Hepworth & Associates

Personal Advocacy, Elder Planning & Family Support

... peace of mind for those you care about

Advance Care Planning for You

A first step to true peace of mind

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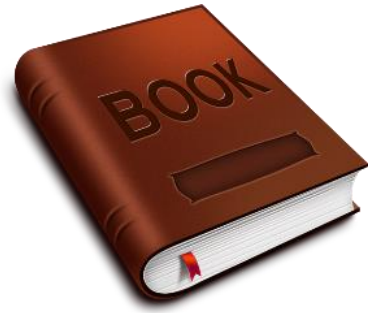
About This Book



One of the first things we do with our clients, when helping them put together their Life Course Plans, is to ask if they have an Advance Care Plan. If their answer is no, it becomes our first priority.

Current statistics indicate that only 1/3 of the population has an Advance Care Plan in place, which means the other 2/3 are likely not aware of the risks to themselves and their families of not having one.

Advance Care Planning is a process for thinking about and sharing your wishes for future health and personal care. It can help you tell others what would be important if you were ill and unable to communicate. It is a process of reflection and communication. It is a time for you to reflect on your values and wishes, and to let people know what kind of health and personal care you would want in the future if you were unable to speak for yourself.

It means having discussions with family and friends – especially your Substitute Decision Maker, who is the person who will speak for you if you cannot speak for yourself. More about this person later.

The process may also include writing down and formalizing your wishes and talking with healthcare providers and financial or legal professionals.

The result of this planning effort is a document called an **Advance Care Plan**, sometimes referred to as a Living Will or an Advance Care Directive.

This book was created by Hepworth & Associates as a useful introduction and guide to the Advance Care Planning process, and to get those who have not assembled their own plan, started with some newfound confidence.

Why An Advance Care Plan?

When it comes to your health, you will receive medical care regardless of whether or not you have an Advance Care Plan. However, if you cannot speak for yourself and do not have an Advance Care Plan, a physician will generally look to your family, friends, or clergy for decisions about your care.

Your plan will tell others the type of care, procedures and treatments that you do, or do not, want. It will also set out the names of the people you have chosen to make healthcare decisions for you when you cannot express your wishes, such as your Substitute Decision Maker.

Providing such guidance may also prevent painful family arguments about how they think you would want to be treated, which could result in you potentially receiving certain care and treatments that you would not choose for yourself were you able.

Note that your Advance Care Plan speaks specifically to medical decisions that must be made should you be unable to speak for yourself, and not to other wishes you may have regarding your property or financial matters.

For clarity, a Continuing Power of Attorney for Property covers your financial affairs. It appoints another person to make decisions for you and to act on your behalf when you are unable to do so.

What Goes Into My Plan?

Your plan contains a combination of inner reflection and research regarding realities and situations and medical options and treatments, all resulting in an articulation of your wishes should those realities and situations occur, and medical intervention be required.

The value of the plan is as much in the final instructions and wishes as it is the process of developing it, as it causes a mature reflection and consideration of you and your future…. someone you may not always be thinking about.

It's also taking into consideration those people who care for you, and who want the best for you.

The Substitute Decision Maker

A critical element of your Advance Care Plan is the **Substitute Decision Maker**.

This is the person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf you when you are incapable of communicating your wishes yourself. This is the person (or the people) that will give or refuse consent to treatments proposed by a health practitioner if you are incapable of doing so yourself.

The core qualification in your selecting your Substitute Decision Maker is ***trust***. It is vitally important that you choose someone you can trust.

Your Substitute Decision Maker needs to be willing and able to make potentially difficult treatment decisions for you. You must discuss your desires, values, fears, and preferences

about health care in various situations with the Substitute Decision Maker so that he or she can be trusted to carry out those wishes that are most important to you, and to make the decisions you would make yourself, if you were able to do so.

The Substitute Decision Maker may also be referred to as a Medical Proxy, a Medical Agent, or a Power of Attorney for Personal Care.

Building Your Plan

We view the Advance Care Planning Process as of one made up of six steps, with each one requiring thought, a little research, and some decision making on your part.

The six steps are comprised of:

1) **Consider**
2) **Research**
3) **Decide Who**
4) **Have The Talk**
5) **Formalize**
6) **Enjoy**

Let's take a walk through each of these steps to add some clarity as you begin to ponder the components of your Advance Care Plan.

Step One – Consider

A good start to developing your Advance Care Plan is to consider what your views, standard values, and beliefs when it comes to your care and those specific medical procedures that you may have to confront.

For example, under what conditions would you prefer not to be kept on life support, palliative sedation, or medically assisted death?

