



community living society

# Late Life Planning Guide

## Easy Read Version

Developed by the BC CEO Network with funding provided by the Ministry of Social Development & Poverty Reduction  
Easy Read Version Adapted by Carol Erkila, Byron Schiller, Susan Powell and Kami Davis from the  
BC CEO Network Late Life Planning – a guide for Disability Service Providers (2024).



This document may not be reprinted without written permission from the original creators.

**DISCLAIMER**

The material in this guide is about general information. The material in this guide does not replace professional medical or legal advice. Always ask your doctor or another health worker, or a lawyer, about your own situation with late life planning.



## THE IMPORTANCE OF PLANNING

## LATE LIFE PLANNING

= planning for how  
**YOU** want to live  
as an older person

It is important to make plans for how you want to live as an older person. This is called Late Life Planning. These plans will make a difference to how you feel about your life, and your health, in the future. Late Life Plans need to be recorded.

This guide will go over many topics to help you make your plan. The topics are:

- how to plan
- positive relationships
- health care
- legal matters, and
- looking after your money



Late Life Planning means thinking about all the things that make your life good. It means making sure these things are still part of your life as an older adult. Late Life Planning involves making many decisions. You will probably need to talk with your family, friends and people you trust, many times as you make your plan.

Late Life Planning also includes what you want at the end of your life. It is a way for you to make clear what you want to happen (and don't want to happen) BEFORE you die.

Your family and friends are key people to talk with as you make your plans. It is important to share your plans with them. This way you will have them around you when others need to know what is important to you. You may want to include staff who are important to you. Staff are only allowed to do some things in Late Life Planning or End of Life Planning. It will be important for you to check the rules in the organization that supports you to know what staff are allowed to do and can't do.



There are 3 videos you may want to watch as you begin to think about Late Life Planning. One video shows people talking about death and dying. Another video shows a person talking about what is important to him. There is also a video about a woman completing a workbook. You can watch these videos at any time as you make your Late Life Plan.

There is no right or wrong way to start thinking and talking about Late Life Planning. What is important is that you make a plan for your future as an older adult.

Here are the videos.

<b>Let's Talk About Death and Dying</b>	<b>Thinking Ahead</b>	<b>Advance Care Planning</b>
Length: 5 minutes long. Topic: It discusses why talking about dying and death can be helpful. Link: <a href="https://www.youtube.com/watch?v=4Bfomd2mq7w">https://www.youtube.com/watch?v=4Bfomd2mq7w</a>	Length: 10 minutes long. Topic: It shows Eugenia working through a workbook as she thinks about her decisions for her plan. Link: <a href="https://www.youtube.com/watch?v=Oku0vMUhtBU">https://www.youtube.com/watch?v=Oku0vMUhtBU</a>	Length: 4 minutes long. Topic: It shows Mark talking with others about what he wants if he gets very ill. Link: <a href="https://www.caresearch.com.au/tel/Videos">https://www.caresearch.com.au/tel/Videos</a>
		

Click on the link (or scan the box with your cell phone) if you want to watch any of them.

# What is in This Guide?



**Contents list:** This lists topics and the pages in the guide where you can find the information. **There is a lot of information. You may only want to look at one section at a time and then talk about it with others.** In the Resource Section you will find many materials that include pictures that talk about some of the topics in this guide.



**Checklists:** In the guide there are several checklists. You can read them at any time to see what needs to be done. Or you may want to check off points as you make your Late Life Plan. Do what works best for you.



**Information:** The information in the guide may make you think about others in your life who have died. Sometimes these memories make us sad. Remember to take care of yourself as you talk about your Late Life Plan.

The guide will also go over information you need as you think about the end of your life.



**Summary Diagram:** At the end of the guide is a Diagram that shows the main points to think and talk about in Late Life Planning and End of Life Planning. You may want to look at this to see a picture of what is in these plans.



**Forms:** There are many Forms mentioned in the guide. Some of these forms come from other places and can't be changed. You will probably fill these forms out when you talk to others about your Late Life Plan. You will need to print the forms in order to use them.

**Glossary:**

There are many words that may be new to you. The glossary lists words and what they mean.



**Resources:** In the end of the guide there is a section telling you about several Resources. The Resource Section includes workbooks, information sheets and websites about Late Life Planning. Click on the links to look at any of the resources or scan the code to open up the resource.

Some of the resources are workbooks from other countries. This means terms and forms may be different than the ones we use. But you may still find parts of the workbook helpful. There is no right or wrong way to use the workbooks or resources.



One workbook that was written for people in BC is

**Easy Read Advance Care Planning (ACP) Guide – Fraser Health**

This fillable ACP picture based workbook can help an individual, and the people who matter to them, work through the steps of planning for their future health. Remember you can also scan the code to see a copy of this guide.

<https://patienteduc.fraserhealth.ca/file/my-voice-action-a-workbook-for-advance-care-pla-583174.pdf>

Contents

- THE IMPORTANCE OF PLANNING ..... 3**
  - What is in This Guide?..... 6
  - Values: What is Important to YOU ..... 9
  - Doing Well as YOU Get Older ..... 10
    - Planning ..... 10
    - When to Plan..... 10
  - Who Needs to Know..... 12
    - When There is No Family..... 12
- MAKING A LATE LIFE PLAN ..... 13**
  - What is Late Life Planning?..... 14
    - Social-emotional well-being (Positive Relationships) ..... 15
    - Health..... 16
    - Legal ..... 23
    - Financial ..... 25
  - Late Life Planning Checklists..... 27
- END OF LIFE PLANNING ..... 31**
  - What Is End of Life Planning..... 32
    - Socio-emotional well-being (positive relationships)..... 33
    - Health Care ..... 34
  - End of Life Checklists ..... 38
- MORE HELPFUL INFORMATION..... 40**
  - Summary Diagram..... 41
  - Forms ..... 42
  - Glossary..... 56
  - Resources ..... 57
    - Workbooks ..... 57
    - Information ..... 58
    - Websites..... 61
    - BC Health Authorities ..... 64
    - Notes..... 65





## Values: What is Important to YOU

As you get older your life changes. A long life means more than your age. It means making decisions about how you want to live, and what you want to do, as an older adult. Planning early can make a difference to your health and how you feel about your life.

You may already make plans and set your goals for a year. Late Life Planning is like that. But it means doing more thinking and talking about your life as an older adult.

Other people will probably be planning with you. It will be important that they treat you with respect, even if they have different ideas. The goal of Late Life Planning is to figure out what is most important to **you**, and for others to support you with these decisions.

You might want to think about learning or doing new things. You probably will want to think about what you enjoy doing with your friends and family. An important thing to think about will be your health.

You choose the people you want to talk to about Late Life Planning. They can help you make decisions, but not make them for you. They can help you get and understand information.

Your family, friends and people you trust are key people to talk with as you make your plan. They may need to let others know your wishes, so your life is positive even as you age. It is important to have discussions early, and often, with the important people in your life. This makes it clear to everyone what is important to you as you get older.

Late Life Planning also includes what you want at the end of your life. It is a way for you to make clear to others what you want to happen (and don't want to happen) BEFORE you die.

# Doing Well as YOU Get Older

## Planning

Changes happen to a person when they age. They may be thinking about retirement. They may be noticing changes to their health or how hard it is to do things. This is normal as we get older.

As a person ages their interests, health, safety and comfort are very important to think about. Making decisions and planning early about these areas helps an older person have a life that means a lot to them. It is important to record this information through something called Late Life Planning.



**See the  
workbooks or  
information  
material listed in  
the Resource  
Section**

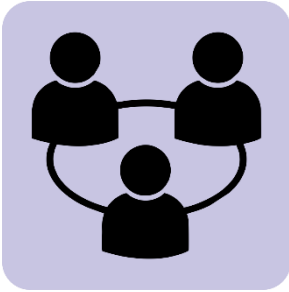
## When to Plan

The best time to start Late Life Planning is from 45 - 50 years of age. However, if you are older than 50 when you read this don't worry! It still is not too late to get started.

Late Life Planning is like other types of planning you may have been part of. It puts the person, YOU, at the center of the plan. It means thinking, talking, sharing and planning in 4 main areas:

- positive relationships (called socio-emotional well-being)
- health care
- legal
- financial matters

These areas will be discussed many times in the guide.



## Socio-Emotional Well-Being (positive relationships)

Social-emotional well-being is about the positive relationships in your life. Late Life Planning means talking about who you want to live with, who you want to go out with, where you want to live and, what you want to get done as an older person. Think about your Bucket List!



## Health Care

Thinking and sharing your ideas about your future health and personal care is an important part of Late Life Planning. You will need to say who can speak up for you if you can't do this for yourself. Late Life Planning includes talking about what is most important to you, like family, what you believe, your place of worship or being in nature. The languages you speak, important holidays, festivals and the special food you eat are all important to share. This will help others understand your wishes.



## Legal

Legal documents are a part of Late Life Planning. That means creating and sharing your documents with the people you trust and those who need to be told about your decisions. This will include the names of the people you choose to make decisions for you when you can't.



## Financial

It is always important to manage your money. In Late Life Planning this includes planning for what happens to your things and money after you have died.

## Who Needs to Know

Late Life Planning includes making sure everyone understands your wishes. For most people this will mean talking to their family. This may mean giving consent for some documents to be shared with lawyers, doctors, nurses and staff. This lets everyone know your wishes and advocate for what you want.

It is also important that the staff caring for you know what you want to take place with your health, your life and finances. Remember there are rules that say what staff can and can't do.

## When There is No Family

Some people may not have any close family to help them with their planning. It is still important for you to talk and share how you want to live as an older adult. Pick someone you trust to talk about what makes you feel positive about your life, your health and your finances. You will want this person to be someone who will look after your wishes if you can't.

You may want to make this plan legal. If this is the case, you can write a Representation Agreement. You can find more information about this on page 24 or in the Glossary section.




## **MAKING A LATE LIFE PLAN**

# What is Late Life Planning?

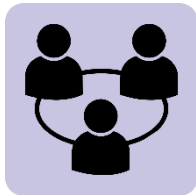
Late Life Planning means thinking, talking and sharing your ideas about having a good life as an older adult. It needs to be recorded. It can be in writing, in a video or in an audio recording. It needs to be clear.

**Making a plan** means talking a lot with others about what is important to you. Who you talk to is your decision. Not everyone will always agree with what you want. This is why it is important to talk about your wishes before there is an emergency. Your plan will let family, friends and staff know what you want them to do.



