Personal Journal for Advance Care Planning & Goals of Care

Advance Care Planning

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

CONVERSATIONS MATTER

Plan your healthcare together

Goals of Care Designations

CONVERSATIONS MATTER

Talk about your medical wishes with loved ones and healthcare providers

This Personal Journal belongs to:

Name: _____

Phone #: _____

If you find this journal, please contact the owner to arrange return.

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Introduction

This Personal Journal is intended to:

- Give you information about the Advance Care Planning process
- Assist you when talking with the important people in your life
- Assist you when talking with healthcare providers
- Be a record of your journey through the Advance Care Planning process

We encourage you to write your thoughts, feelings and questions throughout the Personal Journal.

Advance Care Planning

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

CONVERSATIONS MATTER

Plan your healthcare together

This is not a legal document.

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**

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

Notes and Questions

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 choose to do for yourself. It is also a gift you give to the important people in your life if you have a health crisis and cannot speak or make decisions.

Notes and Questions

Tip from a healthcare provider:

It is our hope that everyone can make their own healthcare decisions right up to the end, but we can't predict that.

I have 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 of 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.

Important things in my life

The important people in my life are:

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The other important parts of my life are:

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My religious or spiritual beliefs are:

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Notes from loved ones

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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 a life worth living.

A note to my loved ones

Dear Loved Ones,

Notes from loved ones

This is not a legal document.

A life worth living

To me, a life worth living is:

Notes from loved ones

What others need to know about my health

The areas of my health that I think are important for other people to know are:

Notes and Questions

What I would like to know about my health

The areas of my health that I would like to know more about are:

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Notes and Questions

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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.'

I think past experiences are what give people the most insight into their own choices – it's what you've lived. Those experiences can inform you about what you might want for your future care.

Healthcare experiences that are powerful to me

Based on my past medical experiences and those of people I know, these are the types of things I do and do not want:

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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 close to you.
- You can have more than one Agent.
- If you do not want a family member, a friend or someone close 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.

Tip from a healthcare provider:

Most people automatically go to family when considering who to ask to be their Agent.

But I like to say to people, 'If you're going to name this family member, it's good to consider if he or she does well in a crisis or if he or she is going to fall apart.'

It's better to go even one step outside your immediate family circle, like a cousin or friend or someone who will support your decisions and your family, but who can also make the tough decisions.

My Agent

The person (or people) I want to be my Agent(s) is/are:

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Notes and Questions

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This is not a legal document.

Talk with your Agent

Tip from a healthcare provider:

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

You can say something like, 'I have given it a lot of thought and if something happens to me and I can't talk or make decisions, I would 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?'

When asking someone to be my Agent I would say:

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Talk with your loved ones

Tip from a healthcare provider:

It's important that the people in your life know who you have picked to be your Agent.

I recommend that when you pick your Agent that you are transparent with everyone else in your life so that if something happens, there's no fighting.

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.

These are the people I will talk to about my Agent:

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I will tell these people:

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Talk with your loved ones

Tip from a healthcare provider:

It's very important to let the people in your life know your wishes for healthcare so they are not surprised if something happens.

You can say, 'If I'm no longer able to walk or do the things that I enjoy in life, I don't want my life prolonged unnecessarily.' Or something like, "If I have a bad stroke and the doctors don't feel I'll recover to where I was before but I still know who you are, I want everything done to keep me alive. But if I am in a coma and am not going to recover, please let me go.'

These are the people I will talk to about my wishes:

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I will tell these people:

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Talk with your loved ones

Tip from a healthcare provider:

Keep the conversations going over time, especially if your health or something important changes in your life.

Grief is never easy, but I think when someone knows your wishes and respects them at the end of life, there is more of a sense of peace that what was done was what you wanted.

I think when people feel like they're guessing about someone's wishes, the grief after they die can be longer or more difficult to come to terms with because you're always wondering, 'Did I make the right choice? Should I have done something different?' So just having the conversation can make a big difference to the people in your life.

Notes and Questions

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 or make decisions. It gives your Agent and the people in your life 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.
- Your Personal Directive does not come into effect unless you are not able to tell healthcare providers your healthcare choices.

Tip from a healthcare provider:

If you tell us you want us to try everything, we'll try to fix what's wrong.

But sometimes, the doctor might say, 'I don't know if there's going to be any benefit to doing this treatment.' At that point we have faith, hope and belief but if you can't speak, it would be on your Agent to make some difficult choices.

The Personal Directive document gives him or her the legal right to do that. We hope we never have to use it, but we don't know what the future holds. It's very good to be prepared.

Personal Directive

- 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**
- You can write down your cultural, religious, and/or personal beliefs that guide you on what care you want.
- **It must be signed by you and your witnesses.**

Tip from a healthcare provider:

I'll give you a scenario when it would be really important to have a Personal Directive.

Say you got very sick, couldn't talk or make decisions anymore, you're unable to move back to your home, and a decision was made that you had to go to a care facility, a nursing home or something.

Before you could go to a care facility, if you didn't have a Personal Directive naming who can speak for you, we'd have to keep you in the hospital until someone went to court to become your guardian. That takes time and there are court costs. But if you had a signed Personal Directive, your Agent can legally speak for you and the court process is avoided.

Goals of Care Designations

CONVERSATIONS MATTER

Talk about your medical wishes with loved ones and healthcare providers

Goals of Care

Goals of Care has two parts:

- You talk with any healthcare provider about ***your*** goals for healthcare should you be unable to speak or make decisions 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.

Before signing the Goals of Care Designation Medical Order form, the doctor or nurse practitioner will talk with you about the medical 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.

Goals of Care Designations

There are 3 main Goals of Care Designations:

- Medical Care
- Comfort Care
- Resuscitative Care

You can change your mind about what care you want at any time.