Ask yourself:

- If possible, would I prefer to die at home, in a hospice, or in the hospital?
- What might change my mind about my choice?
- Do I want or not want certain medical interventions (for example, resuscitation or feeding tubes) if I am unlikely to survive or live independently? Why would I want or not want these procedures?
- Do I have any fears about dying (e.g. I'll be in pain, I won't be able to breathe)?
- Is there someone that I can talk to about these fears, such as my doctor?
- What would be meaningful for me at the time of my death (such as family/friends nearby, music playing, etc.)?

Step Two – Research

Find out about different medical issues, conditions, procedures and what they can do….and what they can't do.

Consider those issues, conditions and procedures typical of ageing which including cancer, osteoarthritis, chronic obstructive pulmonary disease, diabetes, depression, and dementia.

While you may not ever confront any of these, your plan will have considered them and articulated your wishes should they arise.

Step Three – Decide Who

Think carefully about who you feel would honour and follow your wishes and would be most capable of making medical decisions on your behalf.

This may be a spouse, an adult child, trusted family member, or a good friend. This person(s) will be your Substitute Decision Maker.

In general, a Substitute Decision Maker can agree to or refuse treatment

and can withdraw treatment on your behalf. Your Substitute Decision Maker can use the information in your Advance Care Plan and what he or she knows about you personally to make these decisions.

For example, your Substitute Decision Maker can consent to surgery, refuse to have you placed on life-support machines, or request that you be taken off life support.

Legal requirements regarding the appointment of a Substitute Decision Maker vary across the country.

Step Four – Have The Talk

While it can be challenging, it is critical to have the conversation and review your Advance Care Plan with your Substitute Decision Maker.

To truly realize the value and benefit of your plan, your loved ones and your doctor need to be keenly aware of your wishes and your plan details, so they need they benefit of a "talk" as well.

We understand the conversation can be uncomfortable. Often, we are asked to assist in getting the conversation started and helping it along the way. Over the years, we've picked up some tips and ideas that we use in our practice, which we've shared in the appendix section at the end of this booklet under "**Planning for The Talk**".

Step Five – Formalize

Now put your plan together in document form and/or make a recording of your plan so that your wishes are formalized and can be communicated to others.

Use a format that is simple and easy to understand, and make your wishes as clear and articulate as possible. You'll want people to be able to complete your requests as accurately as possible, so don't be shy on the details.

See our Appendices to see a format that you can consider using.

Step Six – Enjoy

Enjoy the peace of mind you've created for yourself and your loved ones in having completed your plan.

You are now ahead of 66% of the population who don't have an Advance Care Plan, and you can be confident that your later life course is in more predictable hands.

Now you can get on with living!

All Done…. Now What?

When your plan is all done, you can take a bow and pat yourself on the back… however, there are a few more things to consider.

Where Does It Go?

More often than not, your plan will be needed when an emergency situation has arisen, and when your Substitute Decision Maker needs to be engaged.

It's at this point that you will want to ensure your plan is available and accessible so it can be acted upon.

When your plan is done, you'll want a copy of it to be in the hands of those you've had "The Talk" with -- so, not only your Substitute Decision Maker but your doctor and those other family members who care about you.

As for your own copy, a good place to keep it is with your other official, personal documents, such as Wills and Powers of Attorney.

When Does My Plan Take Effect?

Your Substitute Decision Maker is only called upon if you are unable to make your own health care decisions (such as you're in a coma or your illness impairs your ability to make decisions). And it is only at this point that your written documents and/or plans are referred to.

It is with your latest written Advance Care Plan that your Substitute Decision Maker can guide your care and advocate for your wishes.

What If Things Change?

Life and plans can always change! You can change your Advance Care Plan as often as you like.

Just make sure that your Substitute Decision Maker understands the changes to your plan and has a copy of the most recent version.

What If I can't contact my Substitute Decision Maker?

Emergencies happen when people aren't around, so make sure that your Substitute Decision Maker and your doctor have a copy of any written documents, and that others know who will act as your Substitute Decision Maker should an emergency occur.

As always, have your information handy in your wallet or purse where ever you go. Just in case.

In Closing

If we haven't made the importance of an Advance Care Plan as clear as we could, shame on us. But let's do a final reminder in closing.

Life sometimes presents us with challenges we don't anticipate, and we're forced to make decisions in a hurry that aren't always optimal and clear headed. Imagine those types of situations and now add a few additional challenges……the decisions to be made are medical, potentially life-threatening, and you can't speak for yourself.

It's at times like this where your Advance Care Plan, your selected Substitute Decision Maker and an aware family circle

will be invaluable to ensuring your wishes are undertaken and removing the burden of guessing what you would want.

Now start building YOUR plan!

With Special Thanks

Particular thanks and kudos must go to ***The Speak Up Campaign***, which is part of a larger initiative – Advance Care Planning in Canada. We are grateful both for their efforts around this important subject of Advance Care Planning as well as for their insightful information and content, much of which we are presenting here in our booklet.