**See the workbooks or information material listed in the Resource Section**

Keep in mind there are 4 main areas for you to think and talk about as you put together your late life plan. They are:



Social-emotional well-being (positive relationships)



Health Care

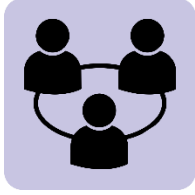


Legal



Financial

**There is a lot of information in each area to think and talk about. You may want to only read one area at a time. You can work on these areas in any order you like.**



## Social-emotional well-being (Positive Relationships)

Questions you can use to talk about your socio-emotional well-being (positive relationships) as an older adult might include:



It is always okay to go back to an answer and talk about it again.



## Health

Your health is very important as you age. People who are aging often show changes in how they think, how they feel, and how they move. One of the most common health problems for some older people is Dementia.

Dementia changes the way a person's brain works. It shows up in different ways in people. A person might find it hard to remember things. A person might find it hard to plan things. Not everyone has Dementia in the same ways.

There are some questions you can answer that let you, and others, know what to do about any changes you are having. There is form called Early Detection Screen for Dementia, in the Form Section of the guide. It can help you and others figure out what is going on. Other people will fill this form out with you.

There are other things that can affect your health as an older adult. It is important for you to tell others your wishes and how you want to be taken care of when your health gets worse. It also means giving the name of someone who can make decisions if you can't.

Planning for your future health needs is called Advance Care Planning.



**See the Forms  
section for the  
Early Detection  
Screen for  
Dementia**



## Advance Care Planning

Your Advance Care Plan is about YOU. It is personal. It will be different from someone else's plan.

There are 5 main steps when putting together an Advance Care Plan:



**See the Glossary  
Section:  
Advance Care  
Planning**

**THINK**

Thinking about what is important to you.

**LEARN**

Learning about your health. Talk to your Doctor or nurse practitioner if you need to know things about your health.

**DECIDE**

Deciding who can speak for you if you can't.

**TALK**

Sharing what matters to you with others.

**RECORD**

Recording your plan. The directions in your Advance Care Plan need to be recorded. It can be in writing, in a video or in an audio recording. It needs to be clear.

**Remember there is a booklet  
you can use to make your  
Advance Care Plan**

Click/Scan here



**for the Easy Read Advance  
Care Planning (ACP) Guide**

There may be a time when you are not able to speak for yourself and let health care workers know your wishes. You will need to create a contact list of people who can speak for you if you can't. BC Law sets out the order of people the hospital will call. These people are called Temporary Substitute Decision Makers (TSDM). The hospital team will contact the first person on the list who is available to make medical decisions for you when you can't. The order of the names on the list is:

- Spouse
- Adult children
- Parents
- Brothers or sisters
- Grandparents
- Grandchildren
- Any person related by birth or adoption
- Close friend
- A person related by marriage

These people must:

- Be 19 years or older
- Able to make decisions
- Been in touch with you in the past 12 months
- Have no disagreements with you

It would be helpful if you use the form Temporary Substitute Decision Maker to make your contact list.

Ask yourself how you feel about your list.

- I am okay with my list.  
 I am not okay with my list.

If you do not like the order of the people on this contact list you can choose to make a Representation Agreement. A Representation Agreement is a legal document. For example, if you would rather your friend and not your brother be asked to make health care decisions for you than a Representation Agreement may be a better idea. Even if you make this Agreement, it can be helpful to give a few names from your contact list in case the person in your Representation Agreement is not available.

All decision makers must honour and respect your wishes and how you want to be cared for if your health gets worse.


You will find more information in the Legal area on page 23 about people you can choose to make health care decisions for you if you can't.

More information is also in the workbook:

**Easy Read Advance Care Planning (ACP) Guide – Fraser Health**


This fillable ACP picture-based workbook can help an individual, and the people who matter to them, work through the steps of planning for their future health.

Click/Scan here




for the Easy Read Advance  
Care Planning (ACP) Guide

<https://patienteduc.fraserhealth.ca/file/my-voice-action-a-workbook-for-advance-care-pla-583174.pdf>



See the Forms  
section for the  
Temporary  
Substitute  
Decision Maker  
form



See the Glossary  
Section:  
Representation  
Agreement

An Advance Care Plan can be changed or stopped at any time. Changes need to be put in writing. If you do this make sure people know about these changes. Your plan needs to be kept in a place that is safe and easy to get to. Give a copy of your plan to family, friends, health care workers, doctors, staff and the person you have named to make decisions for you when you can't.



A Greensleeve is a green plastic folder to help you keep all your documents in one place. You can get a Greensleeve from your doctor’s office, from a clinic or places like a hospice. You can also phone or email the Advance Care Planning team in your health region. Contact information for BC Health Authorities (regions) can be found in the Resource Section of this guide. It is a good idea to take your Greensleeve to all medical appointments, and when you go to a clinic or hospital. Keep it on the fridge or counter in your home. This is where emergency people will look for it if needed.



**See the Glossary  
Section:  
Greensleeve**

The Greensleeve comes with a wallet card. Once you fill the card out put it in your wallet. In case of an emergency it will let people know that you have an Advance Care Plan.

The wallet card may look like this:

', '     with a representation agreement [ sec 7  sec 9]', '     with an advance directive', 'I am an organ donor ', and 'My important papers are located \_\_\_\_\_'."/>

My full name is \_\_\_\_\_

In case of emergency, call:  
\_\_\_\_\_ (name) \_\_\_\_\_ (phone)

My health care provider is \_\_\_\_\_

I have an advance care plan

with a representation agreement [ sec 7  sec 9]

with an advance directive

I am an organ donor

My important papers are located \_\_\_\_\_

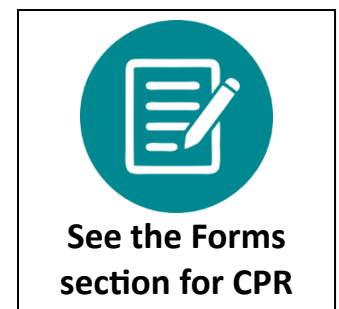
There are other documents to fill out for your Advance Care Plan. One of these is a document called **Medical Order for Scope of Treatment (MOST)**. There is an example of this document in the Forms Section. Medical Orders for Scope of Treatment are official documents.



MOST is set up by talking with a doctor or nurse practitioner. They need to know what is important to you about your health care. After decisions are made, the doctor or nurse practitioner, will record them on a MOST form. This will help people at the hospital honour what is important to you.

The form tells first responders and health care workers about 3 areas:

1. **Cardiopulmonary Resuscitation (CPR)**. This is used when a person's heart and breathing stop. A person or a machine can be used to get a person's heart and breathing working. It is important for everyone to know if you want CPR or not.
2. Care that focuses on giving you comfort with your pain or illness.
3. Medical care that might be used if your health gets worse.



A person is always asked to give consent about their health care as long as they are able. A MOST document can be changed at any time. It is a good idea to look at it with your doctor every year.

It is a good idea to bring your MOST document to the hospital, emergency room and medical appointments. If you move to another setting take it with you so staff will know your health care wishes. Remember it is a good idea to keep a copy of the MOST document in your Greensleeve.

Another choice you might want to make is to write something called an **Advance Directive**. Not many people do this. It is very important to talk with your doctor about this idea. It means a person is able to make decisions NOW about their future health care. This is a legal document. No one else will be asked to make decisions for you.

Keep in mind an Advance Care Plan tells others, and health care workers, what matters to you about your future health. It includes:

1. Information about yourself and what makes your life good.
2. A record of your plan.
3. A contact list of people who can speak about medical decisions for you when you can't.
4. A copy of your MOST document. This includes if you want CPR or not.
5. A Representation Agreement (This is optional so you can decide if
6. you want this or not).
7. An Advance Directive (This is optional so you can decide if you want this or not.) It is very important to talk to your doctor about this legal document.

Remember to keep your Advance Care Plan in a Greensleeve.



## Legal

### Who can make decisions when you can't

Late Life Planning is about making legal decisions. An adult over the age of 19 is seen as being able to make their own decisions. However, as a person ages it can be hard for them to make decisions. If this is not possible someone else can become their legal decision maker. Only some of these people can make decisions about a person's health care.

Some of the people who are legally allowed to make decisions on a person's behalf are:

- **Private Committee:** This person is decided by the courts. They are usually family members or friends. This person can make decisions for someone who is not capable of making their own decisions.
- **Power of Attorney:** You can pick this person. However, they can only look after your financial and legal matters. They cannot make health care decisions. There are legal documents that everyone has to sign when you pick a Power of Attorney.
- **Temporary Substitute Decision Maker (TSDM):** BC Law sets out the order of people the hospital will call if you are not able to make decisions on your own. The people are called Temporary Substitute Decision Makers (TSDM). There are rules about how to pick these people for the hospital to phone. Remember there is information about TSDM on pages 18 and 19. You will find a form to help you make this list on page 54.



See the Glossary  
Section:  
Power of  
Attorney



See the Glossary  
Section:  
Temporary  
Substitute  
Decision Maker

- **Representative:** This person is named in a formal document, called a Representation Agreement. You need to sign this document. Two people need to watch you sign it. There are 2 kinds of Representation Agreements.
  - In one you name someone to help you make decisions or make decisions for you. These decisions are about your personal care, your health care, looking after your money and legal matters.
  - In the second one you name someone to only make decisions about your personal care or health care.



**See the Glossary  
Section:  
Representation  
Agreement**

An Advance Directive is another type of legal document. Not many people do this. It is very important to talk with your doctor about this idea. It means you are able to make decisions NOW about your future health care. No one else will be asked to make decisions for you. The health care team will follow your instructions in this written plan.





## Financial

Late Life Planning means planning for what happens to your things and your money after you have died. A **Will** is the legal document that gives details about what will happen to your money and things after you have died. Anyone over 16 can make a Will. If you do not have a Will the government may decide how to give your money and things away.



**See the Glossary  
Section:  
WILL**

You can decide who you want to look after your money and things. This person can be a family member, a friend, a lawyer or a notary. This person is called an Executor. It is the job of the Executor to make sure your money and things are given away to the people you want to have them. The Executor will also look after your funeral.

There are some basic steps for preparing a Will. You may want to talk about this with someone you trust. The steps are:

1. Choose an Executor.
2. Decide who you want to give your things and money to.
3. Decide on who you want to look after your children, if they are under the age of 16.
4. Decide on what your wishes are for a funeral or burial.
5. Write the Will.
6. Sign the Will. This makes it legal. This means 2 people have to see you sign the Will.
7. The Executor usually keeps the original Will. Put your copy of the Will in a safe place. You can change your Will but there are a number of steps you have to take to make it legal.
8. Think about listing your Will with Vital Statistics (BC government) or with Nidus, (a BC organization).

