence' is used instead of 'capacity'; we will use these terms to mean the same thing.

It is assumed that adults have capacity unless it can be shown that they don't.

What are reasons to question someone's capacity?

There may be valid reasons to question a person's capacity.

A *valid* reason to question capacity might be if the person:

- Acts in a way that threatens the safety of others or themselves
- Seems to have lost some ability to make decisions; for example, family members or health care providers might notice that pain, side effects of medication, or pressure from others is getting in the way of the patient or resident's ability to make decisions
- Is making decisions or choices that do not seem to fit with the values and beliefs they have held in the past

→ It is important to be flexible, even if it means delaying decisions until the patient is in a better position to participate.

An *invalid* reason to question capacity is if the person:

- Makes a decision that other people don't agree with – making unusual choices doesn't necessarily mean that the person is incapable
- Has trouble communicating – a person may not be able to talk but this doesn't mean they are incapable. Every effort should be made to learn their wishes; speech-language pathologists and others have many tools to help people communicate without words.
- Speaks a different language – just because a person doesn't speak the same language as you doesn't mean they are incapable. Efforts should be made to bring in a medical translator.

If a person is found to be incapable of decision-making, then a substitute decision-maker may make decisions on their behalf.

If a patient is considered incapable, can they ever make decisions?

Yes. Loss of capacity can be temporary (short-term) or permanent. Some people with a progressive injury or illness may lose their capacity for decision-making permanently. Other people suffer from a temporary illness or injury and are able to make decisions for themselves again when they get better.

Even if a patient or resident is sick or hurt, they may be able to make certain kinds of decisions but not others. For example, they may not be able to do something that requires a lot of cognitive skills, like driving a car, but they can understand the relevant information about a particular health care decision and the consequences of having it or refusing it. Or, they may be able to make everyday decisions, like what to wear, but not more complicated decisions, like health care decisions. Being able to make some decisions but not others is called having decision-specific capacity. If a patient is thought to have decision-specific capacity, they must be assessed carefully for each particular type of decision to see if they can make that decision for him or herself.

Decision-specific capacity is different from global incapacity. Global incapacity means that the patient can't make any decisions. In these cases, a substitute decision-maker may need to make most or all of their decisions for them.

Capacity can come and go for many reasons, including pain and the side effects of medication. As long as a decision isn't urgent, every effort should be made to let the patient or resident make the decision for him or herself. Discussions should be planned for times when they are likely to be more alert and aware (for example, if they are better at certain times of the day or between medication times). Where possible, decisions should wait to give the patient or resident a chance to feel well enough to participate.

How should a substitute decision-maker make decisions?

There are very clear guidelines for how a substitute decision-maker should make decisions. The most important thing to remember is that the substitute decision-maker should not make decisions based on their own wishes, values and preferences, but on those of the patient or resident where possible. The substitute decision-maker should be involved in the care of the patient or resident and know what has been happening with the person's care. If you are a substitute decision-maker for someone else, here are some things you may wish to consider in order to make a decision:

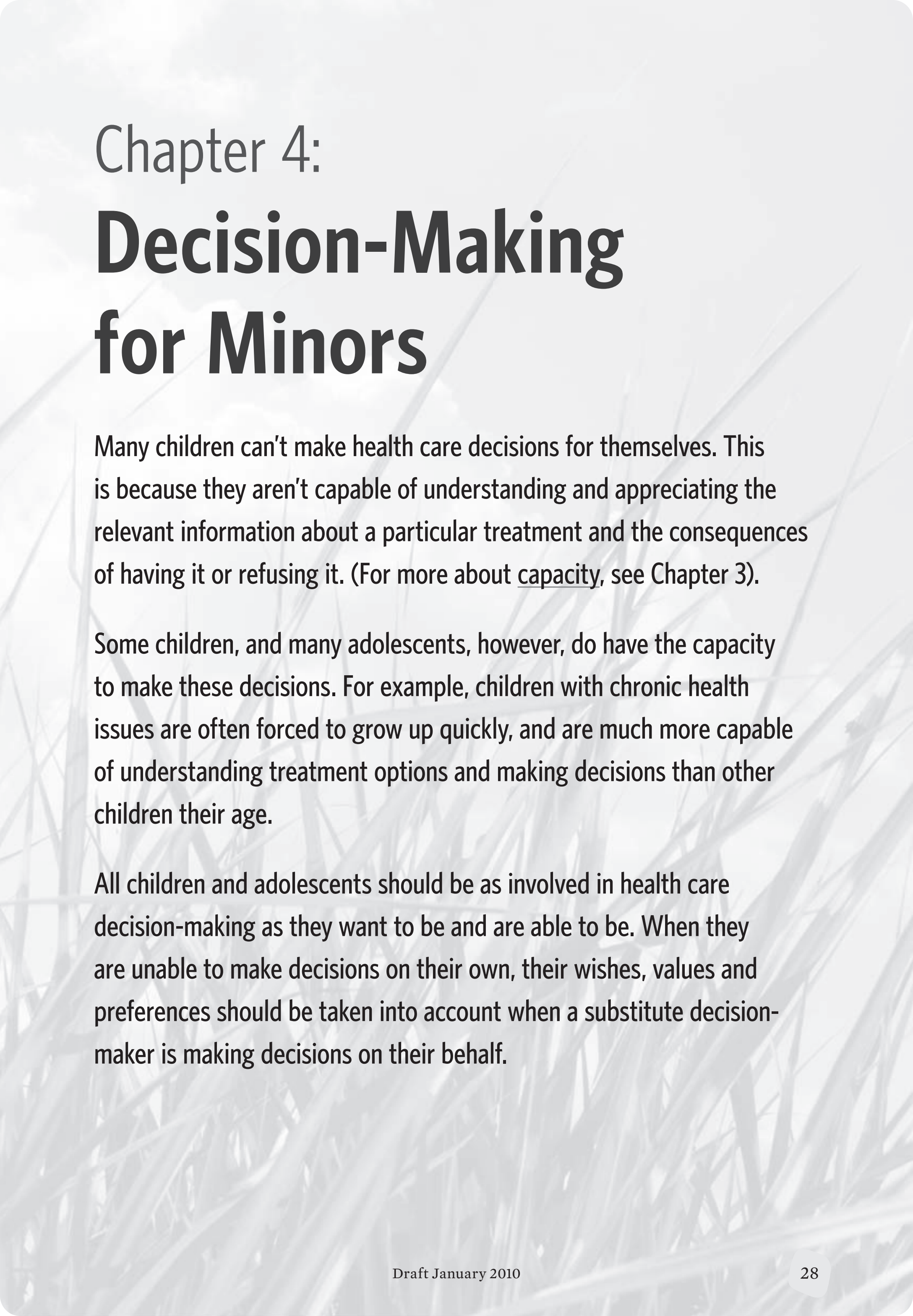
- *Known wishes*: Has the ill person ever said what they would like done in this kind of situation? These wishes may or may not be written down, for example in a personal directive. If you are an agent named in a personal directive, you should follow the person's wishes, if it's possible in the circumstances. If you have been appointed as a Co-decision-maker, Specific decision-maker or Guardian, known wishes must be taken into account as part of the consideration of best interests.

- *Expected wishes*: If they haven't specifically said what they would like done in this kind of situation, what do you think they would want? The decision should be based on what you know about the ill person's wishes, values and preferences. (To help you think about their wishes, see the list of questions at the end of Chapter 1.)
- *Best interests*: If you are an agent named in a personal directive and you don't know enough about the ill person's wishes or values to make a decision on those grounds, what do you think is in that person's best interests? Best interests involve comparing the benefits with the risks of a treatment to see if there are more benefits overall. Part of the decision involves considering what their life would be like with or without the treatment. If you have been appointed a Co-decision-maker, Specific decision-maker or Guardian, all decisions must be made based on best interests, which is defined broadly to include the person's wishes, values and beliefs, as well as an evaluation of risks and benefits.

Even though the ill person can't make the decision him or herself, it is still important to involve them in the decision and to ask them for their opinions, as much as is possible. Respecting the patient or resident by involving them in decision-making is an important part of upholding the dignity of those who are ill or injured. important part of upholding the dignity of those who are ill
or injured.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.



Chapter 4:

Decision-Making for Minors

Many children can’t make health care decisions for themselves. This is because they aren’t capable of understanding and appreciating the relevant information about a particular treatment and the consequences of having it or refusing it. (For more about capacity, see Chapter 3).

Some children, and many adolescents, however, do have the capacity to make these decisions. For example, children with chronic health issues are often forced to grow up quickly, and are much more capable of understanding treatment options and making decisions than other children their age.

All children and adolescents should be as involved in health care decision-making as they want to be and are able to be. When they are unable to make decisions on their own, their wishes, values and preferences should be taken into account when a substitute decision-maker is making decisions on their behalf.

Who is a minor?

In Alberta, a minor is any person under the age of 18.

Who can make decisions for a minor?

If a minor is not capable of making health care decisions for him or herself, the minor's guardian makes them. Parents are usually the joint guardians of their children. Unless a court has granted sole guardianship to one parent, both parents continue to share guardianship even after divorce or separation. This means parents should always consult with one another and come to an agreement about what decision should be made. If parents can't agree on a decision and every effort has been made to help them try to reach an agreement, then they may apply to the court for direction.

Even when parents agree, a health care decision they make on behalf of their child may be overridden (not followed) if it isn't in the child's best interests. If, for example, parents refuse consent to a medically necessary treatment, child welfare authorities may apply to court and may be given either temporary or permanent guardianship of the child so that they can consent to the treatment.

Can a minor ever make decisions?

Yes. If a minor (usually a teenager) has the capacity to make a particular decision, then they are allowed to make the decision for him or herself. Capacity is defined as the ability to understand and appreciate the information relevant to a particular treatment and the consequences of having that treatment or refusing it. A minor who has capacity is called a mature minor. Both parents and guardians must respect the decisions of a mature minor; neither can override the mature minor's decisions.