You can change your Goals of Care Designation as many times as you like.

Tip from a healthcare provider:

We want you to be directing us to giving you the care that meets your goals on living a life worth living for you.

Notes and Questions

Medical Care (M)

M1

- This care is for when you prefer not to have intensive treatments or when intensive treatments would not help you to achieve the way of living that is important to you.
- You can go to the 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 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 or days).
- 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 aggressive treatments to keep you alive as long as possible.
- You could be treated in the intensive care unit, have machines to aid breathing, pushing on your chest and 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 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 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.

Tip from a healthcare provider:

If we don't know what you want we try 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.

Tip from a healthcare provider:

We want to provide patients with the best possible care and we don't want to do things that won't help or that would cause harm.

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. Pushing on the chest and shocking the heart only works about 3% of the time for people who have an existing serious health issue. The people who are revived usually suffer from broken ribs, punctured lungs, they may be in a coma, and they can end up with disabilities that seriously affect their quality of life.

We want patients to be directing us to giving them the care that meets their goals on living a life worth living for them.

Goals of Care Designations

The questions I have for my doctor about Goals of Care Designations are:

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My doctor told me:

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Goals of Care Designations

The Goals of Care Designation my doctor and I decided on is:

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We decide on this designation because:

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In future conversations with my doctor I may change my Goals of Care Designation. A change to my Goals of Care Designation is written here or on Page 46/47 of this journal:

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My Agent's thoughts on my Goals of Care Designation are:

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The thoughts of other important people in my life on my Goals of Care Designation are:

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Talk with healthcare providers

Tip from a healthcare provider:

You don't have to wait for your doctor to start talking about Advance Care Planning. You can start the conversation.

The kind of conversation you could have with your doctor is you possibly saying, 'These are the kinds of procedures and treatments that I'll agree to if I'm ill or injured.'

Or possibly saying something like, 'You know, I want to have surgery if the outcome is likely to be positive but not if there's a big chance that my quality of life is going to be really low.'

Notes and Questions

Talk with healthcare providers

Tip from a healthcare provider:

Once you've done Advance Care Planning, it's best to tell every doctor who cares for you that you have an Agent and goals of care. Any doctor can do the goals of care: family doctor or specialist, but if your family doctor doesn't know you did it with a specialist, the family doctor may ask you to do it again.

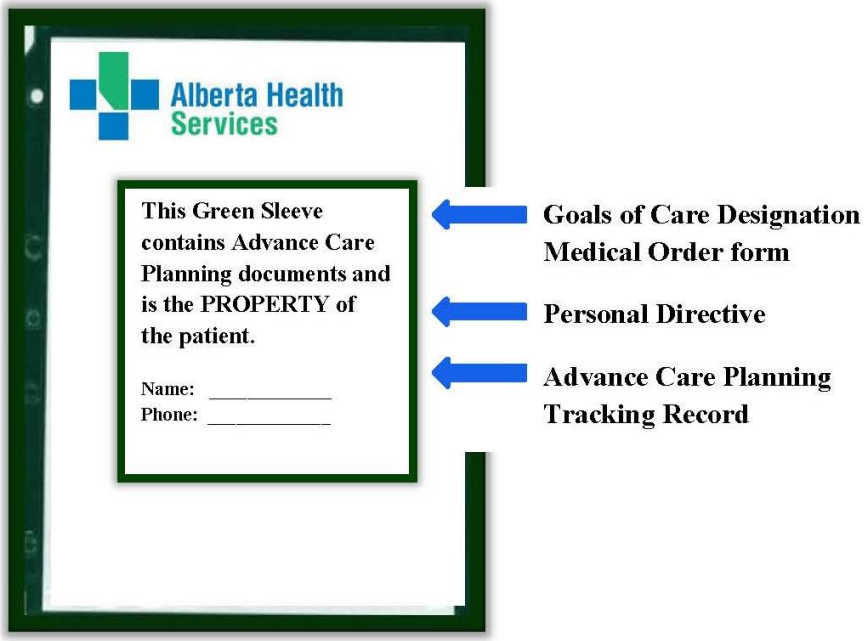
The more people who understand what your healthcare wishes are, the better it is for you, the people in your life and healthcare providers. We can then manage your care the way you want.

Notes and Questions

Green Sleeve

Your Health Passport

A critical piece of your health record that you own



Conversations Matter

Document medical plans together with loved ones and healthcare providers

This is not a legal document.

The Green Sleeve = Your Health Passport

- It 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
- It should contain the following Advance Care Planning documents:
  - Your Personal Directive
  - A signed Goals of Care Designation Medical Order form
  - An Advance Care Planning tracking record
  - An up-to-date list of your medications (if possible)

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.
- The 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.

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.

The tracking record helps to keep your health plans living and active.

Notes and Questions

Checklist for managing your Green Sleeve

- ☐ My name and phone number is on the front cover
- ☐ My Personal Directive is inside
- ☐ My signed Goals of Care Designation Medical Order form is inside
- ☐ My up-to-date medication list is inside
- ☐ My Advance Care Planning tracking record is inside
- ☐ It is on or near my refrigerator
- ☐ My doctor has a copy of everything inside
- ☐ Other doctors who care for me have a copy
- ☐ My Agent has a copy of everything inside
- ☐ Other important people to me have a copy (if you wish)

Notes and Questions

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This is not a legal document.

Advance Care Planning checkups

Date of my Advance Care Planning checkup:

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Changes that were made to my documents:

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Date of my Advance Care Planning checkup:

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Advance Care Planning checkups

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Changes that were made to my documents:

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Additional Notes and Questions

Additional Notes and Questions