Hear Our Voice
A workbook for parents and guardians to support Advance Care Planning for children and youth

Body
People
Feelings
Meaning
Tougher Stuff

Alberta Health Services
Alberta Children's Hospital
Credits
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Dear Families,

Sometimes families have to make hard medical decisions for the people they love. We know that having a child with serious, chronic, or life-threatening illness isn’t easy.

Advance care planning is a process that has you think about your values and your wishes for your child’s care. It also gives family members the information they need to fully understand the illness and talk about treatment choices they may have to make later on. Part of advance care planning is talking with your child’s healthcare team about short and longer-term care goals for your child. This type of planning makes sure that your child’s healthcare team knows exactly what your wishes for your child are and that you know what treatment options there might be.

You child’s healthcare team may begin talking or asking about your Goals of Care for your child. These goals tell your child’s healthcare team the type of care and treatment you and your child’s doctor decide is best for your child. The Goals of Care Designation uses a letter and a number to represent types of medical treatment. The designation becomes part of your child’s medical record so that everyone caring for your child knows the choices you and your child’s doctor have made for your child’s care.

These conversations are meant to be an ongoing part of your child’s care. We know that these conversations aren’t easy, but we do believe they’re important. Help your child’s healthcare team care for your family in a way that honours your needs and wishes.

Sincerely,

Your Healthcare Team
Having to decide about your child’s care is never easy. We hope that this workbook gives you information that will help you decide the care you wish for your child. A workbook gives you the chance to think about things in your own time and way. You can also write down your thoughts, feelings, and questions.

The first section of this book explains some of the words that you will often hear in the healthcare setting. It also explains the treatments your child may be offered and the different Goals of Care Designations that your healthcare team will talk about.

Some of this information will apply to your child, and some of it may not. At the end of each section there is a space for you to write down questions to ask your healthcare team. This is your workbook so use it in any way that works for you.

The second section of this workbook asks questions that will help guide you to think about your child’s care. Remember: this workbook is just one part of a process - you aren’t expected to know the answers to all the questions or to come up with a Goals of Care Designation. Rather, use this workbook to help guide the thoughts you have and to communicate with the healthcare team.

The final section of this workbook includes other resources for you and your family. You can also write down resources you find.
Advance care planning is a process for you to:

- think about what’s important to you when making choices about your child’s healthcare, now and later on
- learn about medical information that’s important to your child’s health concerns
- talk about your wishes as a family
- write down your wishes so that your family and healthcare providers know them.

If your child has an illness that may change over time, there may come a time when your wishes for your child’s care become very important for the healthcare team to know. The information in this workbook and the advance care plan you develop for your child will tell your healthcare providers what’s important to you and your family.

Talking About Your Wishes

It’s good planning to talk to your family and to your healthcare team about your wishes for your child’s care. It will help those who may need to help you make decisions later on about a treatment. Talking about these decisions can be hard. It may bring up questions, concerns and uncomfortable feelings. Give yourself the time you need to make your decisions and to make sure healthcare providers understand your family’s wishes. Healthcare providers will always talk with you, your child and your family about the healthcare choices you have.
Advance care plans are verbal or written instructions made about healthcare goals and decisions. These plans describe the kind of treatments you want (or don’t want) for your child.

Capacity is the ability of a person to understand the information and possible treatment outcomes when making a decision.

Guardian is the person who has the legal authority (and duty) to care for the personal and property interests of someone 17 years or younger.

Comfort measures include medicines, wound care, oxygen, positioning, and other psychological, social or spiritual measures used to relieve pain and suffering.

CPR (cardiopulmonary resuscitation) is a medical procedure done when the heart has stopped and involves a health care provider pushing on a person’s chest. The purpose of CPR is to keep oxygen going to the brain until the heart can be restarted (see Resuscitation for more information).

Goals of Care are your values, beliefs and preferences for your child’s care. Goals of Care may include: 1) curing a condition, 2) controlling a condition so it doesn’t get any worse and 3) managing symptoms, such as pain or discomfort, even if the disease isn’t curable.

Healthcare provider is anyone who provides a health service(s) (for example, a doctor, nurse, social worker or physiotherapist).

ICU (Intensive Care Unit) is a unit in a hospital that gives advanced and specialized care to very sick people who need constant care and monitoring with special equipment.

Informed consent is the permission you give to your healthcare providers to do medical investigations and/or treatments. Healthcare providers will tell you about the procedures and their risks. A consent form may have to be signed before some procedures will be done.

Intubation is when a tube is inserted in a person’s airway so that a breathing machine (ventilator) can be used to support breathing.