Your Will comes into effect after you have died.



A lawyer or notary can create a Will with you but it will cost some money. BC has an event called “Make A Will Week”. It is usually in October. Also, there may be some places in your community where you can get advice, or help with writing your Will, that are free. Check in your community for people and activities that support people to make their Wills.

In BC it is legal to create an E-Will. For more information on how to do this, so it is legal, go to [www.gov.bc.ca/makeawill](http://www.gov.bc.ca/makeawill). Another website that has information about an E-Will is [www.nidus.ca](http://www.nidus.ca).

Remember a properly written Will gives you, and the important people in your life, peace of mind.



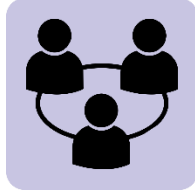
## Late Life Planning Checklists



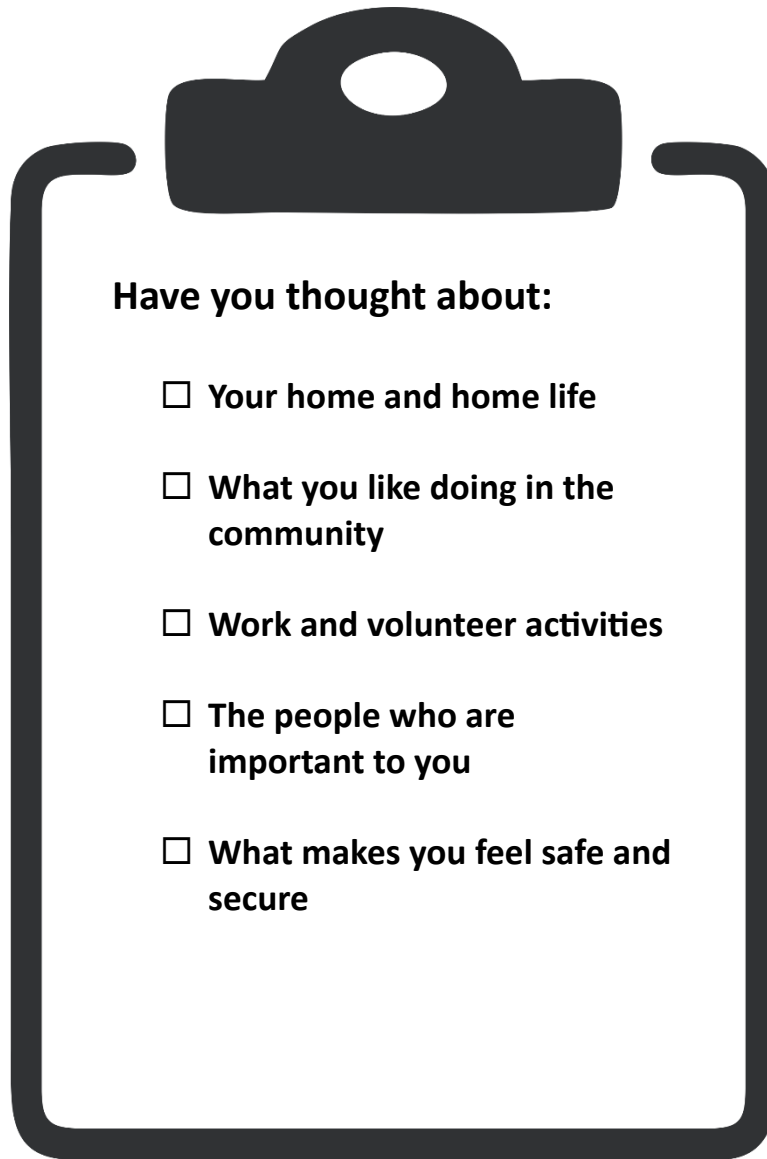
As you age, it is important to create a Late Life Plan. You might get very sick or have an injury. This can change your life. This can make it hard to think clearly or to make decisions.

If you have all your documents complete and in order it can help you, and others, move forward with your life. It is a good idea to review your documents every year.

These checklists can help you make sure all your paperwork is in order.



**Socio-emotional well-being (positive relationships)**  
is about what you want your life as an older adult to look like.

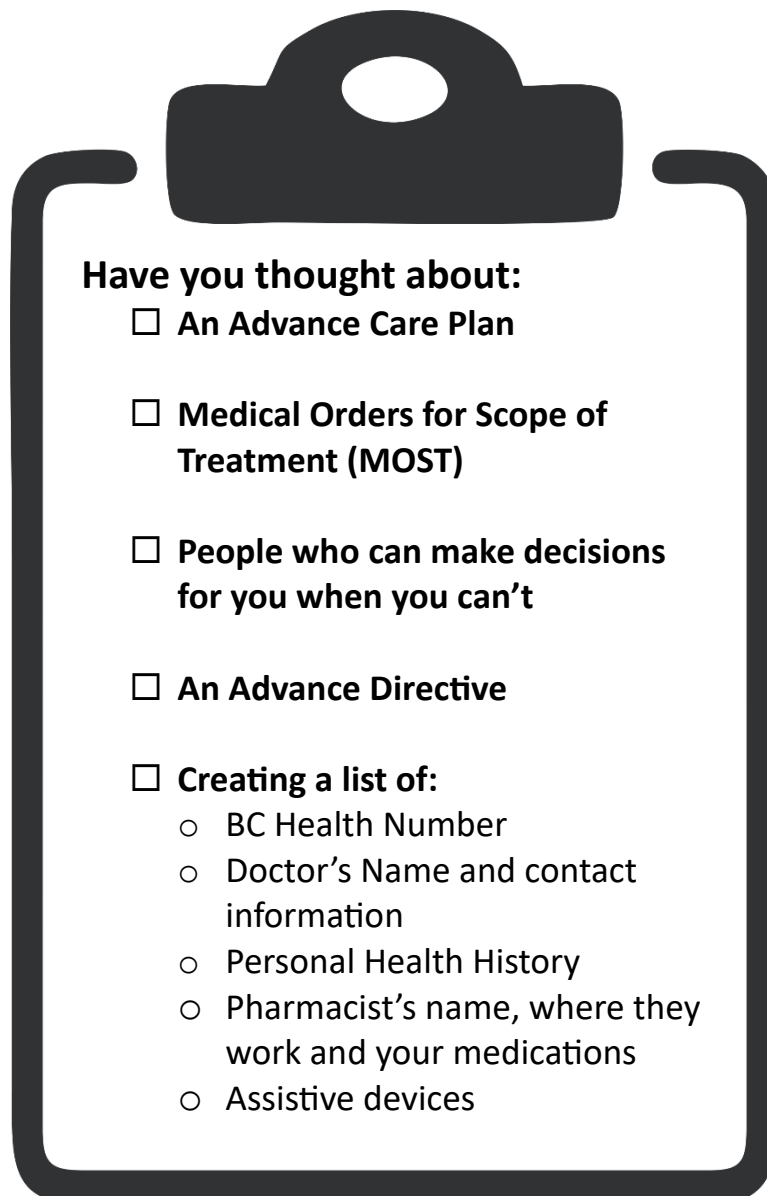
A large black outline of a clipboard with a handle at the top. Inside the clipboard frame, there is a checklist.

**Have you thought about:**

- Your home and home life**
- What you like doing in the community**
- Work and volunteer activities**
- The people who are important to you**
- What makes you feel safe and secure**



**Health Care** includes understanding your health, and what it might look like as an older adult. A plan helps you make health decisions now for what happens in the future. It will be helpful to you, and others, to have a detailed record of all your health information.

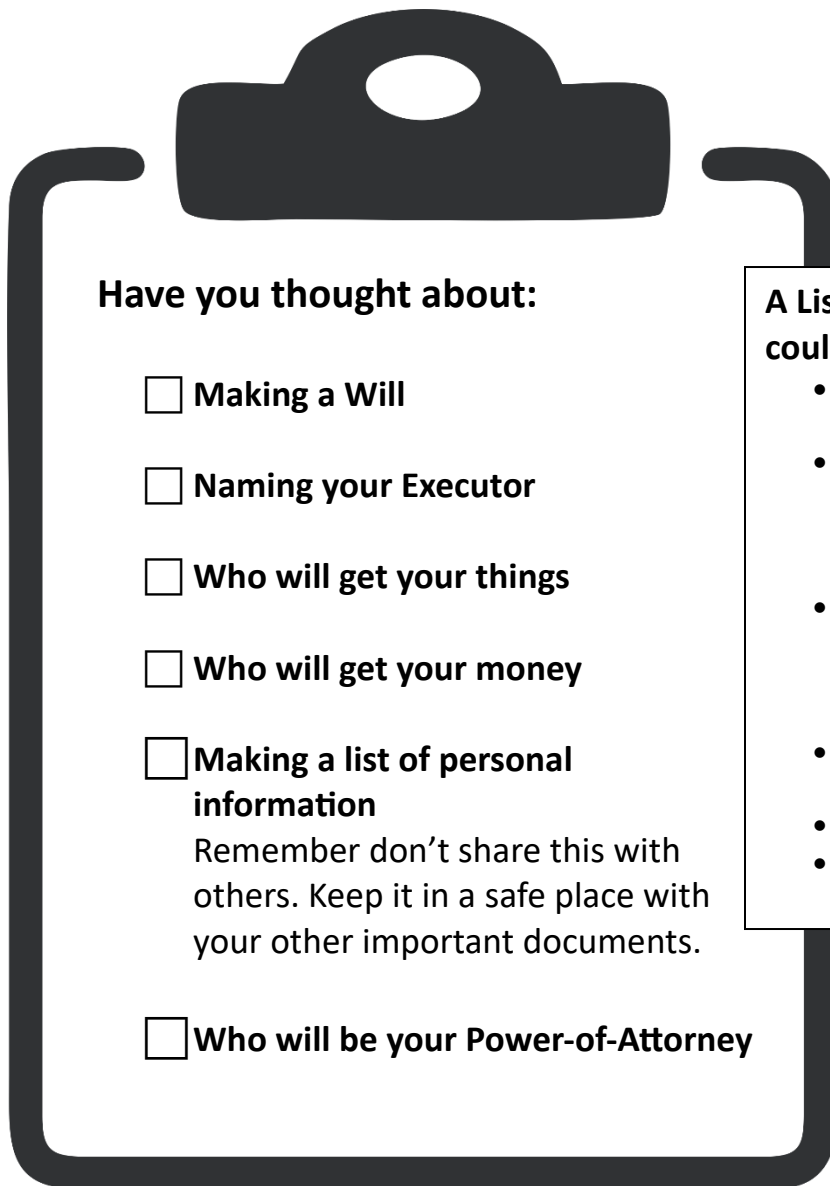


**Have you thought about:**

- An Advance Care Plan**
  
- Medical Orders for Scope of Treatment (MOST)**
  
- People who can make decisions for you when you can't**
  
- An Advance Directive**
  
- Creating a list of:**
  - BC Health Number
  - Doctor's Name and contact information
  - Personal Health History
  - Pharmacist's name, where they work and your medications
  - Assistive devices



**Legal and Financial** is about having people in place who will look after your legal and money matters. You can decide who these people will be. They can be family members, a friend, or someone you trust. Their job is to follow the instructions you give.

