Advance Care Planning & Goals of Care

Information Booklet

August 20, 2015

Advance Care Planning

A guide for making healthcare decisions with loved ones and healthcare providers

CONVERSATIONS MATTER

Plan your healthcare together

- **Talk about your values, beliefs and experiences**
- **Pick an Agent to speak for you if you cannot speak**
- **Complete a Personal Directive**

Make your wishes for future healthcare known
Talk to a healthcare provider today

Advance Care Planning is a process that helps you to:

- **Think about what is important to you**
- **Talk about your goals for healthcare**
- **Create plans that reflect your goals**
- **Document your future healthcare plans**

When Advance Care Planning is needed

Some people are able to guide their healthcare right up until their death.

Some people are not able to speak for a period of time because of situations such as coma, stroke, and advanced Alzheimer's.

Should you be ill or injured and be unable to speak for yourself, Advance Care Planning ensures you have someone else to speak for you so your healthcare wishes are heard and respected.

Advance Care Planning is a gift you give to others. There can be less stress in a crisis if the important people in your life and healthcare providers know the type of care you want rather than them having to guess.

Advance Care Planning is important

Advance Care Planning is for every adult, not just people with health issues.

It is best to do Advance Care Planning when you are feeling able rather than during a crisis.

No one can make you do Advance Care Planning. Should you choose to do Advance Care Planning, healthcare providers can give you information, answer your questions and help you with the process.

Advance Care Planning is something you do for yourself and for those people important to you

Tip from a healthcare provider:

It's my hope that everyone can make their own healthcare decisions right up to their death, but we can't predict that.

I've heard of healthy people who slipped on the ice, hit their head, had a brain bleed and it was just totally unexpected.

Advance Care Planning is a little bit of peace of mind. We can't protect ourselves all the time and walk around in bubble wrap, but if you plan ahead, at least other people know the type of healthcare you want if something happens.

Advance Care Planning process overview

- You meet with a healthcare provider to talk about your wishes for future healthcare as many times as you like.
- You are encouraged to invite the important people in your life to join the talks.
- You are encouraged to ask questions. Your healthcare provider is happy to help you through the process.
- You will be asked to pick an **Agent**.
    - ❖ An Agent is someone who will speak for you and help healthcare providers hear your voice if you cannot speak or make decisions for yourself.
- You will learn what is available to you and you will decide if those healthcare options are going to be helpful to you to achieve ***your*** goals for a life worth living.
- **Nothing is set in stone.** You can change your wishes whenever you want, as many times as you want.

Your values and beliefs

An important part of Advance Care Planning is your healthcare providers learning about you. For example,

- Who are the important people in your life?
- What else is important to you?
- What makes you happy in your life?
- Do you have religious or spiritual beliefs?
- What do you think makes your life worth living?

Learning about your health is also very important, especially if things change and you have a new health challenge. Learning about your health can help you to make decisions about the type of care you want.

Past healthcare experiences

Your past health experiences and those of people you know can help to guide the type of healthcare you would want in the future.

Tip from a healthcare provider:

I believe that the life experiences that you've had are the most powerful things because you've lived them, you've seen what choices people have made in different situations.

So I suggest you look to your past, your family, your friends, anyone who's had health challenges or been in situations, and say, 'I want this because I think that makes sense to me,' or 'I don't want this because that was what happened here, and I don't want to go down that road.'

Sometimes the healthcare experiences of others cause us to feel anxious or afraid.

It is important to share those fears so that your healthcare providers can find ways to reassure you that they will help you to achieve your goals for care.

Tip from a healthcare provider:

You can be healthy even when you're ill. Being healthy means

- having strong, healthy relationships,
- being in control of what happens to you,
- being able to talk about the things that make you afraid or angry, and
- being able to talk about the things that are important for living and life worth living.

Select an Agent

An Agent can be anyone over the age of 18 years who has capacity to make decisions.

Agents can be a family member, a friend or someone important to you. You can have more than one Agent.

If you do not want a family member, a friend or someone important to you to be your Agent, you can get a Public Guardian.

An Agent should be someone you count on to share your health information and wishes for care with healthcare providers if you cannot speak or are unable to make decisions.

Talk with your loved ones

It is very important to make sure the person (or people) you wish to be your Agent(s) is/are aware you want them to do that for you and (s)he/they agree to be your agent.

Tip from a healthcare provider:

You can say something like, 'I've given it a lot of thought and if something happens to me and I can't talk, I'd really like you to be my Agent. That's the person who tells my doctors what type of care I want. Are you willing to be my Agent?'

It is important to let the people in your life know who you have picked to be your Agent.

There are always lots of emotions in a crisis and if everyone knows who will speak for you if you can't speak or make decisions, that relieves some of the stress.

Personal Directive

A Personal Directive is a legal document in which you name your Agent, the person to be your voice when making decisions about your healthcare and personal care if you cannot speak. It gives your Agent and your family direction.

