Who Will Speak for You?

Advance Care Planning Kit for Northwest Territories





Table of Contents

Understar	nding Your Personal Directive	page 3
Considerir	ng Your Personal Values	page 3
Considerir	ng Your Medical Priorities	page 5
Why You !	Should Appoint An Agent	page 8
Talking To	Your Agent	page 9
THE PERS	ONAL DIRECTIVE FORM	page 14
Appendix		
I.	Medical Terms Explained	page 17
II.	Frequently Asked Questions	page 19
III.	Further Resources	page 21
About Dyi	ng With Dignity Canada	page 22



Understanding Your Personal Directive

WHAT IT MEANS: Your Personal Directive is a document in which you make known your wishes for your personal care and for your medical treatment or non-treatment. It only comes into effect if you are unable to speak for yourself.

WHY YOU SHOULD HAVE A PERSONAL DIRECTIVE: In a medical emergency, or any other circumstance which leaves you unable to communicate, your Personal Directive will help those responsible for your care to decide on your treatment. And it will help your loved ones to make the right decisions on your behalf.

Without a Personal Directive you may be subject to aggressive medical intervention, which you may not want to have. Or you may have a specific medical condition for which you do want all available treatment.

HOW TO GO ABOUT IT: First, read <u>Considering Your Personal Values.</u> This will start you off thinking about what is important to you in terms of quality of life.

Considering Your Personal Values

- 1. What do you feel gives your life its purpose and meaning?
- 2. What do you particularly value about your physical or mental well-being:

Do you most love to be outdoors?

Are large family gatherings your happiest times?

Do you prefer quiet time alone listening to music or reading?

Have you a favorite pastime such as bridge or crosswords?

Do you have a hobby, perhaps painting or collecting?



- 3. If you were no longer able to enjoy the things that are important to you because of deterioration in your sight, or hearing, or mobility, do you think this would affect the health care decisions you would make?
- 4. If you could plan it today, what would the last day of your life be like?

Where would you be?

What would you be doing?

Who would be with you?

What would you eat, if you were able to eat?

Would you want the comfort of spiritual support, such as a member of the clergy or someone who shares your religious beliefs?

- 5. Are there people to whom you would want to write a letter, or tape a message, perhaps marked for opening at a future time?
- 6. How do you want to be remembered? If you were to write your own obituary or epitaph, what would it say?
- 7. Are there other personal values you want others to be aware of?

NEXT: Read <u>Considering Your Medical Priorities</u>. This is the most difficult part, because it asks you to imagine yourself in various critical conditions, and to then think about what treatment you would want to accept or refuse in each case, and to write down your answers.

Writing down your answers is just for your own information and to help clear things in your mind, so that you are better prepared for the next step.



Considering Your Medical Priorities

1.	Which of the following do y Being in pain Losing the ability Being a burden o	to think	
2.	of life even if family member agreement and comfortable	ers or friend with what shes for tre and friends	atment followed, even if there is disagreement
3.	and this treatment usually and weakness that could la	has very sev st 2-3 mont dure the sid	and doctors are recommending chemotherapy vere side effects, such as pain, nausea, vomiting ths. The effects if the chance of regaining your current of the chance of t
4.	clearly terminal, but the chosix months of life.	emotherapy otherapy eve	evious question, suppose that your condition is y has an 80% chance of giving you an additional en though it has severe side effects, such as pair
5.	the point where you could i	not recogniz	as Alzheimer's disease, and it had progressed t ze or have a conversation with your loved ones ssible, would you want to be fed by a tube into I am uncertain



6. Imagine you had advanced dementia to the same degree as in the above question. You have already been hospitalized twice in the past year for pneumonia and other lung infections which required aggressive medical intervention including massive doses of antibiotics.

The next time you get pneumonia, which if left untreated could be fatal, do you want aggressive treatment again, or would you prefer simply to have comfort care until death comes?

- a) Aggressive treatment including antibiotics
- b) No treatment, comfort care only
- c) I am uncertain
- 7. Imagine you have long-standing diabetes, or a severe circulatory condition such as advanced arterial disease that resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

Would you want the operation or would you prefer to simply have comfort care and allow your untreated medical condition to bring about your death?