The wishes of a mature minor can only be overridden by the court. In a situation where a mature minor refuses treatment that is considered medically essential, child welfare legislation may authorize the court to override the minor's decision. If the treatment is found to be in the best interests of the minor, then the court can order the treatment even if the minor doesn't want it. For more information about substitute decision-making, see Chapter 3.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 5:

Decision-Making and Mental Health

Mental health issues can be very serious and affect people throughout their lives; examples include schizophrenia, bipolar disorder, and depression. These conditions are often managed by a mental health professional on a long-term basis. Being sick or injured can also cause mental health symptoms. These symptoms may be a normal response to a health problem or they may be more serious and require treatment. In some cases, patients or long-term care residents with mental health issues may lose the capacity to make their own health care decisions. (For more about capacity, see Chapter 3). This chapter considers the mental health issues that might arise when a person is ill or injured.

Does everyone who is ill or injured have mental health issues?

No. Many people will not experience any mental health symptoms if they become ill or injured.

It is important to talk about the possibility of mental health issues with health care providers. Knowing that having mental health symptoms is possible can help you to notice mental health changes in yourself or your loved one. Health care providers can also help you tell the difference between normal changes in mental health and more serious conditions that need treatment.

A certain degree of withdrawal and sadness is common for people facing a serious illness or injury and may not require treatment. This is especially true for those with a terminal illness or a progressive illness (an illness that will continue to get worse over time), especially as the person gets near the end of their life. It is very important to give comfort and support to your loved one and family during this time.

What are common mental health symptoms?

The most common mental health symptoms experienced by people who are very ill or nearing the end of their lives are:

- Anxiety (worry)
- Clinical depression (deep sadness), which may include suicidal thoughts
- Delirium – a state of mind in which the person
    - becomes very disoriented (confused)
    - experiences hallucinations (seeing or hearing things that aren't there)
    - has incoherent speech patterns (speech that doesn't make sense)
    - is unable to calm down.

If these symptoms are not recognized and treated, they can affect the person's capacity to make decisions.

A warning sign of mental health issues is if the patient or resident has thoughts of suicide or asks someone to end their life. These cases should be reported to health care professionals. These patterns can be signs of clinical depression, which can often be treated with mental health support and/or medications.

Sometimes these thoughts are not a sign of mental health issues at all. What the person may really want is to end their suffering from pain or other discomforts. This suffering might be dealt with by changing the patient or resident's treatment plan or pain management.

→ A certain degree of withdrawal and sadness is common for people facing a serious illness or injury and may not require treatment.

Are these mental health symptoms treatable?

Yes. These symptoms are often treatable. It is important to make sure the treatments don't interact with other medications the person is taking.

Sometimes mental health symptoms or concerns aren't noticed right away and so treatment isn't started right away. Some reasons that symptoms might not be noticed are:

- Mental health specialists (such as social workers, psychologists, psychiatrists) are not available in all facilities or communities
- These feelings are hidden in an effort to 'stay positive', especially when death is getting closer

Can people with mental health issues ever make their own health care decisions?

Yes. As long as people have capacity, they can make their own health care decisions. It should never be assumed that someone with an existing mental health issue (e.g., depression, schizophrenia) isn't capable of making their own health care decisions.

Sometimes mental health issues that are untreated can interfere with a person's ability to make decisions. For example, a person who has delirium (who is seeing things that aren't there and can't speak in a way that makes sense) may not be able to understand and appreciate the relevant information about a particular treatment and the consequences of having it or refusing it. Capacity may come and go, and it may be decision-specific, meaning that the person can make certain kinds of decisions but not others. In this case, they should be carefully assessed when a new decision has to be made to see if it's one that they can make for themselves.

Efforts should always be made to give the patient or resident the chance to make their own decisions. This might mean waiting to make a decision (if it is safe to do so) until after the mental health symptoms are successfully treated.

If you can, try to talk with the patient or resident when they are feeling well about their wishes, values and preferences for future medical treatments or interventions. This way, if they become incapable – either because of mental health issues or their illness – you (or the appropriate substitute decision-maker) will be able to make decisions that they would have chosen to make for themselves (see Chapter 1 about planning ahead and Chapter 3 about making decisions for others).

When a person has capacity, they may want to write a personal directive, which is a legal document that lets them write down their wishes for future medical care and/ or to name a person they trust to make decisions for them. This document will be used to guide decision-making if they become incapable during their illness (see Chapters 1 and 2).

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

PART III

Treatment Decisions

This part describes various treatment options that may arise when a person is seriously ill or injured and some issues to consider when making these difficult decisions.

……

Chapter 6:
Withholding and Withdrawing Treatment

Chapter 7:
Nutrition (Tube Feeding)

Chapter 8:
Hydration (Administration of Fluids)

Chapter 9:
Resuscitation (CPR)

Chapter 10:
Mechanical Ventilation (Breathing Machine)

Chapter 11:
Palliative Sedation

Chapter 6:

Witholding and Withdrawing Treatment

When a patient or long-term care resident is really sick or hurt, they may be offered various medical treatments to keep them alive (to ‘sustain’ life) in order to give their body a chance to recover. In some cases, the person will get better and these treatments can be stopped. In other cases, the person won’t get better and these treatments might need to be continued for months or years. The patient, resident, or their substitute decision-maker may then have to decide whether the patient or resident wants their life to be sustained (kept going) by these treatments or to stop these treatments.

Stopping a life-sustaining treatment usually means that the ill person will die. If the person is thought to have a very poor prognosis, or medical outlook, then the health care team and patient, resident or substitute decision-maker might think about not starting these treatments at all. This chapter gives some guidance about making these very difficult decisions.

While we discuss some of the treatments that are often considered in times of critical illness in this booklet, we hope that the information raised here will be useful regardless of what treatement you’re considering.

What is a life-sustaining treatment?

A life-sustaining treatment is a medical intervention, technology, procedure or medication that helps a patient or resident to stay alive ('sustain' their life). Often these are machines or tubes that allow the patient to breathe, eat, or drink even if they can't physically do these things themselves.

Life-sustaining treatments that are often considered for very sick or injured patients include cardiopulmonary resuscitation (CPR), artificial nutrition (tube feeding), artificial hydration (fluids), and mechanical ventilation (breathing machine). These treatments are each considered separately in the next several chapters of this booklet.

What do 'withholding' and 'withdrawing' treatment mean?

Withholding a treatment means not starting a certain treatment. A treatment might be withheld for many reasons. For example, the health care team might decide that it wouldn't work for a patient or resident. Or the patient, resident or substitute decision-maker might decide that the treatment doesn't fit with the patient or resident's wishes, values or preferences, or their care goals.

Withdrawing a treatment means stopping a treatment that has already been started. A treatment might be stopped for many reasons. For example, it might no longer be working or the patient or resident's care goals might have changed. In some cases, a treatment might be uncomfortable or get in the way of what the patient or resident thinks is important; for example, they may get very anxious being attached to a feeding tube and try to pull it out.

Many people find it easier to withhold a treatment than to start it and then stop it if the person doesn't get better. However, sometimes withholding a treatment means that no one knows whether the treatment would have helped the person get better. In these situations, it is sometimes helpful to try a ‘time trial’ where the patient or resident (or substitute decision-maker) and the health care team agree to try the treatment for a fixed period of time to see if it has any effect.

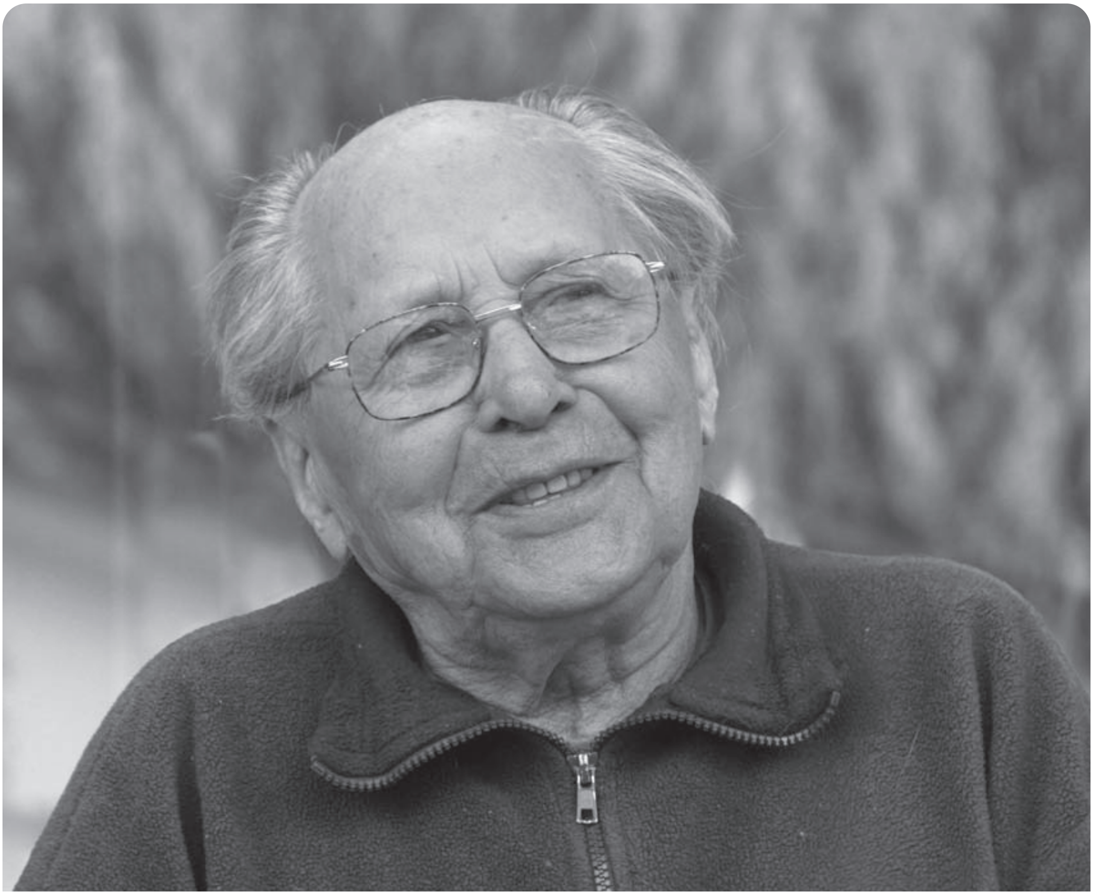
If certain treatments are withheld or withdrawn, this does not mean that *all* treatments should also be withheld or withdrawn. Each treatment or intervention must be thought about on its own. Even if one treatment is withdrawn, a new treatment that might be helpful could be started.