You do not need a lawyer to complete a Personal Directive. As long as you sign it in front of witnesses and your witnesses sign it, it is legal.

It does not come into effect unless you are not able to tell healthcare providers your healthcare choices.

You can get the Personal Directive form from a healthcare provider or the

Office of the Public Guardian for Alberta – phone number: 1-877-427-4525.

You can print off a copy of "Schedule 1 – Personal Directive Form" and "Instructions on using the Personal Directive Form" at this website

http://humanservices.alberta.ca/guardianship-trusteeship/opg-personal-directives.html

Talk with healthcare providers about your wishes

You do not have to wait for a healthcare provider to start talking about Advance Care Planning.

You can start the conversation.

Goals of Care Designations

CONVERSATIONS MATTER

Talk about your medical wishes with loved ones and healthcare providers

Medical Care (M)

Provides all suitable care to manage or cure illnesses without using unwanted intensive treatments

Comfort Care (C)

Provides as much support, care and comfort as possible to ease symptoms from incurable illnesses

Resuscitative Care (R)

Provides all suitable intensive treatments to prolong and preserve life as long as possible

Goals of Care has two parts:

- You talk with a healthcare provider about ***your*** goals for healthcare should you be unable to speak for yourself
- A doctor or a nurse practitioner works with you to fill in a **Goals of Care Designation Medical Order form** before he or she signs it

This process ensures that healthcare providers do only what you want and not things you do not want.

The Goals of Care Designation Medical Order form goes along with the Personal Directive. It is important to have both forms.

Before signing the Goals of Care Designation Medical Order form, the doctor or nurse practitioner will talk with you about the care options available and suitable to you.

You decide what is going to be helpful to you and what will fit with ***your*** goals of care.

There are three **Goals of Care Designations:**

Medical Care

Comfort Care

Resuscitative Care

You can change your mind about what care you want at any time, as many times as you want.

Medical Care (M)

M1:

- This care is for when you prefer not to have intensive treatments like machines to help you breath or when intensive treatments would not help you to achieve the way of living that is important to you.
- You can go to hospital to get treatments for illness or injury but you do not want to go to the intensive care unit for more aggressive treatments.

M2:

- This care can be given if you live in supportive living, a nursing home, or in the community (e.g., your own home).
- You prefer to be treated by a healthcare provider where you live and to avoid further hospital visits, only going to the hospital for treatable problems.
- If you do not respond to the medical treatments possible where you live, then your healthcare team would likely switch to a focus on Comfort Care.

Comfort Care (C)

COMFORT CARE

C1:

- This care is if you have a health situation where we cannot cure your illness but you still have a fair bit of life left to live.
- We support you as much as possible and help to relieve your symptoms like pain.
- We make sure that you are as comfortable as possible in the time remaining until you die.
- Any treatable problems are taken care of, but you prefer not to have any aggressive treatments.

C2:

- This care is if you are very near the end of your life (in the final hours, days or weeks).
- All of your care is focused on helping you to be comfortable until you die.
- We help you to have a comfortable and dignified death in the place you want.

Resuscitative Care (R)

RESUSCITATIVE CARE

R1:

- This care is for when you want to have intensive or aggressive treatments to keep you alive as long as possible.
- You could be treated in the intensive care unit and have machines to aid breathing, pushing on your chest or shocks to restart your heart, and all life-sustaining machines and treatments deemed appropriate by a doctor.

R2:

- This care is for when you want to have intensive or aggressive treatments to keep you alive, *except* pushing on your chest because that does not help you to meet your goals for care.

R3:

- This care is for when you want to have intensive or aggressive treatments to keep you alive, *except* machines to aid breathing, pushing on your chest or shocks to restart your heart because those do not help you to meet your goals for care.

We want to provide you with the best possible care. We do not want to do things that will not help you and that may end up hurting you.

Most people believe that pushing on the chest and shocking the heart always work and that they will be as they were before their heart stopped.

Unfortunately, that's not the case. According to research, pushing on the chest and shocking the heart only works about 3% of the time for people who have a serious existing health issue.

The people who are revived usually suffer from broken ribs, punctured lungs, they may be in a coma, and they usually end up with disabilities that seriously affect their quality of life.

We want to help you to find the care that is most likely to let you live the life you want, a life worth living for you.

Tip from a healthcare provider:

If we don't know what you want, we do everything. So if your heart were to stop, we'd push on your chest, hook you up to a machine to help you breath, shock your heart to try to restart it, all the aggressive treatments we think are appropriate to keep you alive as long as possible.

But some people say to us, 'I don't want you pushing on my chest because you're going to break some ribs and it's not likely that I'm going to do well or survive.'

So if there are things you don't want, that's when it's really important that we know because we're wired to do everything deemed appropriate for your situation.

Talk with healthcare providers

Any doctor or nurse practitioner can fill in a Goals of Care Designation Medical Order form.