- a) I would want the surgery
- b) No surgery, comfort care only
- c) I am uncertain
- 8. Imagine that you are physically frail and you need help with most routine daily activities, such as dressing, bathing, eating, and going to the toilet. You live in a nursing home and your mind is fairly clear and capable most of the time. You develop a severe kidney infection which if left untreated would lead to multiple organ failure and death. Would you want to be hospitalized and receive aggressive medical intervention, or would you prefer not to be treated but to simply have comfort care and allow your untreated medical condition to bring about your death?
 - a) Treated in hospital
 - b) No treatment, comfort care only
 - c) I am uncertain
- 9. Imagine you have congestive heart failure that causes your lungs to fill up with fluid, leaving you extremely breathless, and that also causes your ankles to swell up so that walking is difficult. You are always short of breath and tired, and unable to walk even one block. Your health is poor but you are alert and able to enjoy time with family and friends.

One day you have a heart attack and your heart stops beating. Would you want CPR started and 911 called?			
No	I am uncertain		
cal breathing and to o you that decisions	and your body is maintained by artificial abe feeding. about your treatment or discontinuation of or spiritual values that you hold? I am uncertain		
11. If you were terminally ill with a condition that caused you much pain, would you want to be sedated even to the point of unconsciousness, if it were necessary to control your pain?			
No	I am uncertain		
12. Would you allow yourself to be placed on life support if your heart, kidneys, pancreas, lungs, or liver could be used in transplant operations to save lives after your death? Yes No I am uncertain			
	I am uncertain and talk over these questions and		
	No a permanent coma a cal breathing and to o you that decisions the religious beliefs No Il with a condition the e point of unconscio		

When you are ready to continue, the **NEXT STEP** is to think about appointing <u>an Agent</u>. Your Agent is the person you authorize to make decisions on your behalf if you are unable to speak for yourself.

answers with your loved ones and with your caregivers.

Although appointing an Agent in your Personal Directive is optional, we strongly advise that you do so.



Why You Should Appoint An Agent

If you become critically ill, and unable to communicate your wishes, the physicians treating you will consult with your Agent concerning the terms of your directive. This gives you another layer of protection in ensuring your wishes are respected.

Although you may have written a Personal Directive, a situation may arise where your medical condition at the time is not one that is addressed in your directive. Your Agent would then be able to make a decision on your behalf, based on his/her understanding of what you would decide for yourself, if you were able to do so.

Should you suffer a mental impairment, and are unable to communicate your wishes your Agent has the authority to make arrangements for your personal care. Your Agent is concerned with all aspects of your future care, such as where to live; whether or not you have special dietary or clothing needs, and if so, to ensure these needs are accommodated; arranging for additional help to assist you in daily living, should you gradually come to need this.

WHO TO APPOINT: Your Agent must be over 19 years of age and someone whom you trust to carry out your wishes.

You have the option to appoint more than one Agent. In this instance you should name one person as Agent and the next person or persons as Alternate Agent or Agents. If you appoint more than one Agent, you can choose to have them act **jointly** or act **independently**

Under the law, having them act jointly means they must all agree on all decisions before action can be taken. If there is disagreement over your care, a majority decision will be deemed to be the health care decision of all. If there is no majority, the Agent named first in the directive makes the health care decision.

Under the law, having your Agents act independently means that if the person you first named as Agent is unable or unwilling to act on your behalf, the person you named as Alternate Agent is automatically authorized to assume the duties.

We advise that you appoint your Agents to act independently.



Talking To Your Agent

Your Agent is the person you authorize to speak on your behalf. How well do they know you and your health care wishes? This short form with questions and answers will help you find out how well you have communicated your wishes to them and how well they have understood your wishes.

This is exactly the same form as <u>Considering Your Medical Priorities</u> (page 5), which you filled in earlier. Your Agent now answers the same questions as if they were doing so on your behalf, under conditions in which you could not speak for yourself.