It is important to know that even if a treatment is withdrawn, this does not mean that *care* for the patient or resident will be withdrawn. Health care providers will continue to look after the well-being of the patient or resident, whatever decisions they have made about various treatments.

Is withholding or withdrawing treatment euthanasia?

No. Euthanasia means ending someone’s life on purpose in order to end their suffering or give them a good death. When euthanasia is talked about in health care, it is usually used to mean ‘active euthanasia’. Active euthanasia means doing something directly to a patient or resident to end their life, such as giving them a drug that will kill them. This form of euthanasia is illegal in Canada.

Withholding and withdrawing treatment means to not give or stop a treatment that the patient or resident no longer wants. Both of these options are legal. When a treatment is withheld or withdrawn, the person may or may not die. It might help to think that if a patient or resident does die, that it was their illness or injury that ended their life and not any decision or action by the patient, resident, substitute decision-maker or health care team.



Who can make treatment decisions?

Any capable adult can make their own treatment decisions. This includes the right to say you don't want a treatment, even if it means withholding or withdrawing a potentially life-sustaining treatment. (For decision-making for minors and those with mental health issues, see Chapters 4 and 5.)

Before a health care provider can begin a treatment, a capable person must give their informed consent to the treatment. Informed consent means that a capable person understands the relevant information about the treatment including its risks and benefits, and they agree to it voluntarily (without any coercion or significant pressure or influence from others).

The ability of a capable adult to make their own decisions about withholding and withdrawing treatment is protected in Canadian common law:

> *Regardless of a doctor's opinion, it is the competent patient who has the final say on whether or not to undergo treatment… The doctrine of informed consent is plainly intended to ensure freedom of individuals to make choices concerning their medical care. For this freedom to be meaningful, people must have the right to make choices that accord with their own values, regardless of how those choices appear to others.* (Malette v. Shulman, Ontario Court of Appeal, 1990)

If an adult is no longer capable, then they can't make health care decisions. If they have a personal directive that gives their wishes about certain treatments, then this document is considered to be a statement of their wishes and should be followed if possible. Their personal directive may also name someone to be their agent (their substitute decision-maker); this person has been given the responsibility of making decisions on the incapable person's behalf.

→ Even if treatments are stopped, this doesn't mean that care for the patient or resident will be stopped.

The patient, resident or substitute decision-maker can always change their mind about a treatment decision. They can ask to stop a treatment that has already been started, or to start a treatment that they had refused earlier.

In some cases, a treatment may not even be offered. If health care providers think that a treatment will provide no benefit, then they don't have to offer it. They probably don't have to continue to provide such a treatment either, even if the patient, resident or substitute decision-maker asks for it.

How should treatment decisions be made?

Decisions about withholding or withdrawing treatment can be particularly hard when a patient or resident is very sick or hurt.

When making these decisions for yourself, it is important to consider your values and goals of care, as well as your quality of life (what makes your life meaningful to you). If you have not already done some advance care planning, thinking about some of the questions at the end of Chapter 1 might help you.

→ When making health care decisions for yourself, it is important to consider your values and goals of care, as well as your quality of life.

If you are a substitute decision-maker, there are some specific rules you must follow for decision-making (see Chapter 3). If the person you are making decisions for has done some advance care planning or made a personal directive, then these documents should be used to guide your decisions. If you don't know the patient or resident's wishes about this situation, then it's important to find out as much as you can about them. Talking to as many of the person's family members and loved ones as possible may help you find out more about their values and what they would want. Health care providers can also be good sources of information about the patient or resident's condition and the treatment being offered.

No matter how incapable the patient or resident is, they should be consulted about any health care decisions made on their behalf (to the extent that this is possible). Open and honest communication with the patient, resident, substitute decision-maker, and health care providers can also help to clarify goals of care and help with decision-making.

What happens if family members disagree?

Understanding and support from the ill person's family can be very helpful for the substitute decision-maker. However, family members may have different values and opinions about a particular medical treatment. Here are a few suggestions to help the family cope when its members aren't in agreement:

- The patient or resident's doctor(s) can give you more information about their condition and prognosis. This can also help you understand more about whether the treatment is medically beneficial and what the risks and benefits are.
- It's normal to feel stress or grief at this time. Trusted health care providers can offer family members emotional support or counselling to help them work through their thoughts and feelings.

→ Differing views about which treatments to offer, withhold or withdraw can often be resolved over time, by seeking a second opinion or with the help of an outside facilitator.

- Remember the importance of knowing what your loved one would want under the circumstances. Personal, cultural and spiritual beliefs are all relevant and should always be treated with respect by the health care team.
- If family members still disagree or are upset about a decision, sometimes the health care team may suggest having a case conference with the family. A case conference is a group meeting with some or all of the key health care providers involved in your loved one's care (physicians, nurses, social workers, clergy) to share information and opinions. The team may also suggest that the family talk with the Ethics Consultation Service in the facility or area.

What happens if the decision-maker disagrees with the health care team?

Sometimes the patient, resident, or substitute decision-maker can disagree with the health care team about treatment decisions. These situations can occur when:

- The patient or resident's condition is getting worse despite the best medical care
- The treatment does not support or advance the patient or resident's goals of care (such as a wish to return home, to live without tubes, or to live without suffering)
- The health care team thinks that a requested treatment probably won't work or might even harm the patient or resident
- The treatment might be somewhat successful but would have no significant or lasting benefit

Disagreements can be difficult and painful for everyone involved. There are several ways to help resolve these problems:

- *Allow time*: Unless a decision needs to be made quickly, everyone involved should take some time to think about their views. It might help for the patient, resident, substitute decision-maker or family members and the health care team to take some time to discuss decisions together in a thoughtful manner. Sometimes a compromise can be reached, such as trying a treatment for a fixed period of time when some people want the treatment and others don't. Whenever possible, try to hold discussions when the patient or resident is feeling at their best.

- *Second opinion*: Any of those involved can ask for a second, professional opinion about the patient or resident's care. A second opinion should come from a health care provider who is not involved in caring for the patient or resident but who has relevant expertise in their condition. Getting a second opinion can be particularly helpful if the patient, resident or family is uncertain about the ill person's diagnosis or prognosis.
- *Facilitation*: In some situations, it may be helpful to bring in a facilitator to guide a discussion between the patient, family and care team. Facilitators may be trained health care staff or members of a clinical ethics team. This is particularly helpful in situations where the patient, resident, or substitute decision-maker doesn't feel that they are being heard or understood, or if an agreement with the health care team can't be reached.
- *Patient or resident care transfer*: If none of these methods works and disagreements continue, then the patient, resident, substitute decision-maker or a member of the health care team may ask for other health care providers to take over the care of the ill person.
- *Court application*: In certain circumstances, an application may be made for a court order to stop a health care team from withdrawing or withholding treatment. Such an application should always be a last resort.

Good communication that takes place early in the ill person's care can usually avoid these disagreements. Having open, honest and sensitive discussion can help to make sure that everyone understands the patient or resident's wishes, values, and preferences. It can also help to clarify their goals of treatment.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 7:

Nutrition (Tube-Feeding)

Some people who are very sick or hurt can't eat by mouth. For these patients or long-term care residents, nutrition can be given to them through a tube that goes directly into their stomach (a feeding tube). Feeding tubes may benefit some people but not others.

Legally, a feeding tube is considered a medical treatment or intervention. Like other medical interventions, a decision to have a feeding tube must be made carefully.

The patient, resident or their substitute decision-maker should make sure they understand the risks and benefits of having a feeding tube, and consider the decision in light of the patient or resident's wishes, values, preferences and care goals.

What is a feeding tube?

A feeding tube is a tube that allows liquid formula and water to go directly into the stomach.

There are two kinds of feeding tubes:

1. A *nasogastric (NG) tube* is for short-term use. It goes through the nose, down the throat and into the stomach.
2. A *percutaneous endoscopic gastrostomy (PEG) tube* (also called a gastrostomy or G-tube) is for longer periods of time or even permanent use. This tube goes directly into the stomach through the skin. Putting in a PEG tube requires a fairly simple surgical procedure. The tube also has to be replaced every 6 to 12 months.

When might a feeding tube be needed?

A feeding tube might be a treatment option in any situation where a person can't feed themselves, such as if they have had a stroke or are unconscious. Many terminally ill people will need help getting nutrition as they near the end of their life. The most common reason for needing a feeding tube is when someone has a condition called dysphagia. Dysphagia is when a person can't swallow anything by mouth, including food and water.

Tube feeding might be chosen:

- To provide nourishment and sustain life when a person can't eat in the usual way.
- Because it meets the patient or resident's goals of care.

Does tube feeding benefit everyone?

No. Tube feeding may benefit some people in some circumstances, but not others. Like any medical intervention, careful thought should be given to the benefits and burdens of tube feeding, as well as to the ill person's values, preferences and quality of life. (For more information about decision-making, see Chapters 1, 3 and 6.)

Below are some guidelines about who might benefit from tube feeding.