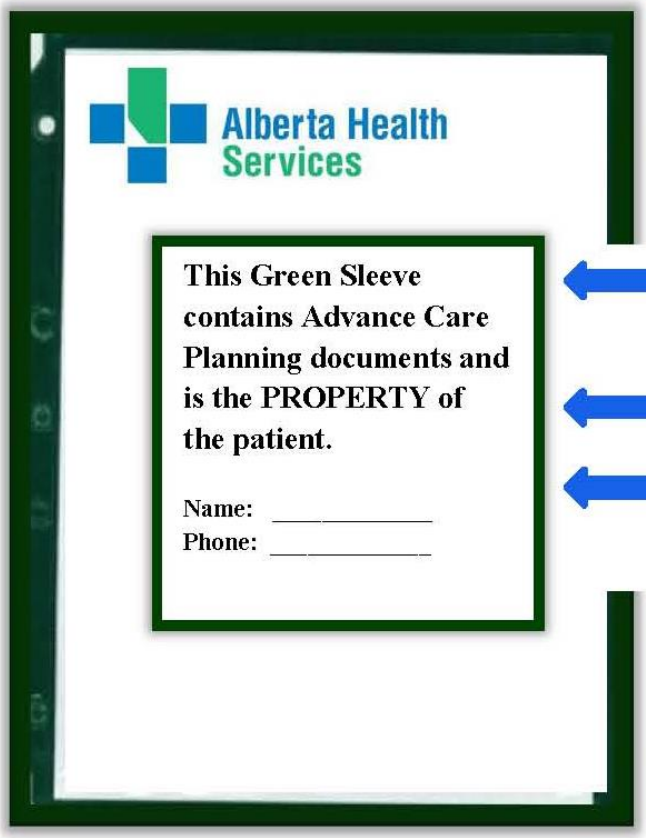
Once you have done Advance Care Planning, it is best to tell every healthcare provider who cares for you that you have an Agent and a Goals of Care Designation Medical Order form.

The more people who understand what your healthcare wishes are, the better it is for you, the people in your life and healthcare providers. We can then manage your care the way you want.

Green Sleeve

Your Health Passport

A critical piece of your health record that you own



- **Goals of Care Designation Medical Order form**
- **Personal Directive**
- **Advance Care Planning Tracking Record**

Conversations Matter

Document medical plans together with loved ones and healthcare providers

The Green Sleeve = Your Health Passport

The Green Sleeve is a critical piece of your health record that you own and manage.

It is a portable gateway to tell healthcare providers the type of healthcare you want – without it, unwanted care may be given.

Your Green Sleeve should contain your:

- Personal Directive
- Signed Goals of Care Designation Medical Order form
- Advance Care Planning Tracking Record
- Up-to-date list of medications (if possible)

Your Green Sleeve should go with you each time you see doctors who have not seen it. They may wish to make a copy for their files.

Your Green Sleeve should be easy to find

The Green Sleeve needs to be placed on the top, front, or side of your refrigerator. If you would rather, you can put a note on your refrigerator if your Green Sleeve is stored somewhere close by (e.g., “My Green Sleeve is in the second drawer beside the fridge”). Emergency response people are trained to look for it around the refrigerator and to take it with you to the hospital.

If an ambulance takes you to the hospital, your Green Sleeve should go with you. If emergency response people cannot find your Green Sleeve, healthcare providers at the hospital may give you care you do not want.

Your Agent should have a copy of everything in your Green Sleeve.

Keep the conversations going

Keep the conversations with your Agent, the important people in your life and healthcare providers going.

You can always change any of your Advance Care Planning documents.

You can change them any number of times.

Tip from a healthcare provider:

If your health changes or you change your mind about your Goals for Care, you may think 'Hey, this isn't what I want. I want this instead.'

You just have to bring in your Green Sleeve and we can change the documents to what you want. It is important that you throw away the old ones so you only have one version.

Advance Care Planning Tracking Record

The purpose of the tracking record is to document what Advance Care Planning and Goals of Care conversations you have had with healthcare providers.

It allows other healthcare providers to see what has been discussed so they are not starting the conversation from scratch each time.

It helps to keep your plans living and active.

Advance Care Planning Checklist

□ Talked with healthcare providers about Advance Care Planning

□ Selected an Agent and he/she agreed

□ Completed a Personal Directive

□ Talked with people important to me about who I selected to be my Agent

□ Talked with healthcare providers about goals for care

□ Talked with my Agent(s) about my goals for care

□ Talked with people important to me about my goals for care

□ Have a signed Goals of Care Designation Medical Order form

□ Have a Green Sleeve and all the necessary documents inside

□ Have my Green Sleeve on or near my refrigerator

□ My doctor has a copy of everything inside my Green Sleeve

□ Other doctors who care for me have a copy of everything inside my Green Sleeve

□ My Agent has a copy of everything inside my Green Sleeve

If you would like more information about items on this checklist, please talk with a healthcare provider. Someone will be happy to help with you.

Personal Notes: