Palliative Care Manual

for Patients and Families



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INTRODUCTION

Being diagnosed with a serious illness turns people's lives completely upside down. It is a difficult time to preserve both the mental and physical health of the patient. The patient and their mily must adapt to the illness and the side effects of treatment, and they must make important decisions quickly.



The unknown is a source of worry and raises questions.

The purpose of this manual is to guide the patient and their family and help them have a better understanding of illness progression at the end of life.

PALLIATIVE CARE

"Palliative care aims to relieve suffering and improve the quality of life for those living with a life limiting illness, as well as their families."

Source: Canadian Hospice Palliative Care Association

Palliative care:

- recognizes death as a normal life process;
- does not speed up or slow down death;
- improves the quality of life of the patient, regardless of how much time hey have left to live;
- relieves pain and other difficult symptoms;
- provides solutions to the physical, psychological, social, spirital and practical issues related to the illness;
- helps the patient maintain a life with as much dignity as possible until death;
- addresses individual expectations, needs, hopes and lears;
- aims to provide support to the family;
- fosters opportunities for enriching experiences, personal growth and individual achievement;
- may be provided in the hospital or at tome.



Palliative care in hospital

The hospitals of Vitalité Health Network provide specialized palliative care in a calm and comfortable environment. Several rooms are reserved to provide a welcoming environment, including chapels and family lounges.

Loved ones are allowed to visit any time. Cots are available for those who want to spend the night with a patient.

It is important for the patient and their family to feel comfortable at the hospital. They should feel free to bring familiar items that help them feel comfortable: toothbrush, toothpaste, deodorant, comb and hairbrush, nail clippers Gectric razor, non-slip slippers, robe, favourite blanket, photos, trinkets, books.

Palliative care team members

- Physicians;
- Registered nurses;
- Licensed practical nurses;
- Patient care attendants;
- Occupational therapists;
- Speech-language pathologists;
- Spiritual care practitioners;

- Social workers;
 Respirator
- Pharmacists
- Nutritionists;
- Physiotherapists;

Chaplains / clergy members (visitor);

Volunteers.



A few clarifications

- Palliative care **is provided to people of all ages** (from early childhood through adulthood).
- Palliative care is delivered by teams of experts trained to respond to the needs
 of patients with a serious illness.
- Palliative care is not provided only in the last few days or weeks of life.
 Palliative care is important to ease the suffering of patients who have a serious illness that will eventually lead to the end of their life.
- Palliative care is for all patients with a potentially fatal chronic illness?
- Palliative care **is provided where people live** because most people before to die at home. It is offered at home, in hospice palliative care and long-term care facilities, in the hospital, etc.
- The primary goal of palliative care is to help the patient cointain their independence and quality of life despite the illness. This may mean planning for devices or strategies so that the patient may continue to live their life fully.
- The end of life **does not always involve pain** but, if it does, this can be treated in a number of ways.
- It is **important to treat pain throughout the illness.** To ensure comfort, the dose of analgesics must often be increased to simportant not to fear an addiction.
- Palliative care does not speed up the progression toward death. Instead, it provides comfort and a better quality of the after the diagnosis of a serious illness until the end of life.
- Addressing the topic of palliative care with the patient and their caregivers
 does not make them lose hope. Palliative care gives the patient with a serious illness
 a better quality of life. Hope becomes less a matter of recovery and more a matter of
 living as fully as possible for the time that remains.
- People to change the way they talk about death. They should think about the care that they want to receive or not receive at the end of life and the type of death that they want. They should talk about it with their loved ones and their physician to make their wishes known.

Note: Text from the Canadian Hospice Palliative Care Association adapted by Vitalité Health Network

SIGNS AND SYMPTOMS

Pain

Everyone experiences pain differently. Proper pain control allows for a better quality of life.

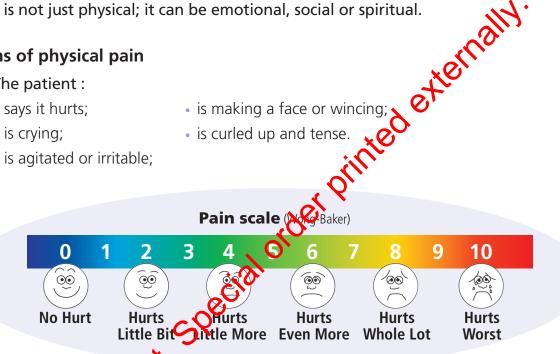
The goal of palliative care is to ease pain and provide as much comfort as possible.

Pain is not just physical; it can be emotional, social or spiritual.

Signs of physical pain

The patient:

- says it hurts;
- is crying;
- is agitated or irritable;



Signs of pain that is not physical

The patient

- talksabut mental anguish;
- has a feeling of despair and emptiness inside;
- says they want to be done with it;
- has financial concerns;
- is afraid of leaving their family behind them;
- feels like they are a burden;
- feels the need to reconcile with a loved one.



Methods other than medication for managing pain

- Distraction:
- Breathing exercises and meditation;
- Music therapy;
- Applying heat or cold;
- Presence of someone to lister

Examples of medications to manage pain

- Non-steroidal anti-inflammatory drugs NSAIDs (Aspirin Reprofen);
 Opioids (morphine, hydromorphone, codeine);
 Anticonvulsants (gabapentin);
 Antidepressants (amitriptyline);
 Steroids (prednisone, dexamethasone)

- Steroids (prednisone, dexamethasone)

To properly manage pain, medications must be taken on a regular basis with additional doses as needed for unusual pain.

Constant pain require constant doses. When medications are administered properly, they are safe and effective.

The care team also addresses the side effects of pain medications, such as:

- nausea and vomiting;
- constipati
- dizziness:
- drowsiness:
- confusion.

These side effects do not always persist. Some of them disappear or decrease after a few days.

Eating

It is normal for the illness to cause a decrease in appetite. The body does not digest food like it did before and the patient often loses weight.

Loss of appetite may be caused by:

- medications;
- pain;
- intestinal blocage or constipation;
- sores in the mouth.

Tips to make eating easier

- Let the patient eat at the time of day that they feel best;
- Let the patient have several small meals a day instead of three large ones;
- Let the family give the patient whatever they prefer to eat;
- Let the patient try fluids and nutritional supplements (sometimes these are tolerated better than soids).



Preparing a good meal for the patient is a way of showing them love. The natural reflex is to encourage the patient to eat and drink to build their strength. However, it is important to member the following:

- The goal is to respect the patient's limits and feed them without causing them discomfort;
- Any food and any drink that the patient asks for is acceptable;
- The patient's preferences are more important that the nutritional value of the food;
- It may be normal for a patient to eat very little or not at all.

Voiding

Toilet habits may change over the course of the illness. Changes in the voiding of stool and urine may be caused by:

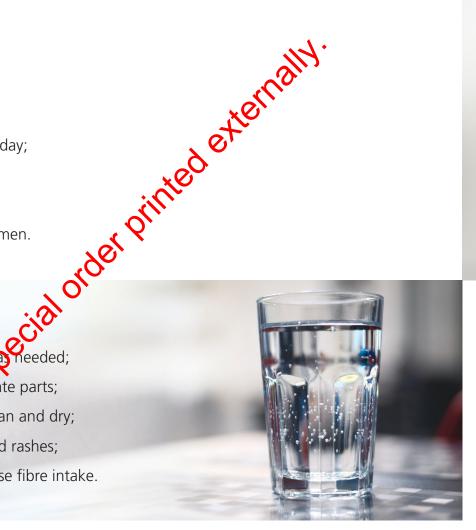
- medications
- the fact that the patient is eating less;
- a reduction in physical activity;
- the illness.

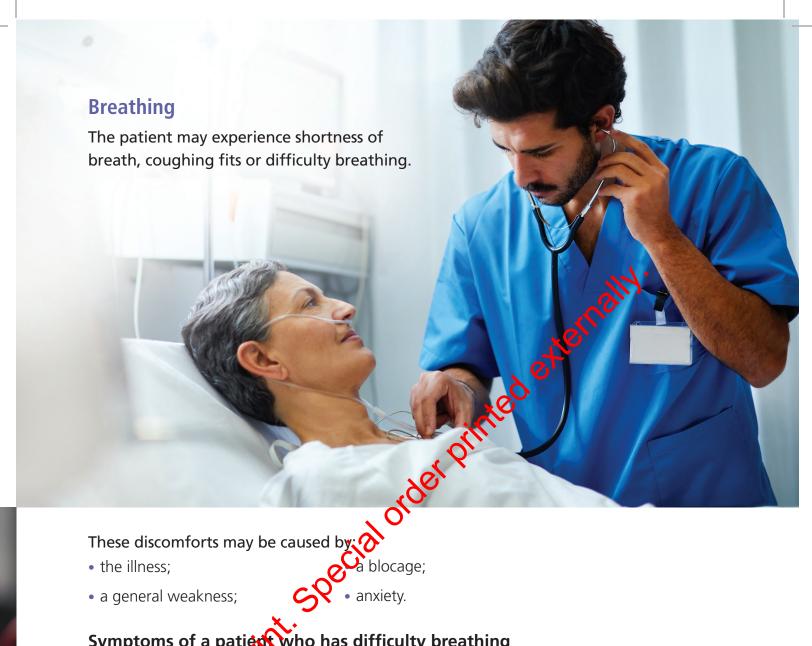
Symptoms to report

- No stool for three days;
- Several bouts of diarrhea in one day;
- Blood in urine or stool;
- Cramps, nausea or vomiting;
- Bloating or swelling of the abdomen.

Tips for voiding

- Use incontinence pads or briefs a needed;
- Maintain good hygiene of intimate parts;
- Keep the skin and bed thens clean and dry;
- Apply a protective cream to avoid rashes;
- Drink plenty owater and increase fibre intake.





Symptoms of a patient who has difficulty breathing

• Headaches;

- Thick secretions and cough;
- Heaviness in the chest;
- Noisy or rapid breathing at rest.

Tips to make breathing easier

- Choose a comfortable position;
- Wear loose-fitting clothing;
- Plan rest periods;
- Avoid smoking;
- Stay away from allergens.

Nausea and vomiting

Nausea is the sensation of feeling sick to your stomach, wanting to vomit or discomfort at the back of the throat. It can adversely affect quality of life.

Nausea may be caused by:

- the side effects of medications;
- constipation;
- irritation of the stomach or intestines;
- infection.

Tips for managing nausea and vomiting

- Eat small portions;
- Avoid fatty, spicy or acidic foods;
- Avoid lying down within two hours after a meal;
- Change positions slowly;
- Perform oral care regularly;
- Keep a bowl handy.

Confusion

neal; printed externally.

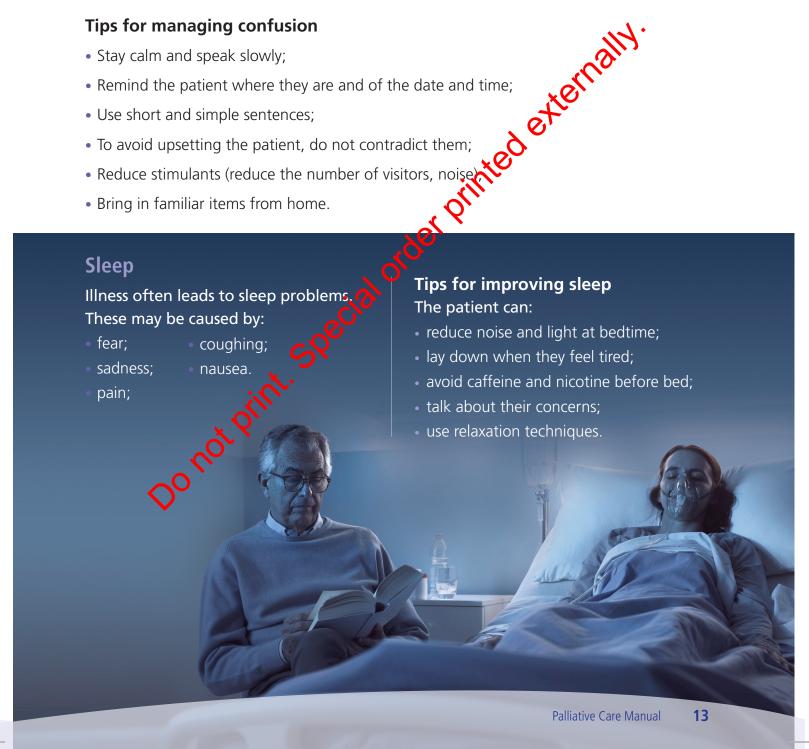
Special order printed. Confusion often occur when the patient has difficulty speaking, thinking, reasoning and understanding wat is happening around them. It may be temporary or permanent, depending on the cause.

Confusion may be caused by:

- the illnes
- infection:
- lack of oxygen;
- medications:
- pain.

Signs of confusion

- Memory or attention issues;
- Lack of concentration, difficulty following a conversation;
- Behaviour problems (aggressiveness, paranoia);
- Hallucinations.