- Tube feeding is *likely to benefit* people who:
    - Have a stable or slowly worsening illness, but still have a good quality of life
    - Can still swallow but need some extra nutrition
- Tube feeding is *unlikely to benefit* people who:
    - Are in a persistent vegetative state lasting more than 12 months
    - Have end-stage dementia such as Alzheimer's disease
    - Have advanced terminal illness and are nearing death
- Tube feeding *may or may not benefit* people who:
    - Are in a persistent vegetative state lasting less than 12 months
    - Have dysphagia, as well as an underlying disease that will continue to get worse
    - Have a poor quality of life

It can be reassuring to know that people who are terminally ill don't experience suffering due to lack of food. In fact, while healthy people feel hunger, people who are very ill often don't want food. In these cases, tube feeding may draw out the dying process rather than sustain life. Those who choose not to have a feeding tube should be offered good comfort care.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 8:

Hydration (Administration of Fluids)

Some people who are very sick or hurt can't drink orally (by mouth). For these patients and long-term care residents, fluids (liquids) can be given to them through a needle placed in a vein or under the skin, or through a feeding tube, if they have one. Giving fluids may benefit some people but not others.

Legally, artificial hydration is considered a medical intervention. Like other medical interventions, a decision about receiving artificial hydration should be thought about carefully. The patient, resident or their substitute decision-maker should make sure they understand the risks and benefits of giving fluids in this way, and consider the decision in light of the resident's wishes, values, preferences and care goals.

What is artificial hydration?

Artificial hydration is a way of giving someone fluids if they can't drink them by mouth. A common reason for needing artificial hydration is when a person has a condition called dysphagia. Dysphagia is when a person can't swallow anything by mouth, including food and water.

Fluids can be provided by:

- A needle into the vein (intravenous)
- A needle under the skin (subcutaneous)
- A feeding tube put through the abdominal wall directly into the stomach

→ Fluids may benefit some people in some circumstances, but not others.

Why are fluids important?

Fluids are normally used to maintain the body's normal processes.

People have *more* need for fluids with:

- Physical activity
- Fever
- Rapid breathing
- Diarrhea

People have *less* need for fluids with:

- Inactivity
- Loss of body weight
- Advancing age, especially if they are nearing death

Do fluids benefit everyone?

No. Fluids may benefit some people in some circumstances, but not others. Like any medical treatment, careful thought should be given to the benefits and harms of giving fluids, as well as to the ill person's values, preferences and quality of life. (For more about decision-making, see Chapters 1, 3 and 6.)

In some cases, giving fluids can:

- Cause more discomfort and suffering. This is especially true when the patient or resident finds it difficult to swallow, has no appetite, or has nausea
- Cause a build up of fluid (edema) in places like the brain, lungs, arms, legs and abdomen. This build up may cause various symptoms, such as pain, shortness of breath or confusion.
- Make some medical conditions worse

In these situations, it may be most appropriate not to give fluids.

For people who choose not to receive fluids, proper mouth care can keep the patient or resident comfortable. Mouth care includes wetting the inside of the mouth with a swab and keeping the lips moist and free of chapping.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 9:

Resuscitation (CPR)

When patients come into the hospital or move to a long-term care facility, they are often asked whether they would want to be resuscitated if they stopped breathing. The most common form of resuscitation is cardiopulmonary resuscitation, or CPR. CPR is performed when a person's heart and lungs have stopped. Resuscitation can sometimes save a person's life. Other times it can be very harmful for them and they will still die.

Having this discussion with health care providers early on is important so that they can consider the person's wishes if they need to make a decision about whether or not to attempt CPR if the patient or long-term care resident stops breathing (arrests). Health care providers must act immediately if they are going to try to resuscitate the person. Like the other medical interventions considered in this booklet, a decision about choosing or refusing resuscitation should be considered carefully. The patient, resident, or their substitute decision-maker should make sure they understand the risks and benefits of resuscitation, as well as the patient or resident's medical condition, wishes, values, preferences and care goals.

What is resuscitation?

Resuscitation means bringing someone back to life, or back to consciousness, who would otherwise be considered dead. CPR is the most common form of resuscitation.

CPR stands for cardiopulmonary resuscitation. It is performed when a person's heart ('cardio') and lungs ('pulmonary') have stopped. If CPR is performed immediately, it can sometimes restart the person's heart and breathing.

CPR can be performed by health professionals or by other trained individuals. It could include any of the following methods:

- Pushing down hard on the person's chest, over and over again, in order to keep some blood moving through the body
- Using electric shock to try to restart the heart
- Breathing directly into the person's mouth (mouth-to-mouth resuscitation)
- Filling the lungs with air by: a) putting a mask over the nose and mouth, or b) putting a tube directly into the windpipe (intubation)

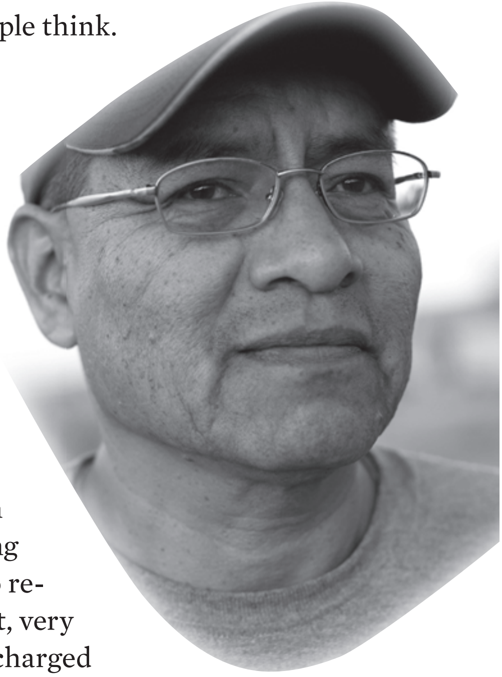
→ Conversations about resuscitation can be very difficult and should be raised in a respectful, supportive and caring environment.

These methods can be harmful. Side effects from CPR include bruising, fractured ribs, and punctured lungs. In some cases, people might show signs of brain damage or go into a coma.

As a result, if CPR restarts the heart, more care is usually needed. Following successful CPR, most people go to an intensive care unit (ICU) or a specialized coronary (heart) intensive care unit (CICU) for follow-up treatment. These specialized care units might not exist in all facilities or communities.

Does CPR always work?

No. Success rates for adults who are given CPR are actually lower than many people think.



CPR is *most likely* to work for people who arrest unexpectedly and are otherwise healthy. With immediate CPR and follow-up treatment, a few of these people will make a full recovery. Others will recover but have ongoing health problems.

CPR is *less likely* to work for people who arrest when they are already in the hospital for other health problems. Success is very low in patients with serious or life-threatening conditions. When CPR does manage to restart the heart in a hospitalized patient, very few will recover well enough to be discharged from the hospital.

CPR has almost *no chance* of success in patients where there is little hope that heart or lung function can be restored through CPR.

The success of CPR depends heavily on:

- The health status of the person before they arrested
- What caused the heart and lungs to suddenly stop
- How quickly the heart and lungs start working again
- How quickly follow-up care is provided

Because CPR does cause harm and its benefits are uncertain, the Canadian Medical Association encourages people to think very carefully about choosing it. They also agree that it can be appropriate (medically and ethically) to withhold (or not offer) resuscitation:

> *After several decades of experience and review, it appears that there are people who benefit from this treatment and others for whom there is no benefit and potentially significant harm. In these latter situations, CPR is not only generally unsuccessful but also inappropriate, as it may serve only to increase pain and suffering and prolong dying. Withholding resuscitation does not imply the withholding of treatment and supportive care.* (The Canadian Medical Association, 1995)

→ Success rates for adults who are given CPR are actually lower than many people think.

What is a DNR or DNAR order?

A DNR or DNAR order is a medical order that is written in a patient or resident's chart. DNR stands for 'Do Not Resuscitate' and DNAR stands for 'Do Not Attempt Resuscitation'. Having a DNR or DNAR order means that if a patient or resident's heart and/or breathing stops, no one should try to restart them.

All health care providers involved in a patient or resident's care should know about the DNR/DNAR order. The order will likely be taken into account in discussions with the patient, resident or substitute decision-maker about the ill person's treatment decisions and care goals.

When should the decision about resuscitation (DNR/ DNAR) be made?

A conversation about resuscitation should begin as early as possible in hospital, or even before a person gets sick. In the case of residents, they are usually asked their preference about resuscitation before moving into a long-term care facility. Thinking about this decision early is helpful because it gives people time to think about their wishes and care goals. It is especially important with people who are terminally ill because they may have less energy and lack capacity to participate in decision-making later during their illness.

Beginning a conversation about resuscitation can be very difficult. This subject should be raised in a respectful, supportive and caring environment. It can be helpful for the patient or resident to involve their loved ones in this discussion. This allows loved ones to hear what the person is thinking and hoping for, so that they can understand and support their decision. Health care providers could also be involved to answer any questions. (For more about decision-making, see Chapters 1, 3 and 6).

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 10:

Mechanical Ventilation (Breathing Machine)

Most people can breathe on their own, by sucking air into their lungs and then pushing it back out. Sometimes an illness or accident makes it hard for a person to breathe on his or her own. In these cases, a machine (ventilator) can be used to help them breathe or to breathe for them. Usually a ventilator is used for a short period of time until the body can recover enough to start breathing again on its own. Sometimes a person might need a small amount of ventilation support over a long period of time. If a person becomes completely dependent on ventilation over the long-term, then the possibility of stopping the ventilator may be discussed.

→ There are several kinds of ventilators, used for different purposes, depending on the breathing support that is needed.

What is mechanical ventilation?

Mechanical ventilation refers to machines that help with or take over a person's breathing. These machines provide a flow of air, oxygen, or both into and out of the lungs. Depending on the the person's needs, the air can be given with the same or changing times between breaths (rate). It can also be given at a constant or changing length of each breath (duration). How much air (volume) is given in one breath and how hard the breath is pushed into and out of the lungs (pressure) can also be set on the machines.

What kinds of ventilators are there?

There are several kinds of ventilators that are used for different purposes. Which ventilator is chosen will depend on the breathing support that is needed for the patient or long-term care resident.