Your Agent completes this section:

1.	Which of the following do you think I fear most near the end of life?
	Being in pain
	Losing the ability to think
	Being a burden on loved ones

- 2. Do you think it is more important for me to (a) have my wishes for treatment followed at the end of life even if family members or friends disagree, or (b) have family and friends all in agreement and comfortable with whatever decision is made?
 - a) Have my wishes for treatment followed, even if there is disagreement
 - b) Have family and friends all in agreement
 - c) I am uncertain
- 3. Imagine that I am now seriously ill, and doctors are recommending chemotherapy and this treatment usually has very severe side effects, such as pain, nausea, vomiting and weakness that could last 2-3 months.

Do you think that I would be willing to endure the side effects if the chance of regaining my current health was less than 25 in 100?

Yes No I am uncertain

4. In the same circumstances as in the previous question, suppose that my condition is clearly terminal, but the chemotherapy has an 80% chance of giving me an additional 6 months of life.

Do you think that I would want the chemotherapy even though it has severe side effects, such as pain, nausea, vomiting and weakness?

Yes No I am uncertain



5. Imagine that I had a dementia, such as Alzheimer's disease, and it had progressed to the point where I could not recognize or have a conversation with my loved ones. When spoon-feeding was no longer possible, do you think that I would want to be fed by a tube into my stomach?

Yes No I am uncertain

6. Imagine I have advanced dementia to the same degree as in the above question. I have already been hospitalized twice in the past year for pneumonia and other lung infections, which required aggressive medical intervention, including massive doses of antibiotics.

The next time I get pneumonia, which if left untreated could be fatal, do you think that I would want aggressive treatment again, or that I would prefer simply to have comfort care until death comes?

- a) Aggressive treatment including antibiotics
- b) No treatment, comfort care only
- c) I am uncertain
- 7. Imagine I have long-standing diabetes, or a severe circulatory condition such as advanced arterial disease that resulted in one leg being amputated because it developed gangrene. Now, the other leg develops gangrene and the doctor recommends amputation because the condition could be fatal.

Do you think that I would want the operation or that I would prefer to simply have comfort care and allow the untreated medical condition to bring about my death?

- a) I would want the surgery
- b) No surgery, comfort care only
- c) I am uncertain
- 8. Imagine that I am physically frail and need help with most routine daily activities, such as dressing, bathing, eating, and going to the toilet. I live in a nursing home and my mind is fairly clear and capable most of the time. I develop a severe kidney infection which if left untreated would prove fatal through multiple organ failure. Do you think that I would want to be hospitalized and receive aggressive medical intervention, or that I would prefer not to be treated, but simply to have comfort care and allow the untreated medical condition to bring about my death?
 - a) Treated in hospital
 - b) No treatment, comfort care only
 - c) I am uncertain



me extremely b difficult. I am a health is poor b One day I have	reathless, and that also causes lways short of breath and tired ut I am alert and able to enjoy	nuses my lungs to fill up with fluid, leaving my ankles to swell up so that walking is l, and unable to walk even one block. My time with my family and friends. Ops beating. Do you think that I would		
Yes	No	I am uncertain		
such as mechan Do you think it	10. Imagine that I am in a permanent coma and my body is maintained by artificial means, such as mechanical breathing and tube feeding. Do you think it would be important to me that decisions about my treatment or discontinuation of treatment be guided by the religious beliefs or spiritual values that you know I hold?			
Yes	No	I am uncertain		
	pe sedated even to the point of	used me much pain, do you think that I unconsciousness, if it were necessary to I am uncertain		
•		laced on life support if my heart, kidneys, splant operations to save lives after my		
Yes	No	I am uncertain		
		n the answers you wrote down for		
-		nds you well, and understands the wishes and medical treatment, and is willing to		
act on your behalf.	i ioi your ruture personal care	and medical deadment, and is winning to		



THE FINAL STEP: Read the <u>Personal Directive Form</u> all the way through (*page 14*) but do not start to fill in the form until you have read the directions on how to do so.

Make sure you completely understand all the information and are satisfied that your Agent understands that these are your wishes, and is willing to act on your behalf. You will then be ready to complete your Personal Directive Form and appoint your Agent.

HOW TO FILL IN THE PERSONAL DIRECTIVE FORM: Read each line carefully and strike out any that do not apply to you, or that you do not agree with. There are extra spaces for you to fill in any circumstances not covered – e.g. you may have a hereditary condition you want to address.