This initiative is overseen by a National Advance Care Planning Task Group comprised of individuals representing a spectrum of disciplines, including health care, law, ethics, research and national non-profit organizations.

For more about this group and initiative, as well as other very useful tools, go to: http://www.advancecareplanning.ca/

About The Author

Gary Hepworth is the Founder and President of Hepworth & Associates, a Personal Advocacy, Planning & Family Support organization in Toronto, Canada.

Hepworth & Associates was created after years of experience in healthcare, home care and many senior support organizations, seeing many in their senior years and their families dealing with these challenges under critical circumstances and when rushed decisions aren't the best decisions.

Over the past 30 years, we know what "aging well" is all about, and that's about being prepared for today and tomorrow. It's about having a plan for what you want, a plan for surprises, a partner that can advise/advocate for you when surprises occur, and then the ability to get back to enjoying that life with peace of mind for you, as well as your family.

We're here to help……

Appendix A – My Care Plan Template

About Me

First Name:	Last Name:
Address:	
Date of Birth:	Home Phone:
Cell Phone:	Email Address:

My Substitute Decision Make

First Name:	Last Name:
Address:	
	Home Phone:
Cell Phone:	Email Address:

People Who Have A Copy Of My Plan

Name	Relationship to Me	Contact Information

My Other Planning Documents

In addition to this Advance Care Plan, I have also completed the following documents:

Document	Location
Will	
Power of Attorney - Property	
Advance Care Plan	
Other	

Specific Plan Items

1) Things that I value most in terms of my mental and physical health? (For example, being able to live independently, being able to recognize others, being able to communicate with others.)

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2) Things that would make prolonging life unacceptable for me. (For example, not being able to communicate with those around me, being kept alive with machines but with no chance of survival, not having control of my bodily functions.)

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3) When I think about death, I worry about certain things happening (for example, struggling to breathe, being in pain, being alone, losing my dignity, etc.).

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4) If I were nearing death, what would I want to make the end more peaceful for me? (For example, family and friends nearby, dying at home, having spiritual rituals performed, etc.)

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5) Do I have any spiritual or religious beliefs that would affect my care at the end of life? (For example, certain beliefs about the use of certain medical procedures.)

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6) Other wishes and thoughts. (Write down anything that would help others understand and support you at the end of life.)

_____ _____

Signature Date

Appendix B – Planning for The Talk

In planning for your talk, whether it's you that is initiating your own Advance Care Plan or broaching the subject with a family member you care about, here are some handy facts to consider, and why having "The Talk" matters.

Here are a few tips to consider as you prepare for The Talk:

Don't Wing It

No matter how you open the conversation, there will undoubtedly be a number of reactions and questions, so plan ahead for them and be as ready as you can in advance. The more confident you are in leading the discussion, the easier it will be for everyone involved from beginning to end.

Plan Your Approach

Do you want The Talk to be "all inclusive", from introducing the subject then presenting your completed plan to all concerned; or would you like The Talk to be one of several, with a first one to just open the concept up for dialogue? Either can work, but both require preparation in advance.

Schedule…. And Do It

Once you've got your content ready, it's time to get the logistics in order.

And as obvious as some of these considerations should be, it's useful to ensure you've considered them in your planning process.

- Who Will You Have The Talk with: Mom, Dad, Sister, Brother, Friend, Partner, Son, Daughter, Doctor, Caregiver, Other?
- When Will You Have The Talk: Next Week, Before the Summer, When I get out of the hospital, After daughter has Baby, Other?
- Where Will You Have The Talk: Kitchen table, At the cottage, While having a walk, Waiting room, Other?

Suggested Opening Lines

These opening lines are only suggestions as your final chosen ones need to "sound like you", but here are a few effective ones:

- *I need your help with something*
- *Even though I'm okay right now, I'm worried about (situation) and I want to be prepared*
- *I'm doing some thinking about my future; will you help me?*
- *I've been working on my Advance Care Plan, and I want you to see my answers….and I'm wondering what your answers might be*

Suggested Opening Subjects

Set the conversation to discussing the last phases of your life and what things are most important to you, and what you'd like it to be like.

Talk about typical illnesses that can emerge during the later life course such as dementia, cancers, various breathing disorders, etc., and what treatments you would and would not accept. and under what conditions would you say "no thank you" to further treatment.

From there you can judge how the conversation is going and whether there is enough comfort to proceed into further

details, or whether this discussion was a valuable start for future ones to come.

As a useful outline, use our My Plan Template in Appendix A to guide the rest of the flow of your conversation, as reminders of where to guide the conversation.

All said, this first conversation, no matter where it goes, has been incredibly valuable to all involved as the conversation has now started!