- *(Invasive) Positive-Pressure Ventilators* – are the most common ventilators. They have very precise controls and can deliver breaths at fixed times or to match the patient's own breaths. Small, simple ventilators of this kind are used in transport and larger ones are used in intensive care settings.

→ Mechanical ventilation is most commonly used for someone whose condition is expected to improve or be corrected.

- *(Non-invasive) Positive-Pressure Ventilators* – are the ones most commonly used in the home. These are known as CPAP (continuous positive air pressure) and BiPAP (bi-level positive air pressure) ventilators.
- *High Frequency Ventilators* – deliver rapid bursts of air with only small changes in pressure into the airway. These ventilators are used to exchange small but frequent volumes of air so that the lungs aren't exposed to large changes in volume that could damage them.
- *Negative-Pressure Ventilators* – were commonly used in the past but are now used only in limited cases. Examples of this type of ventilator include the tank or "iron lung", the pneumowrap, and cuirass or jacket. These ventilators are applied externally over the chest or whole body and so are awkward and difficult to use.

How do these machines attach to the person?

Ventilators can attach to the person in different ways. Most positive-pressure ventilators can be attached either invasively or non-invasively.

Invasive devices enter a person's airway directly. This method means that ventilation can be controlled more completely and precisely. However, invasive ventilators tend to be uncomfortable and need more maintenance. Also, the patient or resident can't eat, drink, or speak with the device in place.

Invasive ventilators can enter the airway in two common ways:

- *Endotracheal tube (ETT)*: A tube is inserted through the mouth or nose into the windpipe (trachea), or
- *Tracheostomy tube*: A tube is inserted into an opening in the windpipe that is created through surgery

Non-invasive devices are applied over or directly to the nose, mouth or both. These are usually more comfortable than invasive devices, and can be taken on and off so that the patient or resident can eat, drink, or speak.

Non-invasive devices can attach to the person in the following ways:

- *Face mask*: A mask sits over the entire face, the nose and mouth, or just the nose
- *Nasal prongs*: Tubing is inserted into the nostrils. This method only allows a very limited amount of pressure to be delivered to the lungs
- *Mouthpiece*: The device stays in the mouth and depends on the patient or resident being able to keep it in place

When might mechanical ventilation be needed?

Mechanical ventilation can be needed whenever a person has difficulty breathing (respiratory failure).

Difficulties in breathing can be caused by various illnesses and injuries that disturb the function of any of the systems involved in breathing: the respiratory system (the airways and lungs), the circulatory system (the heart and blood vessels), the nervous system (the brain and nerves), and the musculoskeletal system (the muscles and bones).

→ It's important to recognize that mechanical ventilation does not cure the condition that led to the breathing problems.

Sometimes more than one of these systems can function poorly at the same time, making it more difficult to control breathing.

Examples of illnesses and injuries that can cause breathing problems in these various systems are:

- Pneumonia, chronic obstructive pulmonary disease (COPD), asthma, and airway obstruction
- Infection (sepsis), congestive heart failure, and significant blood loss
- Stroke, spinal cord injury, cerebral palsy, and poisons
- Muscular dystrophy, and trauma

Who does mechanical ventilation benefit?

Mechanical ventilation can be important in resuscitation or in keeping someone alive. It also has more ordinary applications. For example, CPAP is often used to help people with significant snoring or breathing irregularities during sleep, even though they may not need help when they're awake.

It's important to recognize that mechanical ventilation does not cure the condition that led to the breathing problems. Mechanical ventilation is most commonly used in someone whose condition is expected to improve or be correctable, and so will be able to come off ventilation support.

Sometimes ventilator support is used for chronic (long-term) illness in order to improve a person's breathing enough so that they can enjoy life more than without the use of a ventilator. Usually only non-invasive ventilators are used for these purposes.

Are there any harms of mechanical ventilation?

Yes. Even though ventilation machines can be very sophisticated, they still can't regulate breathing as well as a person can normally do him or herself. Air is sometimes pushed into parts of the lungs at pressures or volumes greater than lung tissues are used to containing. This can stress or traumatize lung tissues so the lungs do not function as well as they used to.

One complication, called a pneumothorax, occurs when there is too much pressure for the lung tissues, causing an air leak. Air that enters the lungs then leaks out of the lungs and stays trapped in the chest. Air fills up space in the body that the lungs and heart normally fill; this can be life-threatening.

Pneumonia often occurs in people who have a tube inserted through the mouth or nose into the windpipe (an endotracheal tube). This is caused by an infection entering the chest along the plastic material of the tube. Pneumonia can be difficult to treat and it makes ventilation harder. Pneumonia can also lead to death.

Being on a ventilator can be uncomfortable. To make patients or residents on invasive ventilators more comfortable, sedation or pain control (‘analgesia’) is usually needed.

Finally, long-term use of a ventilator can lead to the breathing muscles getting weaker from lack of use (muscle atrophy). This can make it more difficult to take the person off the ventilator later.

How long should people use a ventilator?

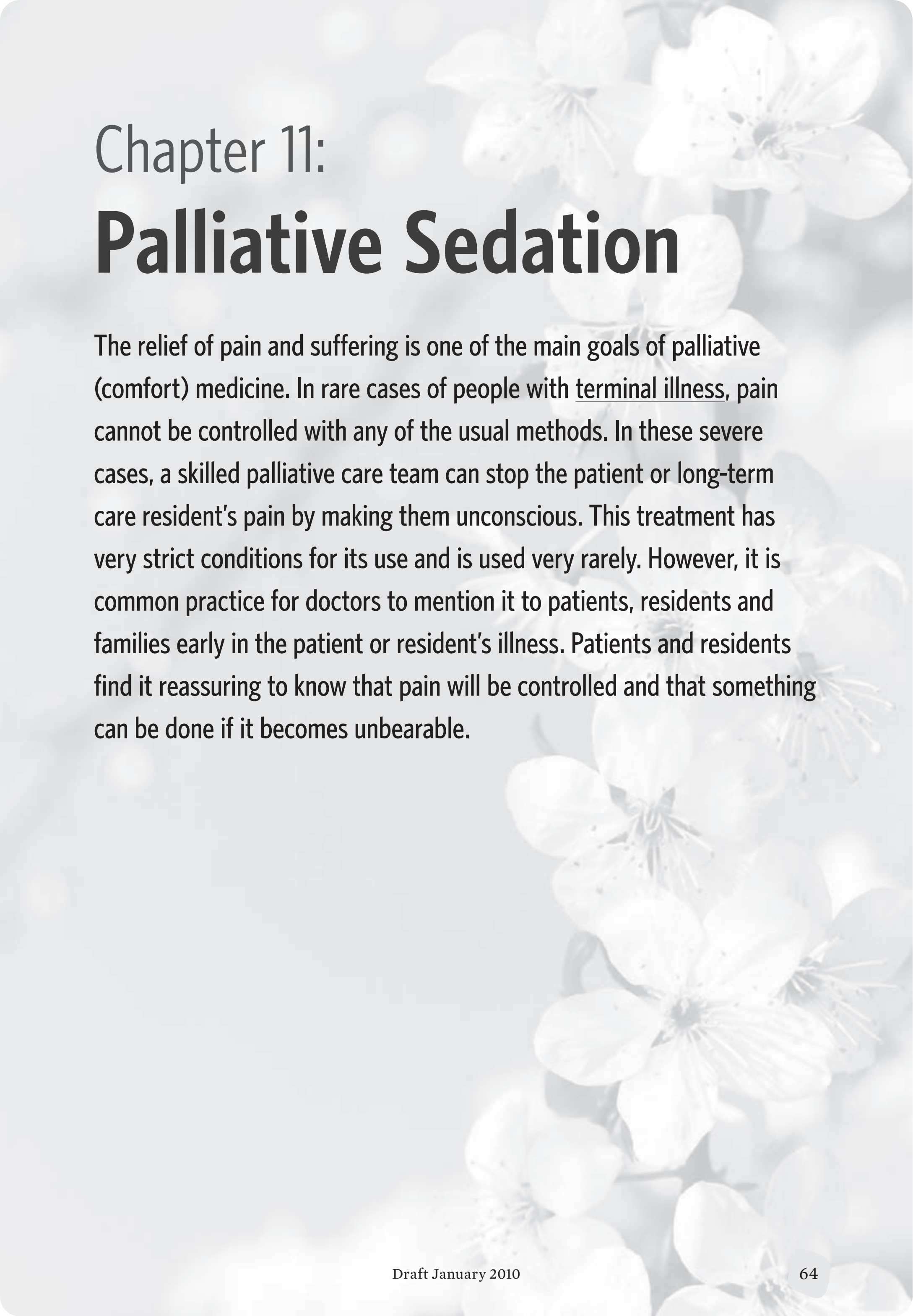
It’s best to take a person off mechanical ventilation as soon as it’s safely possible, because of the complications of ventilation. Ideally, the ventilator’s settings are reduced (weaned) to the point where the patient or resident is only receiving a small amount of help from the machine. If the person is still breathing adequately, then the goal is to remove the mechanical ventilator completely.

A difficult situation occurs when a person is permanently dependent on mechanical ventilation. In some situations, discussions may arise with the health care providers about whether the withdrawal of ventilation might be appropriate. These situations might be if the ventilation is causing more discomfort or complications for the patient or resident than benefits, is maintaining life in a state that is unacceptable, or is even prolonging the dying process. (For more about withdrawing treatment please see Chapter 6.)

If a decision is made to withdraw ventilation support, medications to manage any symptoms or signs of respiratory distress can make sure that this process is dignified and bearable.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.



Chapter 11:

Palliative Sedation

The relief of pain and suffering is one of the main goals of palliative (comfort) medicine. In rare cases of people with terminal illness, pain cannot be controlled with any of the usual methods. In these severe cases, a skilled palliative care team can stop the patient or long-term care resident's pain by making them unconscious. This treatment has very strict conditions for its use and is used very rarely. However, it is common practice for doctors to mention it to patients, residents and families early in the patient or resident's illness. Patients and residents find it reassuring to know that pain will be controlled and that something can be done if it becomes unbearable.