Life-sustaining interventions are therapies that can be used in the end stage of an illness to offer comfort or keep a child alive longer. Examples include tube feeding or giving fluid through an intravenous (IV). These therapies may keep a child alive a little longer, without treating, controlling or curing the medical condition that will eventually lead to the child’s death.
**Life-support** is the support of the body’s vital functions while it heals. This type of care might include life support equipment, such as a breathing machine (ventilator). A child might need to be admitted to the ICU for some of these treatments. If a treatment can’t help, it won’t be offered.

**Palliative care** is the treatment and care of people with a progressive or life-threatening illness and for the people important to them. A treatment aimed at a cure may still be given or palliative care may be the only focus of care. The goal is keeping them as comfortable and free from pain as possible while also meeting their emotional, mental, social, psychological and spiritual needs.

**Resuscitation** is the first efforts done to stabilize vital signs. This may include using a breathing machine, CPR and/or medicine. The person usually needs to go to the ICU after being resuscitated.

**Terminal condition** is an injury or illness that has no cure and from which doctors expect the person to die, even with medical treatment.

**Understanding Resuscitation and CPR**

If a person isn’t breathing or if their heart has stopped beating, there are things than can be done to try to bring back or take over these body functions. These may include using machines that help or maintain breathing, doing CPR and using medicine. Together, these procedures are called resuscitation.

Sometimes families might accept a breathing machine for their child, but not want CPR. CPR isn’t always offered; it works best when the heart stops suddenly, but the person is otherwise healthy. For people with a chronic or a life-threatening condition, CPR works less than 4% of the time. Usually, if resuscitation or CPR is successful, the child will need life-support machines in the ICU to try to stabilize him or her.

When a child stops breathing or has a sudden life-threatening illness, resuscitation, CPR and life-support interventions are used unless an agreement was made not to offer them.

Parents who don’t want life-support equipment need to understand that this means that their child won’t be given CPR.

You may wish to refuse or limit resuscitation for your child. If this is your wish, you need to discuss this with your child’s doctor.
Treatments Your Child Will Always be Given

Healthcare providers work with you and your child to find the best treatment to manage your child’s pain or other symptoms. If there comes a time when you no longer want your child to have life support - or life sustaining - interventions, managing symptoms to make your child as comfortable as possible are still offered.

This may include:

- taking good care of the skin and mouth
- making sure your child is in comfortable positions
- giving medicine to help manage pain
- giving medicine to help breathing problems
- surgery to control pain
- offering psychosocial and spiritual support
Factors That Affect Healthcare Decisions

Your healthcare provider will usually talk with you about treatments. You will also have to give your consent before starting treatments. Sometimes this doesn’t happen because your child’s condition changes so fast that there’s no time to talk. The prognosis, degree of benefit, treatment options, and the Goals of Care Designation are things you can talk to your healthcare team about beforehand. This makes it easier to care for your child if his or her condition changes quickly. Your healthcare team will talk to you more about the terms below.

**Prognosis - Medical Condition and Chance of Recovery**

A prognosis is the expected outcome of an illness or condition. It’s meant to help predict the course of an illness or condition. Understanding what may be expected to happen will also affect the type of treatment(s) you want your child to have or not to have. There can be more than one outcome for an illness or condition. For example:

- an illness/condition from which there is a good chance of recovery
- an illness/condition from which the chance of recovery isn’t known or is uncertain
- an illness/condition from which there is no reasonable chance of recovery

**Degree of Benefit - Will the Treatment Benefit Your Child?**

A treatment:

- is likely to benefit when there’s a good chance that the treatment will restore and/or maintain organ function. There is a high chance that your child will be discharged from the hospital
- is uncertain when it’s not known or is uncertain if the treatment will bring back functioning. The prognosis or the chance of something happening (good or bad) isn’t known or is uncertain
- certainly won’t benefit when there’s no reasonable chance the treatment will help your child

**Treatment Options**

Knowing your child’s prognosis, the likelihood the treatment will benefit your child, and your Goals of Care, your healthcare team will speak with you about treatments that may or may not benefit your child.

When a life-threatening event happens, treatment options are guided by:

- family wishes and
- if the treatment will or will not benefit your child, or if it will cause harm
It’s not possible to know ahead of time about every situation that can happen to your child. However, there are some treatments that are part of the care that you can think about. It’s important to understand what these treatment options are so you’re better informed.

**Goals of Care**

Your values will affect the types of treatment options you wish your child to have or not to have. Your values will also decide what your goals are for your child’s care - what you hope the treatments will do.

Your values and goals may change over time. If they do change, make sure you update your workbook and talk to your healthcare provider(s) and your family.
Your values and goals for living may include:

• living as long as possible (for example, to go to a special event or to honour your faith)
• lessening pain (even if it means that your child is unconscious)
• ensuring quality of life (for example, having procedures that will let your child do certain activities for a longer time) and independence (for example, your child living at home as long as possible)
• having your child treated where you feel most comfortable

Goals of care may also include:

• curing a condition
• controlling a condition so your child doesn’t get any worse
• lessening symptoms, such as pain or discomfort

When recovery isn’t likely, the focus becomes about controlling pain and symptoms and letting death happen naturally.
Are there treatments that you think you don’t want your child to have.