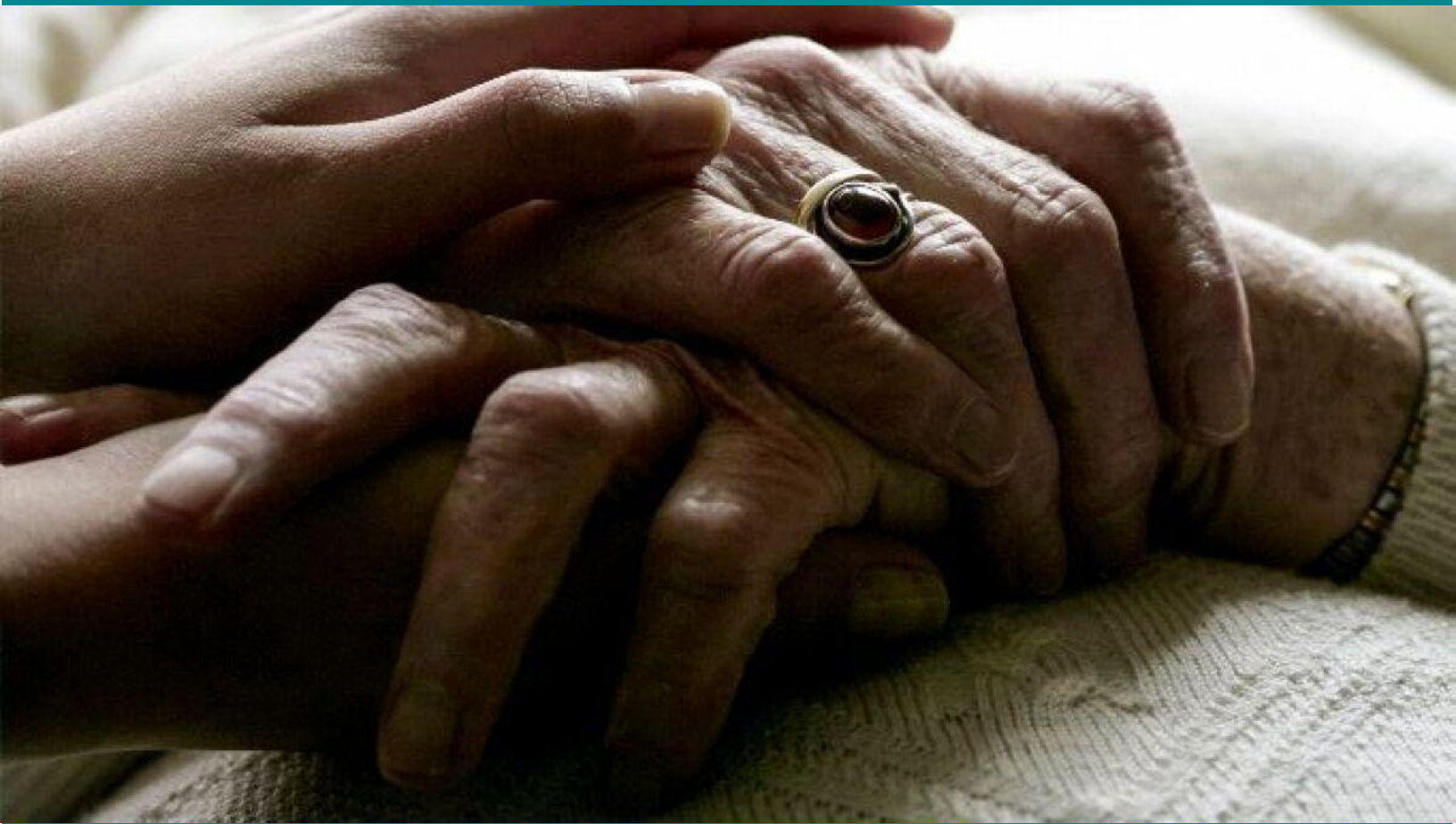


**Have you thought about:**

- Making a Will**
- Naming your Executor**
- Who will get your things**
- Who will get your money**
- Making a list of personal information**  
Remember don't share this with others. Keep it in a safe place with your other important documents.
- Who will be your Power-of-Attorney**

**A List of Personal Information could include your:**

- Social insurance number (SIN number)
- BC Health Number found on your health card, your BC ID number, your Driver's License Number and Passport Number
- The name of your Health Insurance company from your place of work and your ID number
- Information about your bank accounts and credit cards
- Accounts on your computer
- Insurance policies



## END OF LIFE PLANNING

# What Is End of Life Planning

## END OF LIFE PLANNING

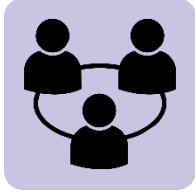
= how, and where  
**YOU** want to spend  
the last days before  
your death

End of Life Planning helps you plan for when you die. The plan will say how, and where, you want to spend the last days before your death. The plan will include your decisions about your money and your health care. These decisions will be followed if you are unable to speak for yourself.

End of life care considers those things that are most important to you like family, being able to worship and being in nature. The languages you speak, important holidays, festivals and the special food you eat are all important as well at the end of life. Knowing the things that are important to you will help others understand your wishes.

Talking about the end of your life can be a very emotional time. It is okay to cry. It is okay to let your feelings out. Sometimes talking about your feelings to people you trust can help. It is important at this time to take care of yourself.





## Socio-emotional well-being (positive relationships)

Many people may be involved in supporting you at the end of your life. This includes family, friends, support staff and health care workers. Their job is to make sure you get support and medical care around your death. If you do not have a family sometimes a person you trust, or a staff person who knows you very well, can tell the health care workers what you want.

It is very important to talk about end of life care early. End of life planning lets others honour your wishes about about doing what you want at this time. It can be hard to talk about what is important to a person if it is left to when the end life is really happening.

When a person gets older it is very important to stay in touch with family and friends. The important people in your life can make sure you are well looked after and treated with dignity. They can do some of your favourite activities with you (like jigsaw puzzles, watching movies, listening to music). They can sit with you and keep you company. All these things can make a difference to how you feel about your life and what is happening to you. The important people in your life can speak up for you if you can no longer do this for yourself.



## Health Care

End of life planning involves a lot of people. This means talking with everyone about what will happen and who can do certain tasks.

As a person is nearing the end of life their body changes. This is normal. Each person is different. You may:

- Sleep a lot
- Eat or drink very little
- Become confused and not know people
- Make noises when you breathe

The people in your life may:

- Sit with you and hold your hand
- Visit only when you are awake
- Give you a little to eat or drink
- Make sure your lips are moist
- Give your hands a massage
- Speak quietly to you

Palliative care may be given when someone is dying. It makes sure you are not having a lot of pain. A referral needs to be made for you to get palliative care. Palliative care can take place:

- At home
- At the hospital



**See the Glossary  
Section:  
End of Life Care**



**See the Glossary  
Section:  
Palliative Care**

- In a hospice (a home like setting for people whose health can no longer be looked after in their own home)
- In a long-term care facility

Medical Assistance in Dying (M.A.I.D.) is about getting help from a doctor or nurse practitioner in ending your life. You must be able to give consent. You must ask for this in writing. Then you will meet with a doctor or nurse practitioner. There will be two meetings. They will ask you many questions. They will decide if you can get M.A.I.D. If both of them say “Yes” then you can have M.A.I.D. A day and time will be scheduled. The doctor or nurse practitioner gives you an injection with a drug that causes death. You can have family or friends with you when you die.

Death Doula is a person you can hire to support you when you have been told you will die soon. They cannot do any medical work. They can do things like:

- Talk and listen to you about your feelings and dying
- Help set up a room so it looks like what you want
- Stay with you while you are dying
- Support your family and friends

What Staff and Health Care Workers Can Do and Not Do

You probably have staff that work with you on a regular basis. They know you very well. They may even go with you to medical appointments.

Staff are only allowed to do certain tasks to help you with your health. Staff need to take new training to do extra health care tasks for you. Only a health care worker can say it is okay for a staff person to do these extra tasks.

Staff can support you to die in your home if that is what you want. Staff will help you feel comfortable. They can help with end-of-life tasks that need to be done, like helping you get your Will written, supporting you to stay in touch with people and talking about how you want to be remembered. They will tell the health care team about any physical or emotional changes they see in you.



**See the Glossary  
Section:  
Hospice**



**See the Glossary  
Section:  
Medical  
Assistance In  
Dying**



**See the Glossary  
Section:  
Death Doula**

Health care workers help with things like:

- Looking after your pain
- Medications
- Skin care

Sometimes dying at home is not possible. Your health may be getting worse. Sometimes the kind of care or type of medications you need can't be given at home. You may have changed your mind about dying at home. Your roommates may be getting very upset. If these things happen you may have to be moved to a hospital, a long-term care facility or a hospice. Remember that the people who work there will follow the plan you recorded. Your family and friends can still come and visit you.

Living with someone who is dying can cause stress and worry for the people who live with you. If you live with other people, it will be important for them to understand what is happening. They may want to help out. They may need to know what happens after you die. They may need help with their feelings.

The routines in your home may change. More people may be coming and going. This can be hard for everyone. All of this may mean staff will need to spend more time than usual with the other people in your home.

### **Saying Goodbye**

It might be important to you to say good-bye to others. You may want to write a letter or card, or talk on the phone. You might want to make a video call to say good-bye. It will be up to you if this is something you want to do and how to do it.

## After You Die



End of Life Planning includes talking about whether or not you want to be buried or cremated. If you want to be buried your body will be put in a coffin. The coffin will be buried in a cemetery. Another word for cemetery is graveyard. There is a marker or headstone telling others that this is where you are buried.

You may prefer to be cremated. This happens at a place called a crematorium. Here the coffin is turned into ashes. Your ashes will be given to your family or friends.