What is palliative sedation?

Palliative sedation is a technique used by doctors to bring about a state of unconsciousness (coma) so that a person is unaware of any sensations. Palliative sedation is also called ‘terminal sedation’ or ‘total sedation’.

Palliative sedation is widely accepted as an effective way to bring relief to those who are suffering from very hard-to-control symptoms, which sometimes occur at the end of life. These symptoms of pain and suffering are sometimes called ‘intractable symptoms’ or ‘intractable suffering’.

What method is used?

The drug most commonly used to perform palliative sedation is midazolam. Midazolam is in the class of drugs called sedatives. Morphine is not used for palliative sedation. If a person is already taking morphine (or another opioid) for the management of pain, this will often be continued as well.

Note that midazolam may be prescribed in lower doses for other reasons. For example, the drug is sometimes prescribed for mild sedation, for the relief of moderate anxiety, or to control involuntary muscle jerking. These are approved and common uses for this drug and they are in no way related to palliative sedation. If you are using midazolam for these other purposes, your doctor will explain why it has been prescribed.

Midazolam is given by an injection in the vein (intravenous) or under the skin (subcutaneous). Just enough of the drug is used so that the person isn’t aware of their surroundings or of people who may be present, and doesn’t feel any sensations. Normal body processes continue, and brain signals continue to tell the heart to beat and the lungs to breathe as usual.

When might palliative sedation be needed?

Palliative sedation is only rarely needed. This is because health professionals who care for terminally ill patients or residents usually have excellent knowledge about managing pain and suffering. Most patients and residents are able to live comfortably and pain-free with more common treatments.

Palliative sedation is only considered under very strict conditions. In general, the following conditions must be met:

- The person must be within hours or days of dying from a terminal illness.
- The person should be under the care of a palliative care team that is skilled in symptom management.
- The person (or their substitute decision-maker) and the attending physician must have chosen not to undertake resuscitation in the event of natural death.
- The person must be suffering from very severe symptoms, including
    - awareness of overwhelming pain
    - agitation
    - confusion
    - severe seizures that won't stop
    - severe breathlessness
    - prolonged choking.

All reasonable efforts to control the symptoms using known treatments must have been tried and failed.

Is palliative sedation euthanasia or assisted suicide?

No. Palliative sedation is not a form of euthanasia or assisted suicide. It might seem that giving someone this drug is similar to bringing about an early death because they are no longer awake or aware. However, palliative sedation does not typically speed up or delay death in any significant way. Rather, death occurs when it was already likely to occur. The only difference is that the person approaches their death without pain and suffering.

→ Palliative sedation is rarely needed because health professionals have excellent knowledge about managing pain and suffering.

Sometimes medication creates a relaxing effect and the body can conserve energy that was fighting pain symptoms. In these cases, the person may actually live slightly longer than they would without the medication - perhaps hours or occasionally one or two extra days. Prolonging life slightly through the relief of pain and suffering is widely considered acceptable.

Sometimes the patient or resident may die slightly sooner with the drug. This effect on the timing of death is justified by the doctrine of double effect. This doctrine considers the intention of an action and not the action itself. Because the clear *intention* of palliative sedation is to relieve unmanageable suffering while the person is alive, it’s considered ethically justified even if it has some effect on the time of death.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

PART IV

Decisions after Death

In this part, we consider decisions that may arise after a person has died and give some guidance about making these decisions.

Chapter 12:
Organ and Tissue Donation

Chapter 13:
Body Bequethal

Chapter 12:

Organ and Tissue Donation

In a situation where a loved one is approaching death or has died, the individual (if they are still alive and able to communicate) or his or her family members may be asked about donating some of the deceased (dead) person's tissues or organs to help others in need. Dozens of people can potentially benefit from organs and tissues donated from one person. There is a large shortage of donated organs and tissues in Canada.

Ideally, the deceased would have thought about whether they wanted to be a donor in advance, and made sure their family members knew their wishes. They might have indicated their wishes by signing the back of their Alberta Health Care card. If they haven't discussed this with their family or signed their health care card, then the deceased person's family will have to make this decision themselves, based on what they know of their loved one's wishes, values and preferences.

What is organ and tissue donation?

Organ and tissue donation refers to the removal of organs and/or tissues from one person for the purpose of transplanting them into other people. It may also include donation for research or medical education.

Organs for transplant can come from those still living or from those who have suffered brain death. Most often, the person who donates organs has died an unexpected, tragic death as a result of something such as a motor vehicle accident, spontaneous brain haemorrhage (bleed), or an accident like a fall. In this case, organs can be donated only after brain testing is completed and the donor is declared ‘neurologically brain dead’.

Only about 2-3 percent of people die in a way that causes brain death and in circumstances where organ donation is possible. People who are brain dead are kept on life support (mechanical ventilation) until the organs can be removed.

Most people who die in the traditional sense of death (when the heart stops beating) can be considered for tissue donation. People who donate tissues do not need to be on life support.

What is brain death?

To remove organs from someone who has died, they have to meet the criteria for neurological brain death.

Brain death occurs when severe damage to the brain causes it to swell. The skull is rigid, so as the brain swells it could potentially stop all blood flow in the brain. If this happens, the brain no longer receives oxygen or nutrients necessary for survival, and therefore the brain dies. This is how brain death occurs. Once brain death occurs, a person no longer has any limb movement, reflexes, or the ability to breathe on their own. In most cases, the heart will continue to beat with the support of a ventilator (breathing machine) and then the rest of the body can continue to function until the organs are removed.

Brain death is diagnosed primarily through a series of clinical tests that are performed by two doctors who are experienced in this area. In some cases where these tests cannot be completed, other testing is performed.

Brain death can't be reversed and, once it is diagnosed, it can be considered the time of a person's death.

Which organs and tissues can be transplanted?

Organs	**Tissues**
Heart	Heart Valves
Lungs	Corneas
Liver	Sclera (white of the eye)
Kidneys	Skin
Pancreas	Bone/Tendon
Small Bowel	Veins

Why might someone want to donate organs or tissues?

Many people across Canada have benefitted from donated organs and tissues. One organ and tissue donor can potentially help over 80 people. However, there is a shortage of donors and, therefore, a shortage of healthy organs and tissues for transplant.

Families are usually grateful that organ and tissue donation has given the gift of life to another person. Helping others during an otherwise tragic situation can help to ease grief and bring about a sense of purpose from their loss.

Who can plan to be an organ or tissue donor?

Any adult can decide to be an organ and/or tissue donor upon his or her death. Contrary to what is commonly thought, age is not a barrier to organ or tissue donation.

If you or a loved one is considering donating organs and/or tissues, gather information, talk to health care providers, contact the province's Organ and Tissue Donation Programs, or perhaps speak to a donor family. You may also know someone who has had a transplant who would be willing to tell you their personal experiences as an organ or tissue recipient.

Most importantly, let your family know your wishes. Though your informed consent gives health care providers full authority to use your body or the part(s) you specify for transplants, health care providers and donation agencies are often reluctant to act against the wishes of the next of kin.

It is always best to discuss your organ and tissue donation wishes with loved ones when you are healthy and before a tragedy occurs. If discussed in advance, knowledge of your wishes may help making the decision about donation easier for your family members who might have to act on your behalf.

→ It is always best to discuss your organ and tissue donation wishes with loved ones when you are healthy.

There are two ways that you can consent to the transplantation of your organs/tissues after your death:

1. You can sign the back of your Alberta Health Care card, along with a witness, or
2. You can consent in a document you have created yourself, so long as this is dated and signed by you and a witness. (If you cannot sign the document, the document should be signed by 2 persons who saw you agree to the donation. They must state that they each received instructions from you to document your consent, and state how your agreement to donate came about).

Who makes the final decision about donation?

If a person has not signed the back of their Alberta Health Care card or expressed their wish in a dated, signed and witnessed document, their next of kin can still consent to donation (though not if they have reason to believe that the deceased would have objected). With the informed consent of the deceased's next of kin, health care providers and donation agencies can carry out the process of transplantation unless these providers or agencies have actual knowledge that either the deceased or a person more closely related to the deceased would have objected.

→ If you are considering donating organs and/or tissues, it is important to let your family know your wishes.

For organ and tissue donation, the next of kin may be asked by a doctor, a registered nurse, a social worker, spiritual care advisor, or a representative of an organ donation agency if donation was something that their loved one had discussed with them or if there was any knowledge of their wishes.

Throughout the organ and tissue donation process, family members are encouraged to keep in touch with the donor coordinator from their organ or tissue donor programs. The coordinator can offer a range of information and supports, including:

- Information about the donation experience in general
- Linkages to other health care providers as required
- Liaising between donor families and recipients
- Education about organ and tissue donation

Can all potential donor organs and tissues be used?

No. Organs and tissues must first be determined to be healthy and suitable for transplant into another person(s). Timing is also critical - if too much time passes between death and organ/tissue recovery, the opportunity to donate may be lost.

Once donation consent has been obtained, either you, your family or the person(s) who knew you the best will be asked to provide answers to a standard medical/ social questionnaire consisting of approximately 45 questions. This questionnaire is used to determine whether the donor's organs or tissues are safe to transplant into another person. The questions relate to illnesses the donor may have had or been exposed to and the donor's lifestyle prior to his or her death.

Before organs or tissues are sent to potential recipients, a number of tests are run to make sure they are healthy, functioning well and free of disease. Blood and urine testing is performed on all organ and tissue donors and sometimes a biopsy of the organ is required.