Please pay special attention to section 4 in the Personal Directive Form

If you **DO NOT WISH** to have your life prolonged under the conditions you have set out in Sections 1, 2 and 3 then you must *strike out section 4 completely.*

If you **DO WISH** to have your life prolonged under any circumstances, and are requesting all treatment applicable to your medical condition, then you must *strike out sections 1, 2* and 3 completely and leave only the directions you are giving under section 4.

SIGNING AND MAKING COPIES: Please note that both you and your Agent or Agents must sign in the presence of a witness. The following persons may NOT act as witness:

Your spouse,

The person you have appointed Agent

The Agent's spouse

Make copies of the Personal Directive Form before you sign and date, so that each copy has the original signatures.

Talk to your physician and ask that a copy of the Personal Directive be entered in your medical records. Give a copy to whoever will be making decisions on your behalf if you cannot do so for yourself. Keep a copy where it can be easily found in an emergency situation. Leave a note in a prominent place – perhaps with a fridge magnet – saying where to find your Personal Directive and who to call in an emergency.

Do not store your Personal Directive in a safety deposit box.



CHANGING YOUR MIND: You can always change your mind. We advise that you review your Personal Directive at least every three years. If there are no changes to be made, sign it again with the new date. There is space at the bottom of the form for you to do this.

There is no requirement under Northwest Territories law that you update your signature. However, we advise you to do so. Your Personal Directive may not come into effect for some considerable time. If you have not updated your signature, there is no evidence that you have recently reviewed your directive and that your wishes are unchanged.

If your medical condition has changed, or if you have reconsidered some of the answers you wrote down, ask us to send you a new form, and start over. Begin by revoking your previous Personal Directive and continue on as before.

Be sure to tell everyone involved in your care that you have revised your Personal Directive.

Please note:

If you feel you have special circumstances that the Dying With Dignity forms do not address, we suggest that you consult with your lawyer.



PERSONAL DIRECTIVE

I revoke any previous Personal Directives written by me.

If the time comes when I lack the capacity to give directions for my health care, this statement shall stand as an expression of my wishes and directions.

If I am unable to make decisions only because I am being kept sedated, I would like the sedation lifted so I can rationally consider my situation and decide for myself to accept or refuse a particular therapy.

I designate		as my Agent
If the above nan	ned	should be or
become at any t	ime unable or unwilling to act on my behalf,	
I designate		as my Alternate Agent
	t the authority to make decisions on my behature, that relate to me.	alf for all personal matters of a
instructions to b	o designate a Agent, but provide the followir be followed by my health care provider sust choose only one option and strike out w	
me comforta a) b)		prolonged: ersible nature; nt nature;
a) b) c)	Antibiotics; Transfer to an intensive care unit or similar	nulation of my heart; ntral intravenous line; myself; facility;



- 3. I specifically **direct** the following:
 - a) Provide necessary medication to control my pain and control my symptoms even if such medication might shorten my remaining life;
 - b) Provide me with palliative care;

c)	I would prefer to be cared for and to die at home; OR
	I would prefer to be cared for and to die in hospice;
(you must ch	oose only one option under 3c and strike out what does not apply
d)	
e)	
	· X

Section 4 note:

If you **DO NOT WISH** to have your life prolonged under the conditions you have set down in sections 1, 2 and 3, you must **strike out section 4 completely.**

If you **DO WISH** to have your life prolonged under any circumstances, and are requesting all treatment applicable to your medical condition, you must **strike out sections 1, 2 & 3 completely and leave only the directions you are giving under section 4.**

- 4. I specifically **direct** the following:

 I desire that my life be prolonged, and that I be provided all life-sustaining treatments applicable to my medical condition.
- 5. If my health care provider will not follow this Personal Directive, I ask that my care be transferred to another health care provider who will respect my legal rights.
- 6. If I should be a patient in a hospital, or resident in a health care or long term care facility which will not follow this Personal Directive, I ask that I be transferred to another hospital or care facility.

Signature:	()	Originally Dated:
Print Name:		
<u>Witness</u>		
I have signed this Persona	al Directive in the	presence of the maker. I have signed this
Personal Directive on the	date shown above	e.
Signature		
Print Name		
Address		



A	g	e	n	t

I declare I am eligible to be an Agent, and accept the instructions in this Personal Directive and the duties of an Agent under the Personal Directives Act Signature: _____ Date: Print Name: _____ Date:____ Witness I have signed this Personal Directive in the presence of the Agent whose name appears above. I have signed this Personal Directive on the date shown above. Signature Print Name Alternate Agent I declare I am eligible to be an Alternate Agent, and accept the instructions in this Personal Directive and the duties of an Agent under the *Personal Directives Act* Signature:______ Date:_____ Print Name: _____ Witness I have signed this Personal Directive in the presence of the Alternate Agent whose name appears above. I have signed this Personal Directive on the date shown above. Signature _____ Print Name _____ Address Signature_ Reviewed on _____

Reviewed on _____

Reviewed on

Signature_____

Signature _____



APPENDIX I - Medical Terms Explained

Antibiotics: drugs commonly used to successfully treat infections. Some of these infections can be life-threatening for a grievously ill person. Examples would be pneumonia or an infection in the blood or brain.

Artificial Nutrition: being fed by a method other than by mouth. This would apply if you were in a coma or otherwise unable to swallow, and may be by:

Nasogastric Tube (NG tube) - a tube inserted through the nose and into the stomach. The tube may also be used to suction excess acids from the stomach. Gastrostomy tube (G-tube or PEG tube) – a tube placed directly into the stomach for the long term administration of food, fluids and medications.

Artificial Hydration: being given fluids via a small tube inserted into a vein (venous catheter or IV). Terminal patients who wish to voluntarily stop eating and drinking (VSED) and to simply receive comfort care, should also request to discontinue artificial hydration by IV, as this prolongs the dying process.

Cardio-Pulmonary Resuscitation (CPR): applying pressure to the chest, or an electric charge to re-start the heart, and sending air directly into the lungs to assist in breathing. CPR can be life-saving, but the success rate for critically ill patients is extremely low.

Cerebrovascular Accident (CVA): see Stroke

Chronic debilitating suffering of a permanent nature: a medical condition for which there is no cure. Examples would be Parkinson's disease or terminal cancer.

Coma: a profound state of unconsciousness in which a person cannot be awakened by pain, light, sound or vigorous stimulation. There may be some movements but these are not conscious acts. A patient in a coma state which is of short duration can recover. Over four weeks in coma, the patient may progress to a vegetative state.

Comfort Care: for the dying patient when further medical intervention is rejected or has been judged futile.

Dementia: a condition that impacts a person's ability to perform everyday functions. Examples would be Alzheimer's disease, or loss of thinking skills and memory following a major stroke.

Electrical, mechanical or other artificial stimulation of my heart: see CPR



Heart Failure: a condition where the heart is damaged and fails to pump enough blood to the critical organs in your body.

Hospice Care: for terminal patients, and may be given in the home or in a hospital or care facility. The emphasis is on pain and symptom control for the dying patient, and there is normally no aggressive medical treatment.

Intensive Care Unit (ICU): sometimes referred to as the Critical Care Unit is a hospital ward with highly specialized staff. It is for the patient with a life-threatening illness or injury, including major surgery with a threat of complications, which needs constant monitoring and the support of specialized equipment.

Life-sustaining treatment: replaces or supports defective bodily functions. It may be used temporarily for a treatable condition until the patient is stabilized. If there is no hope of the body regaining the ability to function normally, life support may simply prolong the dying process without the benefit of increased quality of life.

Mechanical Breathing: used to support or replace the function of the lungs. The ventilator or respirator is a machine attached to a tube inserted into the patient's nose or mouth and down into the windpipe, in order to force air into the lungs. It helps people with a short term medical problem. People with irreversible respiratory failure such as that caused by injury to the spinal cord, or a progressive neurological disease will require long term ventilation; and in this case, the tube in inserted through a small hole at the front of the throat into the trachea (tracheostomy tube).

Palliative Care: is most often care in a hospital setting and may be given in conjunction with medical treatment such as chemotherapy or radiation. The emphasis is on pain and symptom control, and the management of side effects of the treatment, such as weakness and nausea.

Stroke: damage to the brain caused by a blockage of blood flow, or bleeding into the brain. The degree of disability resulting depends on the location and severity of the initial cause.

Terminal illness: a medical condition which has progressed to the point where death may be expected within weeks or months.

Vegetative State: a result of damage to the parts of the brain that control thinking, memory, consciousness and speech. The patient may have no damage to the part of the brain that controls breathing and heart rate, and may continue to survive in an unresponsive state.



APPENDIX II - Frequently Asked Questions

Q - Can someone else create a Personal Directive on my behalf?

A - No. But if you are unable to write, your Personal Directive may be given orally and written down by someone else, whose signature must be witnessed in your presence. The witness can NOT be the person you appoint as Agent, or the spouse of your Agent.

Q - What if I have a written Personal Directive in which I refused a certain treatment, and then when in hospital I change my mind?

A - You can change your mind at any time. Any instructions you give orally will over-ride previously written instructions provided you are competent when you express them.

Q – I am just not comfortable imagining all these medical conditions you describe. Why can't I simply say I don't want my dying to be prolonged?

A – You may certainly do so. Many people have a general directive such as this. However, if you do not set down specific instructions, your Personal Directive is open to interpretation – and you may be treated in ways you would not want.

Q - What happens if I have no Agent? Who will make my health care decisions?

A – If you become unable to make health care decisions for yourself and have not appointed an Agent, the Personal Directives Act sets out a list of who will be asked to act as your Substitute Decision Maker and in what order. With persons of the same rank, the eldest takes precedence.

Your spouse or the person with whom you cohabit as spouse

An adult son or daughter

A parent or legal custodian

An adult brother or sister

A grandparent

An adult grandchild

An adult uncle or aunt

An adult nephew or niece

If you have no relatives able or willing to act on your behalf you may appoint the Public Guardian as an Agent by prior written consent.



Q – My son is named as sole Agent in my directive. If he moves out of the country can he delegate one of my three daughters to act instead?

A – No. You would have to make out a new Personal Directive appointing one of your daughters as Agent. To prevent a similar situation arising, you should also appoint each of the other daughters as Alternate Agents, and we advise that you appoint them to act individually rather than jointly.

Q – I have two sons and I want to give them equal rights. Why should I not appoint them to act jointly?

- A If appointed jointly a situation may arise where they disagree on your care. Perhaps you could consider appointing one son your Agent for decisions on personal care and medical treatment, and give the other son authority to act in financial and legal matters by giving him Power of Attorney for Property.
- Q My sister and I are not on very good terms, but I have no other relatives, so I have appointed her my Agent. What happens if she goes against the wishes in my Personal Directive and makes other decisions for me?
- A If your physician or any other interested party sees that your wishes are not being followed he/she can apply to the Supreme Court who may suspend or terminate the authority of your sister as Agent, and who may then appoint another Agent.



APPENDIX III – Further Resources

Personal Directives – a publication by the Northwest Territories Health and Social Services.

available through the website: www.hlthss.gov.nt.ca

Legislative Resources

Personal Directives Act 2005 – Northwest Territories Department of Justice available through the website www.justice.gov.nt.ca



ABOUT DYING WITH DIGNITY CANADA

OUR MISSION

Dying With Dignity Canada is a national registered not-for-profit organization. Our mission is to improve quality of dying and to expand end of life options.

OUR MANDATE

Dying With Dignity Canada has a three-part mandate. We provide:

- 1. Education on medical rights, end of life options, and the importance of advance care planning.
- 2. Support for individuals at the end of their lives, including support at the bedside for those wish to determine the nature and timing of their death, provided they have met our stringent criteria for such support.
- 3. The reasons why appropriately-regulated medically-assisted dying should be legalized in Canada.

FUNDING

We are funded by memberships and donations. Dying With Dignity Canada receives no government funding. Many of our services are provided by volunteers.

CONTACT INFORMATION

Address: 55 Eglinton Avenue East, #802, Toronto, Ontario, Canada. M4P 1G8

Telephone 416-486-3998 Toll-Free 800-495-6156 Fax 416-486-5562

Website www.dyingwithdignity.ca
Email info@dyingwithdignity.ca