After you die people will fill out some forms. Your doctor or the coroner will write the **Medical Certificate of Death**. Your Executor, the person you said can look after your things and money, will need this form to go ahead with your instructions. If you have a funeral, then the Funeral Director will need this form.

It will be helpful to your family and friends to know if you want a funeral, a Celebration of Life, or some other way to celebrate you after you have died.



# End of Life Checklists

## Questions for you and others to talk about:

- Do you want to stay at home or go to a hospice?
- Who do you want to visit you?  
You can say no one or say the names of certain people you want to see.
- Have you decided who will take care of your pets?
- Are there any special things you want people to do?
- Do your roommates know what is happening?

## End of Life Checklist

- Is your Will up to date?
- Is your Advance Care Plan up to date?
- Is your MOST (Medical Orders) up to date?
- Is your CPR order up to date?
- Are the addresses, emails and phone numbers of your family and friends up to date?
- Do you have someone to talk to about your feelings?



**How Do You Want to Be Remembered  
(End of Life Recognition)**

- Do you want something in writing (called an obituary) that tells others about you and your death?
- Have you decided if you want to be buried or be cremated?
- Have you decided if you want a funeral, a Celebration of Life or another way for the people in your life to come together?
- Have you decided what you want in the service that celebrates you?
- Do you want people to make a donation to a charity in your name?

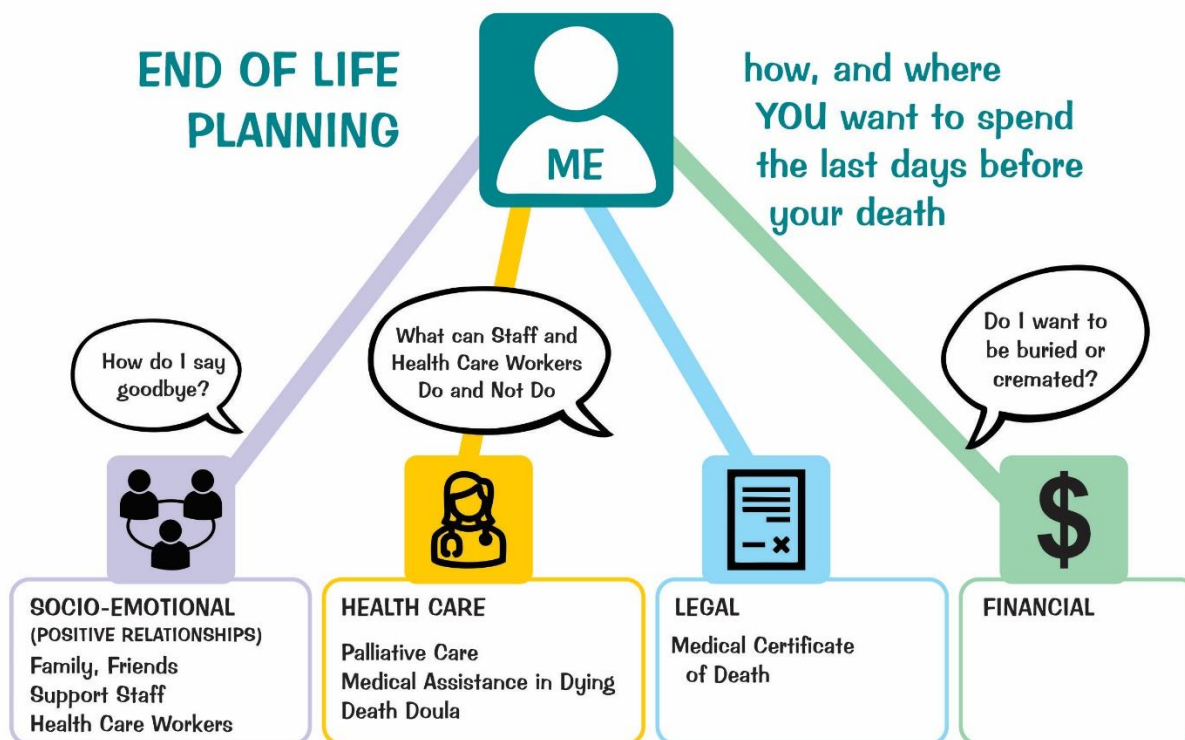
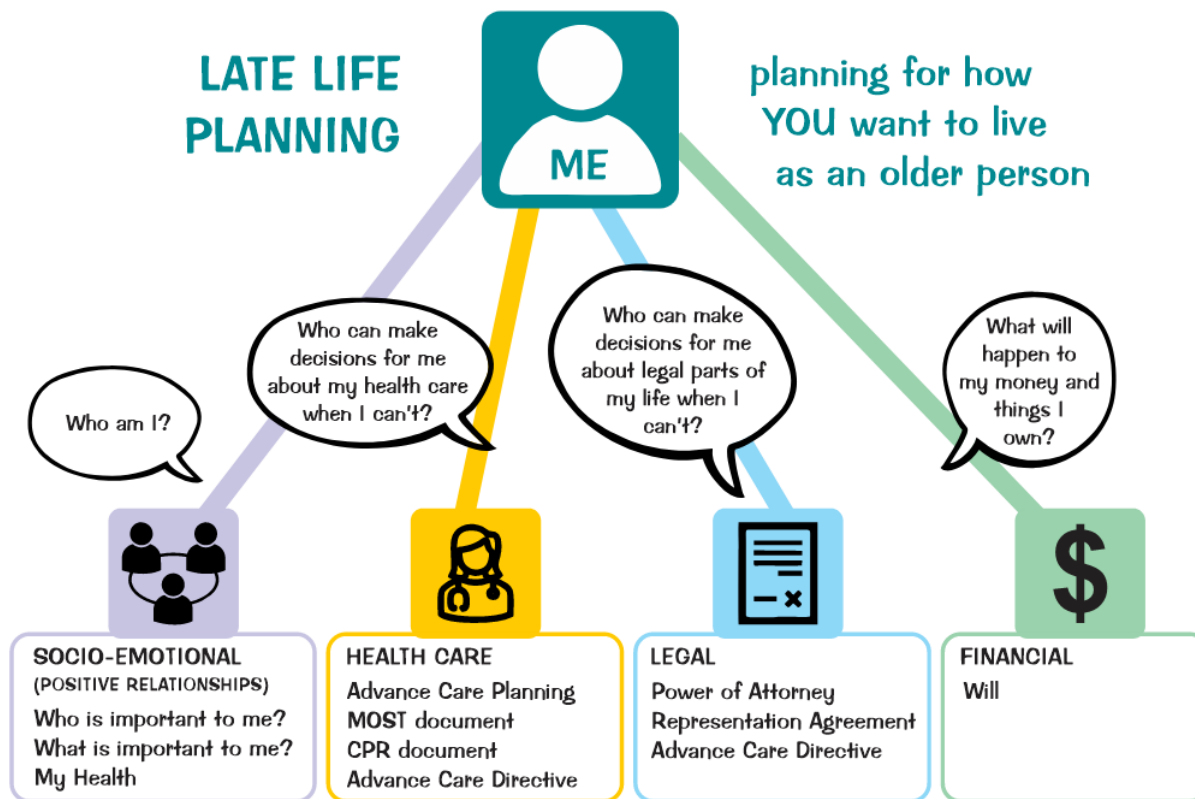


**MORE HELPFUL INFORMATION**





# Summary Diagram





## Forms

- **Early Detection Screen for Dementia:** This form helps you and others figure out what is going on if you are having a hard time doing everyday tasks or remembering things. You will fill this form out with others.
- **Advance Care Plan Summary:** This form is like a checklist. It helps you see if you have included all the information that is important to you in your Advance Care Plan. You can fill this form out yourself.
- **Medical Order for Scope of Treatment:** This form is filled out by a doctor or nurse practitioner. It is an official written document.
- **No Cardiopulmonary Resuscitation (CPR):** This is an official document filled out by a doctor or nurse practitioner.
- **Temporary Substitute Decision Maker:** This form is a contact list of people who can speak for you if you can't. BC Law sets out the order of people the hospital will call. The hospital team will contact the first person on the list who is available to make medical decisions for you when you can't. You can make this list following the rules set out by BC Law.

# Early Detection Screen for Dementia



NTG-EDSD v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID\*, can be used for the early detection screening of those adults with an intellectual disability who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness

Visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions ([www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)).

# Early Detection Screen for Dementia

DATE COMPLETED \_\_\_\_\_

ORGANIZATION/AGENCY \_\_\_\_\_

NAME OF PERSON COMPLETING FORM \_\_\_\_\_

RELATIONSHIP TO PERSON (staff, relative, assessor, etc.) \_\_\_\_\_

DATES FORM PREVIOUSLY COMPLETED \_\_\_\_\_

NAME OF PERSON: FIRST NAME \_\_\_\_\_ LAST NAME \_\_\_\_\_

DATE OF BIRTH \_\_\_\_\_ AGE \_\_\_\_\_ SEX  Female  Male

## BEST DESCRIPTION OF LEVEL OF INTELLECTUAL DISABILITY

- No discernable intellectual disability
- Borderline (IQ 70-75)
- Mild ID (IQ 55-69)
- Moderate ID (IQ 4—54)
- Sever ID (IQ 25-39)
- Profound ID (IQ 24 and below)
- Unknown

## CURRENT LIVING ARRANGEMENT

- Lives alone
- Lives with spouse or friends
- Lives with parents or other family members
- Lives with paid caregiver
- Lives in community group home, apartment, supervised housing, etc.

## GENERAL CHARACTERIZATION OF CURRENT PHYSICAL HEALTH

- Excellent
- Very Good
- Good
- Fair
- Poor

## GENERAL CHARACTERIZATION OF CURRENT MENTAL HEALTH

- Excellent
- Very Good
- Good
- Fair
- Poor

## DIAGNOSED CONDITION (check all that apply)

- Autism
- Cerebral Palsy
- Down Syndrome
- Fragile X Syndrome
- Intellectual Disability
- Prader-Willi Syndrome
- Other: \_\_\_\_\_

- Lives in senior housing
- Lives in congregate residential setting
- Lives in long term care facility
- Lives in other \_\_\_\_\_

## COMPARED TO ONE YEAR AGO, CURRENT PHYSICAL HEALTH IS

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

## COMPARED TO ONE YEAR AGO, CURRENT MENTAL HEALTH IS

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

**CONDITIONS PRESENT (check all that apply)**

- Vision Impairment
  - Blind (very limited or no vision)
  - Vision corrected by glasses
- Hearing Impairment
  - Deaf (very limited or no hearing)
  - Hearing corrected by hearing aids
- Mobility Impairment
  - Not Mobile – uses wheelchair
  - Not Mobile – is moved about in wheelchair

**SEIZURES**

- Recent onset seizures
- Long term occurrence of seizures
- Seizures in childhood, not occurring in adulthood
- No history of seizures

**DIAGNOSTIC HISTORY**

Mild Cognitive Impairment (MCI) or Dementia previously diagnosed?