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Are there treatments that you think that you would want for your child?

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In Alberta, when you make a care decision that should be shared with others, it can be written by a doctor as a Goals of Care Designation Order. This is a way your child’s doctor can communicate instructions to everyone who may care for your child, in a way that respects the choices you and your doctor have made for your child.

Goals of Care Designations describe types of medical treatments and the places where those treatments can be offered. These care decisions are described by a picture and a letter:

- **Resuscitative (R)**
  A focus of care that includes resuscitation and life support measures.

- **Medical (M)**
  A focus of care to manage a condition, but that does not include resuscitation or life support measures.

- **Comfort (C)**
  A focus of care to provide comfort and relieve symptoms.

You can change the Goals of Care Designation when your child’s health changes or if you change your mind about the care you want your child to have.
A Goals of Care Designation can be changed when your child’s health changes or if there is a change in your preferences for care.
This section helps you think about some of the information you’ve been given and how it relates to your child and your family. There is no right or wrong answer. These answers may change over time so it’s important to go back to the questions as many times as you want.

**Body**

1. In your own words, describe the illness/condition you are facing as a family:

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2. How has this diagnosis changed your life as a family?

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3. Are there symptoms that your child has that you find hard to cope with?

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4. How well do you feel your child’s pain is being managed? Do you have questions about managing your child’s pain and symptoms?

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5. When you think about the future and you’re child’s illness/condition, what information would you still like to have?

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Feelings

1. When you think about your child’s illness/condition, what words come to your mind?

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2. Strong feelings are part of the illness/condition experience. What are some of your feelings and what do you do to express these feelings?

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3. Are there medical treatments that you feel strongly about? What are they and how do they make you feel?

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People

1. When going through a hard time, are there certain people you want to have near?

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2. Have you met other families who have had a similar experience? Is this something you have found (or might find) helpful?

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3. How do you feel your family is coping with your child’s illness?

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4. Are there activities that are important for your child and your family to do together?

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5. Write down the names of people you can rely on for support. Include members of your healthcare team. Put an * beside the people you might include in a conversation about your child’s Goals of Care Designation:

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Meaning

1. Is there a religious faith or spiritual belief system that is important to you and your family? Can you describe how this helps you?

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2. What do you do to take care of your inner self?

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3. If your child could leave behind a special way to be remembered, what would that be?

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Tougher Stuff

1. What are the things that worry you the most about your child’s illness/condition?

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2. In the past, who or what has helped you figure out an answer to a decision that’s been hard to make?

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3. What are some of the things you hope for?

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4. Who would you like to talk to about the choices you’ve made/had to make?

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Please write down your questions about the information in this workbook and/or the decisions you face about your child’s medical condition.

1. Questions for my child’s healthcare team:

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2. Questions for my family members or friends:

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3. Questions I need to think about a bit longer:

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Resources to provide guidance and support to Alberta children and families:

**Advance Care Planning for Children and Families**

hearmyvoice@albertahealthservices.ca
- Hear My Voice cards – an interactive family activity to promote conversations about what matters to your family
- Hear Our Voice workbook – a place to record your thoughts and feelings as you consider goals for your child’s care and support

**Pediatric Palliative Care**

Palliative care for children is provided as extra support along with other medical care. Team members have special skills in how to manage symptoms, control pain and support care decisions. You can call and ask for a meeting.

**Northern Alberta**
780-407-7825

**Southern Alberta**
403-955-7744

**Spiritual Care Services**

Spiritual and religious support offered in a respectful, compassionate, multi-faith environment

**Stollery Children’s Hospital, Edmonton**
780-407-8447

**Alberta Children’s Hospital, Calgary**
403-955-7868

**Clinical Ethics Service**

An Ethics consultation provides a safe process to help families and health care professionals engage in fair and transparent decision-making that includes all voices and concerns of those who will be impacted by the decisions and actions.

clinicalethics@albertahealthservices.ca
Toll Free: 1-855-943-2831

**John Dossetor Health Ethics Centre**
- Edmonton: 780-492-6676
- Calgary: 403-943-2821

**Medical Social Work**

Medical social workers are trained to help families understand the resources to support personal, emotional, financial or other needs during illness, treatments or hospitalization. Ask any member of your healthcare team to contact a social worker.

**Family & Community Support**

**Family & Community Resource Centre**
1-877-943-3272 (toll free in Alberta)

**Alberta Children’s Hospital, Calgary**
- Calgary Family Support Specialists
  403-955-3272
- Child Health Information Specialist
  403-955-7745