Once the organs are deemed healthy and suitable for transplant, those who will receive the organs are selected based on:

- Medical urgency
- Blood group
- Height and weight
- Length of time on the waiting list
- Geographical location (since organs must be transplanted quickly)
- Tissue typing (for some organ donation)

Those who receive tissue donations are not selected in the same way as organ recipients. This is because tissue transplants are not as urgent. When a tissue is prepared for transplant, potentially anyone can receive that donor tissue. Often patients require tissues for transplant as part of a surgical procedure such as an orthopaedic hip revision, cornea transplant, or other procedure.

What other factors might influence my decision to be a donor?

There are a number of concerns that you might worry about when wondering whether to donate your own or a loved one's organs and tissues after death. Some of these concerns are addressed below:

- *Cost:* Organ and tissue donation is provided at no cost to the donor family. Alberta Health and Wellness covers all medical expenses.

- *Quality of Care*: Whatever decision you make about donating your organs or tissues upon death will not change or influence the type or quality of medical care you receive while alive.

- *Funeral Plans*: Family members can generally expect their loved one's body to be released for the funeral within 24-48 hours after beginning the donation process. Organ and tissue donation does not mean delaying or postponing funeral plans. Also, everything possible is done to ensure the dignity of the donor is maintained. All areas that are disturbed during the removal of the tissues are reconstructed. With eye tissue donation, the eye area is reconstructed so it's not possible to tell that surgery has been performed.

- *Religious Concerns*: Most religious groups do not discourage organ and tissue donation, and most major religions respect the individual's right to make a personal decision regarding donation. If you are at all concerned about the religious implications, please discuss the issue with a trusted religious leader.

- *Privacy*: Personal information isn't disclosed in the donation process, except as necessary to facilitate the donation process (for example, to assess a donor's suitability to donate). In Alberta, the law states that information which could identify a donor or recipient must not be made in a way that the information could become known publicly, unless the individuals have consented to this. In practice, organ donation agencies will not give the name or other identifying information of the donor to the recipients and vice versa. All deceased donors are assigned a unique identifier and new hospital number after consent is given.

Thank you to the Northern and Southern Alberta Organ and Tissue Donation Programs for their permission to base this chapter on their material (November 2007).

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book.

Chapter 13:

Body Bequeathal

While most people are buried or cremated after they die, some people may choose to donate their body for teaching purposes. An individual should give careful thought to whether they want to choose this option, and register their intentions to donate with their nearest medical school. It's very important to have clear discussions with their family since health care providers and donation agencies will often look to the next of kin to confirm the deceased's wishes. Though the informed consent of the deceased is enough to grant authority for the use of the deceased's body for the specified purpose, health care providers and donation agencies are often reluctant to act against the wishes of the next of kin.

Family members can also decide to donate the body of a deceased person to medicine if the person had not registered their wishes, as long as there is no reason to believe the deceased would have objected. Health care providers and donation agencies can use the deceased's body for this purpose with the consent of the next of kin, unless these providers and agencies have actual knowledge that either the deceased or a person more closely related to the deceased would have objected.

What is body bequeathal?

Body bequeathal is the donation of a person's body to a medical institution for study. Both the University of Alberta and the University of Calgary have medical schools that accept the donation of bodies for teaching purposes.

Donating a body is seen as a very generous gift by medical schools, which can use them to train new doctors:

> *Anatomical gifts are regarded by the medical community as precious gifts to medical education. Donors and their families can be assured their contribution is greatly appreciated by both students and faculty. All anatomical donations are treated with utmost respect.* (University of Alberta, Statement from the Division of Anatomy, 2004)

In rare cases, individuals with certain diseases or rare conditions may be able to donate their body, or parts of their bodies, for specific research. In most cases, however, medical institutions prefer to receive the donation with no restrictions. For more information, speak to the staff at the specialist clinic where you receive treatment.

What should be considered before choosing body bequeathal?

It's important to consider your personal values, religious beliefs and family support when deciding whether to bequeath your body upon death.

Asking yourself the questions below can help you explore your wishes. Some of these questions may also be helpful for family members who are trying to decide whether to donate the body of a loved one after death.

- Is body bequeathal acceptable in my culture?
- How does bequeathal fit with my religious, spiritual and moral beliefs?
- My remains will be cremated after study - is this acceptable to me?
- How does my family feel about bequeathal?
- Have I made my wishes about donation known to my family?
- If I decide to donate, how will this affect my family?
- Will my family carry out my wishes?
- Am I satisfied that my body will be respected during and after scientific study?
- Are there other people I would like to talk with about this?

Before signing the consent forms, potential donors should discuss their wishes for body bequeathal with family members and their physician, and carefully read any additional information given at the time of registration. Potential donors are also strongly encouraged to contact the medical school to ask any questions they may have.

How is consent given for body bequeathal?

If you decide to donate your body to a medical institution, you should register your intentions with your closest medical school (see the Resource Section at this end of this book). After making sure you understand all the information, you will be asked to sign some consent forms and will be given a registration card. You should carry this registration card next to your Alberta Health Care card so that both cards can be found immediately if you are ill or injured.

If you change your mind and decide to revoke (take back) your consent, you must do that in a dated, signed and witnessed document. And you must provide this document to any person who has a copy of the consent you gave as soon as possible.

Some people choose to write their intentions to donate their body in their will. Writing these wishes in your will alone is not recommended because wills are often read after the funeral, when it's usually too late for donation. If you do write these wishes in your will, make sure that your family and the executor or executrix of your will know that this is your intention.

→ If you decide to donate your body, you should make arrangements well in advance and make sure your family understands and supports your wishes.

If you have not registered with a medical institution prior to death, your bequeathal wishes can still be carried out by your surviving family. They must notify the medical school immediately upon your death and sign the consent forms. If you have no next of kin, or no next of kin is readily available, the person who has legal custody of your body after death may make the donation.

Family members or next of kin can also consent to body bequeathal without knowing the deceased person's wishes, as long as there is no reason to believe that the deceased would have objected.

Ideally, you should make arrangements well in advance and make sure your family understands and supports your wishes. They will have to carry out your wishes and make sure arrangements are made for the delivery of your body to the medical school. Being prepared for this process in advance will make things easier for them. Knowing your wishes early also allows the bequeathal process to take place before funeral arrangements are made.

Are all potentially donated bodies accepted?

No. There are some restrictions on which bodies can be accepted for study. To be accepted, the body must be needed and medically acceptable.

A donation may *not* be accepted if:

- An autopsy has been done
- Cavity embalming was done in the funeral home (medical schools have a special technique for embalming)
- Death was caused by disease, an accident, or some manner that makes study impossible

When death is fast approaching, or immediately at the time of death, the executor/executrix or next of kin should phone the medical school. A staff member of the anatomy department will assess the situation and confirm whether they are able to accept the donation. The medical school will also help your executor/executrix or next of kin arrange for the signing of the necessary forms and the delivery of the body.

There may be costs to the estate or surviving family members associated with body bequeathal; the Alberta Funeral Association can answer specific questions in this regard (see 'To learn more').

How does body bequeathal affect funeral plans?

It's recommended that families have an alternate plan for the body in case the donation is not accepted by the medical school. Arrangements can be made with a funeral home or memorial society.

If the body is accepted for medical study, family members can still hold a memorial service, which does not require the presence of the body. Memorial services are usually very important to loved ones and can be arranged at the funeral home of your choice.

Generally, there's no set time or limit for the scientific study of a donated body. This flexibility is due to when courses are scheduled and when donations are received. In some cases, the body may not be needed for several months and scientific study may not be completed for up to 2 to 4 years.

Following anatomical study (which is usually completed 1 to 2 years after receipt of the body), the medical school holds a memorial service for the cremated remains at the university cemetery plot. Family members, friends, medical students and faculty are invited to this communal service to honour the generous anatomical contributions that were made.

TO LEARN MORE

For more information related to this chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** and see the Resources section at the end of this book

Glossary

Advance care planning:
The process of reflecting on and communicating (often in written form) an individual's wishes about future health care. Preferences developed through advance care planning are based on personal values, wishes, and beliefs.

Agent:
An adult (18 years of age or over) who is named in a personal directive as having the legal authority to make personal decisions, including health care decisions, on behalf of someone else in case the latter person does not have the capacity to do so.

Artificial hydration:
A medical treatment in which fluids are provided through a tube, which is inserted either intravenously (in a vein) or subcutaneously (under the skin).

Artificial nutrition:
A medical treatment in which nutrition is provided through a tube, either via the nose and throat (NG tube) or directly into the stomach through the abdominal wall (PEG or G-tube).

Assisted suicide:
Providing someone with the means to end their own life when they cannot do so alone.

Autopsy:
The medical examination of a body after death.

Best interests:
A decision about what is good for someone, determined by comparing the benefits and harms of the action (e.g., treatment) being considered. For substitute decision-makers discussed in the *Adult Guardianship and Trusteeship Act* (all except agents named in a personal directive), best interests are defined as including a broad range of factors in additional to an evaluation of harms and benefits, including the wishes, values and beliefs of the individual.

Brain death:
A neurological definition of death caused by severe swelling in the brain. The swelling eventually blocks all blood flow to the brain, thereby depriving it of essential oxygen and nutrients and causing it to die. Brain death is irreversible and results in a loss of limb movement, reflexes, and the ability to breathe on one's own.

Capacity:
A person's ability to understand and appreciate the relevant information about a particular treatment and the reasonably foreseeable consequences of having that treatment or refusing it. Capacity can be global or decision-specific. (See Decision-specific capacity and Global incapacity.)

Capacity assessment:
A test to determine whether a person has the capacity to make decisions, including health care decisions.

Cardiopulmonary resuscitation (CPR):
A method of trying to revive someone whose heart and lungs have stopped and who would otherwise be declared dead. It involves one or more of the following techniques: pushing down hard and repeatedly on a person's chest, using electric shock, breathing directly into the person's mouth, and/or filling their lungs with air either by placing a mask over their nose and mouth or a tube directly into their windpipe.

Co-decision-making:
A decision-making option for adults who are not capable of making decisions on their own, but who could make decisions if they had the support and guidance of a trusted person.