- No
- Yes MCI Date of Dx \_\_\_\_\_
- Yes Dementia Date of Dx \_\_\_\_\_ Type of Dementia \_\_\_\_\_

Diagnosed By:

- Geriatrician
- Neurologist
- Physician
- Psychiatrist
- Psychologist
- Other \_\_\_\_\_

Reported date of onset of MCI/Dementia (when suspicion of dementia first arose) \_\_\_\_\_  
Year/Month

**COMMENTS/EXPLANATION ABOUT DEMENTIA SUSPICIONS**

**SIGNIFICANT RECENT (in past year) LIFE EVENT (check all that apply)**

- Death of someone close
- Changes in living arrangements, work, or day program
- Changes in staff close to the person
- New roommate/housemates
- Illness or impairment due to accident
- Adverse reaction to medication or over-medication
- Interpersonal conflicts
- Victimization / abuse
- Other \_\_\_\_\_

(check columns as appropriate)

ACTIVITIES OF DAILY LIVING	Always been the case	Always but worse	New symptom in past year	Does not apply
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)				
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)				
LANGUAGE & COMMUNICATION	Always been the case	Always but worse	New symptom in past year	Does not apply
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
SLEEP-WAKE CHANGE PATTERNS	Always been the case	Always but worse	New symptom in past year	Does not apply
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night				
Wakes earlier than usual				
Sleeps later than usual				
AMBULATION	Always been the case	Always but worse	New symptom in past year	Does not apply
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				
MEMORY	Always been the case	Always but worse	New symptom in past year	Does not apply
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people				
Does not remember recent events (in past week or less)				
Does not find way in familiar surroundings				
Loses track of time (time of day, day of the week, seasons)				

Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
<b>BEHAVIOR AND AFFECT</b>	<b>Always been the case</b>	<b>Always but worse</b>	<b>New symptom in past year</b>	<b>Does not apply</b>
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities				
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
<b>ADULT'S SELF-REPORTED PROBLEMS</b>	<b>Always been the case</b>	<b>Always but worse</b>	<b>New symptom in past year</b>	<b>Does not apply</b>
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
<b>NOTABLE SIGNIFICANT CHANGES OBSERVED BY OTHERS</b>	<b>Always been the case</b>	<b>Always but worse</b>	<b>New symptom in past year</b>	<b>Does not apply</b>
In gait (e.g., stumbling, falling, unsteadiness)				
In personality e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

**CHRONIC HEALTH CONDITIONS (check columns as appropriate)**

\*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)

	<b>BONE, JOINT AND MUSCLE</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
1	Arthritis				
2	Osteoporosis				
	<b>HEART AND CIRCULATION</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
3	Heart condition				
4	High cholesterol				
5	High blood pressure				
6	Low blood pressure				
7	Stroke				
	<b>HORMONAL</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
8	Diabetes (type 1 or 2)				
9	Thyroid disorder				
	<b>LUNGS/BREATHING</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
10	Asthma				
11	Chronic bronchitis, emphysema				
12	Sleep disorder				
	<b>MENTAL HEALTH</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
13	Alcohol or substance abuse				
14	Anxiety disorder				
15	Attention deficit disorder				
16	Bipolar disorder				
17	Dementia/Alzheimer's disease				
18	Depression				
19	Eating disorder (anorexia, bulimia)				
20	Obsessive-compulsive disorder				
21	Schizophrenia				
22	Other:				
	<b>PAIN / DISCOMFORT</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
23	Back pain				
24	Constipation				
25	Foot pain				
26	Gastrointestinal pain or discomfort				
27	Headaches				
28	Hip/knee pain				
29	Neck/shoulder pain				
	<b>SENSORY</b>	<b>Recent condition (past year)</b>	<b>Condition diagnosed in last 5 years</b>	<b>Lifelong condition</b>	<b>Condition not present</b>
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				



	OTHER	Recent condition (past year)	Condition diagnosed in last 5 years	Lifelong condition	Condition not present
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

### CURRENT MEDICATIONS

For reviews, attach list of current medications, dosage and when prescribed

- Treatment of chronic conditions,  
Medication Name: \_\_\_\_\_
- Treatment of mental health disorders or behaviour problems  
Medication Name: \_\_\_\_\_
- Treatment of Pain  
Medication Name: \_\_\_\_\_

### COMMENTS RELATED TO OTHER NOTABLE CHANGES OR CONCERNS

### NEXT STEPS / RECOMMENDATIONS

- Refer to treating physician for assessment
- Review internally by clinical personnel
- Include in annual review/annual wellness visit
- Repeat in \_\_\_\_\_ months

Acknowledgement: Derived from the DSQIID (\*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

© AADMD/NTG 1/2013.1

[www.aadmd.org/ntg/screening](http://www.aadmd.org/ntg/screening)

National Task Group on Intellectual Disabilities and Dementia Practices

# My Advance Care Plan – Summary

Put this summary at the front of your Advance Care Plan.

Full name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_

Date this Advance Care Plan was completed: \_\_\_\_\_

This is a new plan:       Yes                       No

My Advance Care plan is

- in writing
- an audio recording
- a visual recording

My advance care plan includes (check all that apply)

- Information about myself, my health and my wishes
- Contact list of people who can speak for me when I can't
- Representation Agreement (This is optional so you can decide if you want this or not.)
- Advance Care Directive (This is optional so you can decide if you want this or not.)
- MOST document
- CPR document

Copies of my Advance Care Plan are with:

Name	Relationship	Phone number
Doctor's Name		

# Medical Order for Scope of Treatment

<b>MEDICAL ORDERS FOR SCOPE OF TREATMENT (MOST)</b>		Legal Name _____ <small>(Last Name, First Name)</small>	
		Date of Birth _____ <small>(dd/mm/yyyy)</small>	
		Phone _____	
<b>PART 1 – RESUSCITATION STATUS &amp; MEDICAL TREATMENTS</b> Most Responsible Practitioner (MRP) (Physician and/or Nurse Practitioner) to initial in the box beside the chosen resuscitation status/treatments (choose only ONE designation)			
<input type="checkbox"/> M1	<b>Supportive care, symptom management and comfort measures only:</b> Allow a natural death. Care is for physical, psychological and spiritual preparation for an expected or imminent death. Do not transfer to higher level of care unless to address comfort measures that cannot be met in current location.		
<input type="checkbox"/> M2	<b>Medical treatments within current location of care including critical care interventions, cardiopulmonary resuscitation (CPR), intubation, and/or defibrillation, cure location:</b> _____ Allow a natural death. Transfer to higher level of care only if adult's medical treatment needs cannot be met in current location. Goals of care and interventions are to cure or control of symptoms of illness that do not require critical care interventions (CPR, defibrillation and intubation).		
<input type="checkbox"/> M3	<b>Medical treatments including transfer to higher level of care but excluding critical care interventions, CPR, defibrillation and/or intubation:</b> Allow a natural death. Medical treatments are for cure or control of symptoms of illness. Transfer to a higher level of care may occur if required for diagnostics and treatment.		
<input type="checkbox"/> C0	<b>Critical care intervention excluding CPR, defibrillation and intubation:</b> Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered <b>except CPR, defibrillation and intubation.</b>		
<input type="checkbox"/> C1	<b>Critical care interventions including intubation, but excluding CPR and defibrillation:</b> Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered <b>except CPR and/or defibrillation.</b>		
<input type="checkbox"/> C2	<b>Critical care interventions including CPR, defibrillation and/or intubation:</b> Adult is expected to benefit from and is accepting of any medically appropriate investigations and interventions that are offered.		
<b>PART 2 – SPECIFIC INTERVENTIONS</b> (if applicable, refer to details in completed Patient Consent Record)			
Blood/Products	<input type="checkbox"/> YES <input type="checkbox"/> NO	Nutritional Support	<input type="checkbox"/> YES <input type="checkbox"/> NO
Dialysis	<input type="checkbox"/> YES <input type="checkbox"/> NO		
Non-Invasive Ventilation	<input type="checkbox"/> YES <input type="checkbox"/> NO	Other _____	
<b>PART 3 – SUPPORTING DOCUMENTATION</b> (check all documents reviewed)			
<input type="checkbox"/> Previous MOST Form	<input type="checkbox"/> Plan of Care	Representation Agreement	<input type="checkbox"/> Other _____
<input type="checkbox"/> No CPR Form (B.C.)	<input type="checkbox"/> Advance Directive	<input type="checkbox"/> Section 9 <input type="checkbox"/> Section 7	
<b>PART 4 – CONSULTATIONS</b> Refer to consent process on reverse (check all individuals consulted)			
<input type="checkbox"/> Capable Adult	<input type="checkbox"/> Representative (name) _____	<input type="checkbox"/> Inter-professional health care team	
<input type="checkbox"/> Personal Guardian (Committee) (name) _____	<input type="checkbox"/> Temporary Substitute Decision Maker (name) _____	<input type="checkbox"/> Adult incapable/SDM unavailable	
<b>SUMMARY OF MRP ORDER (Physician and/or Nurse Practitioner)</b>			
As the MRP I have considered the documents noted in Part 3 and discussed the benefits, consequences and preferences of the above Order with the individual(s) noted in Part 4.			
Name of MRP (please print)		College ID#	Signature
Date (dd/mm/yyyy)	Time (24 hr)	MRP Office Phone #	Adult Location
Sent to MOST Data Entry Office		Date (dd/mm/yyyy)	Initials
<b>REVALIDATION OF MRP ORDER</b>			
<input type="checkbox"/> MOST FORM Revalidation (No Change)	Date (dd/mm/yyyy)	Name of MRP (print)	College ID#
			MRP Signature
Sent to MOST Data Entry Office		Date (dd/mm/yyyy)	Initials

# No Cardiopulmonary Resuscitation - Medical Order

[Click to access form](#)



BRITISH COLUMBIA | Ministry of Health



BC Emergency Health Services

## NO CARDIOPULMONARY RESUSCITATION – MEDICAL ORDER

Capable patients may request that no cardiopulmonary resuscitation be started on their behalf. This should be done by a physician or nurse practitioner. "No cardiopulmonary resuscitation" is defined as no cardiopulmonary resuscitation (no CPR) in the event of cardiac arrest.

This form is provided to you or your substitute decision maker to acknowledge that you have had a conversation with the physician or nurse practitioner about a No CPR Order, and understand that no CPR will be provided in circumstances where you can no longer be resuscitated. It instructs people such as first responders, paramedics and health care providers not to start CPR on your behalf whether you are in a community or in a residential care facility. The personal information collected on this form assists the health professionals noted above in providing you with the best care possible. If you have any questions about the collection of this information contact **HealthLink BC at 8-1-1** or go to [www.gov.bc.ca/healthlinkbc](http://www.gov.bc.ca/healthlinkbc).

You or someone at your location should have the form available to show to health care providers who may be called to your aid. It is desirable that you wear a MedicAlert® no CPR bracelet or necklet to enable quick verification that you have no CPR. If you do not have a bracelet or necklet, you may obtain a free No CPR bracelet/necklet, please:

1. Complete the form below
2. Fill out the MedicAlert Registration form which can be found at [www.medicalert.ca/nocpr/resources/MedicAlert\\_Application\\_BC\\_NOCPR.pdf](http://www.medicalert.ca/nocpr/resources/MedicAlert_Application_BC_NOCPR.pdf)
3. Mail both of the forms to: MedicAlert Foundation, 100 Spadina Avenue, 10th Floor, Spadina Centre II, 895 Don Mills Road, Suite 600, Toronto ON, M3C 1W3

If you change your wishes about whether you want CPR, please inform your doctor, nurse practitioner or residential care facility nurse, tear up the No CPR form, and contact MedicAlert for a No CPR bracelet or necklet.

Sample

<b>PATIENT IDENTIFICATION</b>	Birthdate (YYYY / MM / DD)	
	and Middle Name(s)	Personal Health Number (PHN)
	Patient Address	Telephone Number
<b>WITNESSED BY THE PATIENT, OR BY THE PATIENT'S SUBSTITUTE DECISION MAKER (SDM) WHEN THE PATIENT IS INCAPABLE</b>	I, _____ (patient's name or patient's substitute decision maker if patient is incapable) have had a conversation with the undersigned physician/nurse practitioner about this No CPR Order in the event of cardiac or respiratory arrest. I understand that in the event of a cardiac or respiratory arrest, no cardiopulmonary resuscitation is to be undertaken.	
	Patient's Signature	Date Signed
	Signature of the Patient's Substitute Decision Maker	Date Signed
	Relationship of the Patient's Substitute Decision Maker to the Patient (e.g. representative, committee of person, or temporary substitute decision maker)	
<b>SECTION TO BE COMPLETED BY PHYSICIAN/NURSE PRACTITIONER</b>		
<b>STATUS OF MEDICAL ORDER</b>	The above identified patient has expressed wishes to not have CPR in the event of cardiac or respiratory arrest. I have discussed the patient's health status, life expectancy, and expressed wishes with the patient/patient's substitute decision maker. Based on this discussion, I order that in the event of a respiratory and/or cardiac arrest no cardiopulmonary resuscitation is to be undertaken. This order shall be in effect until cancelled or repealed.	Date
<input type="checkbox"/> Patient (or SDM) agrees and has signed this form		
<input type="checkbox"/> Patient (or SDM) agrees but has declined signing this form		
<b>ATTENDING PHYSICIAN/NURSE PRACTITIONER</b>		<b>ALTERNATE PHYSICIAN/NURSE PRACTITIONER</b>
Name of Attending Physician / Nurse Practitioner		Name (Print)
License Number of Physician / Nurse Practitioner	Phone Number	Phone Number
Address	Signature	

COPY 1 – TO PATIENT; COPY 2 – TO ATTENDING PHYSICIAN/NURSE PRACTITIONER; COPY 3 – IF APPLICABLE, TO HOME & COMMUNITY CARE OR RESIDENTIAL CARE FACILITY

HLTH 302 Rev. 2019/03/26

This form can be found at [www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf](http://www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf)

## PATIENT/ FAMILY INSTRUCTIONS

Looking at this form may be one of the most difficult things you have ever done. Many thoughts and emotions may surface. So often people try to ignore their mortality, yet we all know it is one of the facts of life: we all, one day, will die.

This form is a medical order that reflects your wishes about what you would like to have happen in the event you stop breathing or your heart stops beating. Take time to thoughtfully consider your wishes and ask your health care professionals what resuscitation would entail and any risks to quality and/or quantity of life that could accompany resuscitation if you decided to have it.

Whether you live at home or in a residential care facility, your care team will help you and/or your substitute decision maker to make choices and plans for end-of-life-care. If you have a life-limiting illness and are choosing to die at home, you will need to make additional plans. The steps you will need to consider are listed below.

If you are a family member who is asked to consider this document on behalf of your loved one, all of what is said above applies also. This can be a stressful decision. Remember to seek support from trusted family members, friends and/or a spiritual advisor if you have one and your health care team.

### IF YOU WANT TO DIE NATURALLY AT HOME, CONSIDER THESE STEPS

#### INDIVIDUAL / FAMILY

##### What to Do Ahead of Time

- > Discuss the option of an in-home death with your physician/nurse practitioner and community nurse.
- > Make a written plan with your physician/nurse practitioner and community nurse so you are clear about what will happen and so family, friends and others may support your decisions and respect your wishes and know what to do at the time of death. You need to write in your plan:
  - who will pronounce death, IF pronouncement is planned. Pronouncement is NOT necessary if a "Notification of Expected Home Death" form has been completed earlier by you and your doctor or nurse practitioner. The form can be found at [www.gov.bc.ca/expectedhomedeath](http://www.gov.bc.ca/expectedhomedeath).
  - how your physician/nurse practitioner can be reached;
  - what alternate arrangements have been made should your physician/nurse practitioner be unavailable or cannot be reached;
  - which funeral home will be called to transport the deceased.
- > Make prearrangements with a funeral home. Such arrangements will normally involve selecting the funeral home and making plans with the funeral director for transportation of the deceased after death and the method of final disposition. For information on funeral homes in your area, you could contact the B.C. Funeral Association at 1-800-665-3899.
- > Ensure that a copy of this form is easily available in your home. If you are away from your home for any reason, take the form with you so it's available should it be necessary.

#### FAMILY / FRIENDS

##### What to Do at the Time of Death

- > DO NOT CALL 911, the ambulance, coroner, police, or fire department. Review your written plan for who to contact at the time of death.
- > CALL family, friends, and the spiritual advisor, if any, you would like to have present.
- > CALL the physician/nurse practitioner or community nurse to pronounce death IF a "Notification of Planned Home Death" form has NOT been completed, AND/OR pronouncement is planned.
  - If your physician/nurse practitioner or community nurse cannot be reached, CALL the backup physician/nurse practitioner or community nurse if prearranged.
- > IF a "Notification of Planned Home Death" form HAS been completed AND is in your home, call the funeral home after one hour or more has passed since your loved one's breathing has stopped.
  - You do NOT need to call a physician/nurse practitioner about completing a Medical Certificate of Death form. The funeral home can contact the physician or nurse practitioner to obtain a signed certificate within 48 hours, because the body cannot be released for burial or cremation without it.

People to Call	Name	Telephone Number
Phys/Nur. Practitioner		
Alternate Practitioner		
Community Nurse		
Funeral Home		
Spiritual Advisor		
Home Support Agency		
Hospice Program		
Family and Friends		

**For more information, go to [www.gov.bc.ca/expectedhomedeath](http://www.gov.bc.ca/expectedhomedeath)**

*There are communities in British Columbia without physicians or nurse practitioners who live in the community and without a funeral home. It is essential that these situations be discussed by the patient and family and physician/nurse practitioner and an appropriate plan suitable for the community be made in advance.*

**PRINT**

**CLEAR FORM**

## My Temporary Substitute Decision Maker (TSDM) List:

Remember the people who you write in your list must:

- Be 19 years or older
- Able to make decisions
- Been in touch with you in the past 12 months
- Have no disagreements with you

**Spouse** (includes married, common-law. Length of time living together does not matter)

Name	Phone number
------	--------------

**Adult Children** (birth order does not matter)

Name	Phone number
Name	Phone number
Name	Phone number

**Parents** (may include adoptive)

Name	Phone number
Name	Phone number

**Brothers or Sisters** (birth order does not matter)

Name	Phone number
Name	Phone number
Name	Phone number

**Grandparents**

Name	Phone number
Name	Phone number

**Grandchildren**

Name	Phone number
Name	Phone number
Name	Phone number

**Anyone else related to me by birth or adoption**

Name	Phone number
------	--------------

**Close Friends**

Name	Phone number
------	--------------

**A person immediately related by marriage (equally ranked)**

Name	Phone number
------	--------------



## Glossary

There are a lot of words specific to Late Life Planning that might need explaining. Here are some of them.

<b>Advance Care Plan</b>	A plan for your future health needs.
<b>Crematorium</b>	A place where your coffin is turned into ashes.
<b>Death Doula</b>	A person you hire to support you when you have been told you will die soon.
<b>E-Will</b>	An Electronic Will that is created online.
<b>End of Life Care</b>	The care you want to be comfortable as you are dying.
<b>Greensleeve</b>	A green plastic folder to help you keep all your advance care documents in one place.
<b>Hospice</b>	A home like setting for people whose health can no longer be looked after in their own home.
<b>Medical Assistance in Dying (M.A.I.D.)</b>	Is giving written consent to a doctor or nurse practitioner to help with ending your life.
<b>Medical Order for Scope of Treatment (MOST)</b>	An official written document set up by talking with a doctor or nurse practitioner. A MOST order includes whether or not you want CPR.
<b>Notary</b>	A person who can write legal documents.
<b>Palliative Care</b>	Is a type of care that makes sure you feel comfortable, and are not having a lot of pain, as you are dying.
<b>Power of Attorney</b>	A person you choose to look after your financial and legal matters.
<b>Representation Agreement</b>	A legal document that says who can make decisions for you when you can not.
<b>Temporary Substitute Decision Maker (TSDM)</b>	People who can speak for you if you can't.
<b>Will</b>	A legal document that gives details about what will happen to your money and things after you have died.





# Resources

## Workbooks



**Thinking Ahead Matters: My Way, My Choice, My Life At the End  
(from California)**

[https://coalitionccc.org/common/Uploaded%20files/PDFs/Thinking-Ahead-Booklet\\_web.pdf](https://coalitionccc.org/common/Uploaded%20files/PDFs/Thinking-Ahead-Booklet_web.pdf)



**Easy Read Advance Care Planning (ACP) Guide – Fraser Health, BC**

This fillable ACP picture based workbook can help an individual, and the people who matter to them, work through the steps of planning for their future health.