Consent (see Informed consent)

Decision-specific capacity:
The ability to make a particular decision (not all decisions) based on the definition of capacity (above).

Delirium:
A disturbance of a person's mental functioning, usually of a relatively short duration. A person with delirium may experience illusions, delusions, hallucinations, over-excitement, restlessness, and an inability to communicate coherently.

Dementia:
A condition caused by damage to the brain due to certain illnesses, such as Alzheimer's disease. Dementia is an irreversible and progressive loss of mental function, marked by impairments in memory and reasoning, among other symptoms.

Diagnosis:
A medical term for the condition or illness causing a person's illness or disease.

Do Not Resuscitate or Do Not Attempt Resuscitation (DNR or DNAR):
A medical order recorded on a person's medical chart, stipulating that in the event a person's heart and/or breathing function stops, health care providers may not try to restart these functions.

Doctrine of double effect:
A principle which states that an action is justified if the intention to bring about a good consequence outweighs a second, unintended but foreseen, bad consequence. For example, providing pain medication with the intention of relieving suffering is argued to be justified even though it may also hasten that person's death.

Dysphagia:
The inability to swallow anything by mouth, including food and water.

Edema:
The accumulation of fluid in the body's tissues. It appears most commonly as swelling in the feet, ankles and legs.

Ethically (Ethics):
Referring to the field of study concerned with being a good person and doing the right thing. Ethics in health care is concerned with the identification, application and analysis of values and principles at the individual, organizational and societal levels.

Euthanasia:
The act of intentionally ending the life of another person for compassionate reasons, such as to relieve unbearable suffering or to provide a good death to a person with an incurable or terminal illness."

Executor/Executrix:
An adult male (executor) or adult female (executrix) who is named in the will of another person. The executor/executrix is responsible for ensuring that the requests of the maker are followed and the estate of the deceased is distributed according to those instructions.

Global incapacity:
The inability to make any decisions, based on the definition of capacity (above).

Guardianship order:

An order issued by the Court that appoints either a private individual or the Public Guardian to make personal and/or health-related decisions on behalf of an incapable person.

Hallucinations:

A sensory impression (i.e., sight, sounds, touch, smell, taste) felt or experienced by a person that is not real. For example, a person may insist that they see bugs crawling on the wall when none can be seen by anyone else. Hallucinations may be caused by psychological disturbances, drugs, alcohol, organic brain disease, or even from exhaustion.

Incapable:

A person who is not capable of making health care decisions.(See Capacity.)

Informed consent:

A capable person's agreement to a proposed medical intervention, after being informed about the relevant facts of the proposed intervention, given without undue coercion or significant pressure from others.

Life-sustaining treatment:

A medical intervention, technology, procedure or medication that helps a critically ill person stay alive and without which they would die.

Mature minor:

A person under the age of 18 who has the capacity for decision-making. Mature minors can choose to take responsibility for their own health care decision-making.

Mechanical ventilation:

The use of machines to help with or take over a person's breathing. These machines provide a flow of air, oxygen, or both into and out of the lungs.

Minor:

A person under the age of majority. In Alberta, a minor is someone under the age of 18.

Opiates/Opioids:

Narcotic medications most often used for the alleviation of pain.

Palliative sedation:

A technique used by a physician to bring about a state of unconsciousness (coma) in a terminally ill patient with intractable (unbearable) suffering. To be eligible, the person must be within hours or days of dying from a terminal illness and have severe symptoms that have not responded to conventional treatments.

Persistent vegetative state:

A medical diagnosis for a patient who has no cognitive awareness of him or herself or their environment, is completely unresponsive to psychological and physical stimuli, and displays no sign of higher brain function. Some key autonomic (lower brain) functions remain, such as breathing and heart rate.

Personal directive:

A legal document made by a capable adult (18 years or older) that records their wishes for future health care and/or other personal decisions in the event that they become incapable of decision-making. A personal directive can either 1) state the maker's health care preferences (most often related to end-of-life care and/or the foregoing of certain treatments in certain situations), and/or 2) name another adult(s) to make health care decisions on their behalf (and who will make sure that the maker's preferences are followed if these are also stated).

Power of attorney:

A legal document prepared by a capable adult (the donor) that names another person to make financial decisions on their behalf. A power of attorney can either be 1) enduring, meaning that it comes into effect once the donor loses capacity or it stays in effect if the donor loses capacity, or 2) not enduring, meaning that it is no longer in effect if the donor becomes incapable.

Prognosis:

A medical term referring to the likely outcome of a person's illness or injury, including the likelihood and extent of recovery.

Quality of life:

The value or meaning of a person's life. It is defined differently by each person depending on the relationships, activities, or abilities that they hold dear.

Specific decision-making:

A family member who is chosen from a specific list of relatives to make a particular decision about health care or about a temporary admission to or discharge from a residential facility on behalf of an incapable adult.

Substitute decision-maker:

An individual who is named or appointed to make health care and/or other personal decisions on behalf of another person who lacks decision-making capacity.

Supported decision-making:

A decision-making option that allows a capable person to have help accessing and understanding information, making a decision, and/or communicating that decision.

Terminal illness:

An illness that will result in the person's death.

Trusteeship order:
An order issued by the Court that appoints either a private individual or the Public Trustee to make financial decisions on behalf of an incapable person.

Will:
A legal document made by a capable adult (18 years or older) which governs financial and property matters. A will outlines the maker's decisions regarding the distribution of his or her personal assets, and may also include directions regarding the handling of the body of the maker after death (e.g., burial, cremation, funeral, etc.). A will also names a person (see Executor/Executrix) who has responsibility for the execution of these requests.

Withdrawing (a treatment):
Stopping a certain treatment once it has been started.

Withholding (a treatment):
Not starting a certain treatment.

Resources

To download a copy of this booklet, for more information on the information discussed in this booklet and to view online resources related to each chapter, please visit **www.phen.ab.ca/hopesandwishes/resources** or contact the Provincial Health Ethics Network.

Provincial Health Ethics Network

507, 10240 – 124 Street
Edmonton, Alberta T5N 3W6
Phone: 780.447.1180
1.800.472.4066 (toll-free in Alberta)
Email: info@phen.ab.ca
Website: www.phen.ab.ca

You may also contact one of the following organizations for information on a specific topic, as outlined below.

Alberta Office of the Public Guardian

The Office of the Public Guardian provides decision-making mechanisms for individuals who are unable to make personal non-financial decisions for themselves. They have a wealth of resources related to personal directives, supportive decision-making options, guardianship and trusteeship.

Room 330, 10405 Jasper Avenue
Edmonton AB T5J 4R7
Phone: 780.422.1868
Toll Free: 1.877.427.4525
Website: www.seniors.gov.ab.ca/opg

Alberta Office of the Public Trustee

Alberta's Office of the Public Trustee protects the financial interests of vulnerable Albertans by administering the estates of dependent adults, deceased persons and minors when there is no one else to act.

Edmonton Office
400, 10365 - 97 Street
Edmonton, AB T5J 3Z8
Phone: 780.427.2744
Toll Free: 310.0000
Website: www.justice.gov.ab.ca/public_trustee

Calgary Office
2100, 411 - 1 Street SE
Calgary, AB T2G 4Y5
Phone: 403.297.6541
Toll Free: 310.0000

HOPE (Human Organ Procurement and Exchange) Program

The HOPE Program is the provincial program responsible for the coordination of donation, recovery and distribution of organs for transplantation within Alberta. It promotes awareness of organ and tissue donation by providing informative and interactive education to health professionals and members of the public.

Southern Alberta Program
Foothills Hospital
1403 29 Street NW
Calgary, AB T2N 2T9
Phone: 403.944.8700
Email: saotdp@albertahealthservices.ca
Website: www.calgaryhealthregion.ca/hope

Northern Alberta Program
8-110 Clinical Sciences Building
University of Alberta
8440-112th Street
Edmonton, AB T6G 2B7
Phone: 780.407.8411

University of Alberta Anatomical Gifts Program

The University of Alberta's Division of Anatomy accepts the donation of bodies for teaching purposes through its Anatomical Gifts Program.

5-01 Medical Sciences Building
University of Alberta
Edmonton, AB T6G 2H7
Phone: 780.492.2628
Email: anatomy@med.ualberta.ca
Website: www.anatomy.med.ualberta.ca

University of Alberta Health Law Institute

The Health Law Institute provides information (not legal advice) to health care professionals, students, community groups and members of the general public about the law as it relates to the provision of health care services.

Law Centre, University of Alberta
Edmonton AB T6G 2H5
Phone: 780 492-8343
Email: hli@law.ualberta.ca
Website: www.law.ualberta.ca/centres/hli

University of Calgary Body Donation Program

The University of Calgary's Department of Cell Biology and Anatomy accepts the donation of bodies for teaching purposed through its Body Donation Program.

Faculty of Medicine
University of Calgary
Health Sciences Centre
3330 Hospital Drive NW
Calgary AB, T2N 1N4
Phone: 403.220.6950
Email: anatomy@uacalgary.ca
Website: www.fp.ucalgary.ca/bodydonation

Serious illness or injury can cause great anxiety and uncertainty for both individuals and their families. In addition to the emotional distress that often accompanies poor health, there are often many important and difficult health care decisions to be made. This booklet is meant to help guide decision-making by giving clear information about medical treatments and ethical issues that may arise in this difficult time.

It may be used during a crisis or in advance of one, to help start discussions with loved ones about future health care planning. It may be a resource for individuals facing their own health care decisions or who are in the position of making difficult decisions for family members or others. We hope that this booklet will help to ease the burden of decision-making and provide comfort in the knowledge that decisions are being made in keeping with your wishes or the wishes of your loved one.

Provincial
Health Ethics
Network

Provincial Health Ethics Network
507, 10240 – 124 Street
Edmonton, Alberta T5N 3W6

Phone: 780-447-1180/ 1-800-472-4066
Email: info@phen.ab.ca
Web: www.phen.ab.ca