<https://patienteduc.fraserhealth.ca/file/my-voice-action-a-workbook-for-advance-care-pla-583174.pdf>



**Living Well: Thinking and Planning for the End of Your Life  
(from the United Kingdom)**

<https://creativeoptionsregina.ca/wp-content/uploads/2015/03/Thinkind-and-Planning-for-the-End-of-Your-Life.pdf>



**Accessible Planning Tool: Glancing Back, Planning Forward  
(from the United Kingdom)**

<http://www.professionalpalliativehub.com/sites/default/files/Accessible%20Planning%20Tool.pdf>








**Your Conversation Starter Kit: When It Comes to End of Life Care, Talking Matters  
(from US)**

<https://theconversationproject.org/wpcontent/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf>

## Information

	<p><b>Let's Talk About Aging: A Booklet About Getting Older for Adults with Down Syndrome</b>  <a href="https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DOWNS-SYNDROME-SCOTLAND_LETS-TALK-ABOUT-GETTING-OLDER_AW_WEB.pdf">https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DOWNS-SYNDROME-SCOTLAND_LETS-TALK-ABOUT-GETTING-OLDER_AW_WEB.pdf</a></p>
	<p><b>Let's Talk About Dementia: A Booklet for Adults with Down Syndrome</b>  <a href="https://www.dsscotland.org.uk/wp-content/uploads/2020/01/LETS-TALK-ABOUT-DEMENTIA.pdf">https://www.dsscotland.org.uk/wp-content/uploads/2020/01/LETS-TALK-ABOUT-DEMENTIA.pdf</a></p>
	<p><b>Getting Older</b>  <a href="https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Ageing-Final-Format-5th-April-DSMIG.pdf">https://www.downs-syndrome.org.uk/wp-content/uploads/2020/06/Ageing-Final-Format-5th-April-DSMIG.pdf</a></p>
	<p><b>Let's Talk About Death: A Booklet About Death and Funerals for People with Down Syndrome</b>  <a href="https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-DEATH_WEB.pdf">https://www.dsscotland.org.uk/wp-content/uploads/2019/05/DSS_LETS-TALK-ABOUT-DEATH_WEB.pdf</a></p>
	<p><b>Talking End of Life with People with Intellectual Disabilities</b>  <a href="https://www.caresearch.com.au/tel/tabid/4881/Default.aspx">https://www.caresearch.com.au/tel/tabid/4881/Default.aspx</a></p> <p>This website includes a number of written documents, online resources and videos for supported individuals, families and support workers. Adults with intellectual disabilities have been part of the research and development of the materials.</p>
	<p><b>Plain Language Introduction to Supported Decision Making from Inclusion Saskatchewan</b>  <a href="https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf">https://7b6cc965-3fed-4f57-9074-90f8363e9ac7.filesusr.com/ugd/df5183_9c518858a895465693153961d87a1dda.pdf</a></p>


	<p><b>Supporting Me to Make a Decision: A Quick Guide</b>  This short plain language guide gives information about making your own decisions. It is from the Down Syndrome Association in the UK.  <a href="https://www.downs-syndrome.org.uk/wp-content/uploads/2021/02/Quick-Guide-Supporting-me-to-make-a-decision.pdf">https://www.downs-syndrome.org.uk/wp-content/uploads/2021/02/Quick-Guide-Supporting-me-to-make-a-decision.pdf</a></p>
	<p><b>Supporting People with Disabilities Coping with Grief and Loss</b>  <a href="http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/mental-health/feelings/SUPPORTING_PEOPLE_WITH_DISABILITIES_COPING_WITH_GRIEF_AND_LOSS.pdf">http://www.apictureofhealth.southwest.nhs.uk/wp-content/uploads/mental-health/feelings/SUPPORTING_PEOPLE_WITH_DISABILITIES_COPING_WITH_GRIEF_AND_LOSS.pdf</a></p>
	<p><b>Preparing for Death – Victoria Hospice</b>  <a href="https://victoriahospice.org/wpcontent/uploads/2019/07/preparing_for_death.pdf">https://victoriahospice.org/wpcontent/uploads/2019/07/preparing_for_death.pdf</a></p>
	<p>The First Nations Health Authority has developed this guide to learn about Advance Care Planning. The goal of planning is to support individuals, families, and health care providers, to walk side-by-side through a person’s illness and journey into the Spirit World.  <b>Your Care, Your Choice – Planning in Advance for Medical Care</b>  <a href="https://www.fnha.ca/WellnessSite/WellnessDocuments/FNHA-Your-Care-Your-Choices-Planning-in-Advance-for-Medical-Care.pdf">https://www.fnha.ca/WellnessSite/WellnessDocuments/FNHA-Your-Care-Your-Choices-Planning-in-Advance-for-Medical-Care.pdf</a></p>
	<p>This document focuses on care conversations for Two-Spirit and Lesbian, Gay, Bisexual, Trans, Queer, and all sexual and gender-diverse people.  <b>Planning for My Care for people who identify as Two Spirit or LGBTQ+</b>  <a href="https://www.virtualhospice.ca/2SLGBTQ/media/igkp01nf/2slgbtq-planning-for-my-care.pdf">https://www.virtualhospice.ca/2SLGBTQ/media/igkp01nf/2slgbtq-planning-for-my-care.pdf</a></p>




A **Representation Agreement** is a legal document where a person writes down the names of people to help them make decisions, or to make decisions for them, if they can not do that on their own. There are 2 different ones. One will cover money matters, legal affairs, health care and personal care. The other one only covers health care and personal care. A fact sheet describing these two types of agreements and other information can be found at the website for Nidus.

<https://nidus.ca/resource/section-7-representation-agreement/>

## Websites

	<p><b>VictoriaandStuart</b> - This website has many resources, including a toolkit, EASYREAD (plain language) information sheets and guides, and videos.  <a href="https://www.victoriaandstuart.com">https://www.victoriaandstuart.com</a></p>
	<p><b>Canadian Virtual Hospice</b> - A resource with information on death and dying, planning for end of life, grief, culture and materials to support the LGBTQ2+ community.  <a href="https://www.virtualhospice.ca/">https://www.virtualhospice.ca/</a></p>
	<p><b>NIDUS</b> - Nidus Personal Planning Resource Centre and Registry is an organization that helps people make and register Representation Agreements. They also help people learn about other legal documents.  <a href="http://www.nidus.ca">www.nidus.ca</a></p>
	<p><b>PLAN: Planned Lifetime Advocacy Network</b> - PLAN works with people to build personal support networks. They help people make plans to secure their futures.  <a href="https://plan.ca/">https://plan.ca/</a></p>
	<p><b>L'Arche Canada: Aging and Disability – Preparing for End of Life</b> - This website gives examples of people preparing for their end of life. There are examples of memorial services, celebration booklets and links to other resources.  <a href="http://www.aging-and-disability.org/en/ending_life_well">http://www.aging-and-disability.org/en/ending_life_well</a></p>
	<p><b>NTG: The National Task Group on Intellectual Disabilities and Dementia Practices</b> - This organization advocates for research and resources for people with intellectual disabilities and their families affected by Alzheimer's Disease or Dementias. The Early Detection Screen for Dementia comes from this organization. The Early Detection Screen for Dementia is being used in BC to assist with monitoring changes for people they serve.  <a href="https://www.the-ntg.org/">https://www.the-ntg.org/</a></p>

	<p><b>The Down Syndrome Research Foundation</b> - This website features a Resource section which has videos, links to others resources and information for families and caregivers.</p> <p><a href="https://www.dsrf.org/">https://www.dsrf.org/</a></p>
	<p><b>The Alzheimer's Society</b> - This website offers information on dementia. There are links to resources and support groups. The website tells you about workshops in BC. You can listen to webinars. Many resources have been translated into other languages.</p> <p><a href="https://alzheimer.ca/bc/en">https://alzheimer.ca/bc/en</a></p>
	<p><b>Birmingham Research Park</b> - This organization is based in the UK. It has resources on aging and people with intellectual disabilities.</p> <p><a href="https://www.bild.org.uk/">https://www.bild.org.uk/</a></p>
	<p><b>Indigenous Cognition and Aging Awareness Research Exchange</b> – Their research provides information and resources to support Indigenous communities respond to aging related changes. New Canadian Assessment tools are now included on the website.</p> <p><a href="https://www.i-caare.ca/">https://www.i-caare.ca/</a></p>
	<p><b>Books Beyond Words</b> - <a href="#">Beyond Words</a> empowers people through pictures. Their word-free books and stories give people information to understand their feelings and what is happening around them. The word-free books supports people to take part in decisions about their lives.</p>
	<p><b>People's Law School</b> - provides free legal education and information to help people in British Columbia resolve everyday legal matters.</p> <p><a href="http://www.peopleslawschool.ca">www.peopleslawschool.ca</a></p>



**Community Living BC Aging Knowledge Hub** - This website helps you find aging-related resources and information for a range of topics in one, easy-to-access location. Twenty topics are covered. When you click on the topic you will see many related resources, like fact sheets and videos to watch. Check out this site at: [communitylivingbc.ca/resources/aging-knowledge-hub](https://communitylivingbc.ca/resources/aging-knowledge-hub)

## BC Health Authorities

<b>Fraser Health</b> EMAIL: <a href="mailto:advancecareplanning@fraserhealth.ca">advancecareplanning@fraserhealth.ca</a> PHONE: 1-877-825-5034
<b>Interior Health</b> EMAIL: <a href="mailto:advancecareplanning@interiorhealth.ca">advancecareplanning@interiorhealth.ca</a>
<b>Island Health</b> EMAIL: <a href="mailto:advancecareplanning@islandhealth.ca">advancecareplanning@islandhealth.ca</a> Advance Care Planning Coordinator 250-370-5687
<b>Northern Health</b> EMAIL: <a href="mailto:advancecareplanning@northernhealth.ca">advancecareplanning@northernhealth.ca</a>
<b>Vancouver Coastal Health</b> EMAIL: <a href="mailto:advancecareplanning@vch.ca">advancecareplanning@vch.ca</a>



# Notes







community **living** society

**7<sup>th</sup> Floor – 713 Columbia Street**

**New Westminster, BC**

**V3M 1B2**

**604.523.0303**

**[www.communitylivingsociety.ca](http://www.communitylivingsociety.ca)**