COMMUNICATION

When the diagnosis is made, the patient and their loved ones must face a new reality. Everyone reacts differently. Addressing difficult subjects and communicating in an appropriate way can be a challenge for the patient and their loved ones.

Tips to make communication easier

Tips for the patient

- Live in the present moment;
- Discuss wishes and worries about your care and death (see Appendix A – What matters to patients at the end of life);
- Find things you enjoy;
- Share your life story;
- Allow yourself to feel your emotions;
- Respect your limits.

Tips for the family

- Be honest, show respect and true to yourself;
- Respect the patient's decisions;
- Continue to do activities with the patient, if possible;
- Do not avoid the object of death or fears;
- Share your fond memories and express your gratitude;
- Help the pitient stay in contact with their friends and family;
- Take the time to share what matters to you without too much delay (this could reduce regrets after death).



SPIRITUAL ASPECT

Spirituality is the way in which a person perceives themselves in relation to others, the earth and the universe. It is also a quest for meaning, a search to find oneself, the elevation of self and the revelation of self.

When people have a serious illness, they are often drawn to seek inner peace and to try to give meaning to their life and their death.

- Perform rituals with the patient (e.g., prayer, visualization);
- Listen attentively to the patient;
- If the patient wishes, ask the care team to contact Opiritual care practitioner or a chaplan for a meeting.



PREPARATIONS BEFORE DEATH

Health care directives and powers of attorney

The patient should speak to their physician about the type of death that they want and the care that they would like to receive at the end of life.

It is good to put their wishes into writing to guide their loved ones and the care team in making decisions.

Three forms can help the patient clearly express their wishes (see Appendices B, C and D):

- Health care directives (these allow the patient to specify the health care that they would like to receive at the end of life, the health care that they do not want to receive and the type of death that they would like);
- Enduring power of attorney for personal care (this allows a power of attorney to be designated for personal care; this person will represent the patient in making decisions in their place if they are no longer capable of doing (a);
- Identification of substitute decision maker for the ompetent patient.

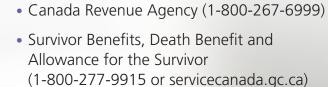
Funeral arrangements

Funeral arrangements involved arious choices:

- Funeral home (contract for fund) arrangements and associated costs);
- Casket or urn;
- Burial plot with graves one or location where urn will be placed;
- Type of ceremony
- Logistics of the ceremony (location, guest list, flowers, food, death notice, etc.);
- Suggestions of organizations (donations in memory of the deceased), registry kept for thanking people.

Financial support | Potential financial assistance

- Compassionate care benefits from Employment Insurance (1-800-808-6352 or servicecanada.gc.ca)
- Private insurance
- Life insurance policies
- der printed externally. • Canadian Cancer Society (1-888-939-3333)



• Veterans Affairs (1-866-522-2022)

• Funeral Benefit from Social Development (1-833-733-7835)

Do not print.

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END OF LIFE

Several signs may indicate that death is nearing. The bodily functions slow and prepare to stop: the patient is no longer hungry or thirsty, they get tired quickly, sleep more and more, and isolate themselves.

It is difficult to predict the exact time death will occur because each person is different.

Signs of the natural movement toward death

- The extremities become cold, blue and mottled;
- The patient is not awake very often;
- The level of conciousness is reduced;
- Breathing changes (becomes slower or faster, with pause sting up to 30 seconds);
- Since the patient is no longer able to move secretions from their airways, a rattling sound can be heard;
- The patient becomes incontinent and voids lither
- The body temperature rises, and the patient may sweat.

At end of life

- Perform oral care;
- Apply moisturizing cream to the skin and lip balm to the lips;
- Keep the environment beaceful and serene;
- Limit visits;
- Continue talking to the patient;
- Report any sign of pain to the care team (groans, frowning, agitation).

In the final moments, allow each person who so wishes to be alone with the patient for a moment.

As needed, reassure the patient and tell them not to worry (this is a little bit like giving them permission to leave).

At the time of death

- Breathing stops; there is often a final sigh;
- The heart stops beating;
- The eyelids may stay partially open, and the gaze may be fixed;
- The mouth may open because the jaw relaxes;
- The content of the intestines and bladder may be released became the muscles relax;



GRIEF

After the death, it is natural to feel grief. Although this journey is different for everyone, most people go through similar stages. Every story and every relationship are unique; there is no single way or set amount of time to grieve.

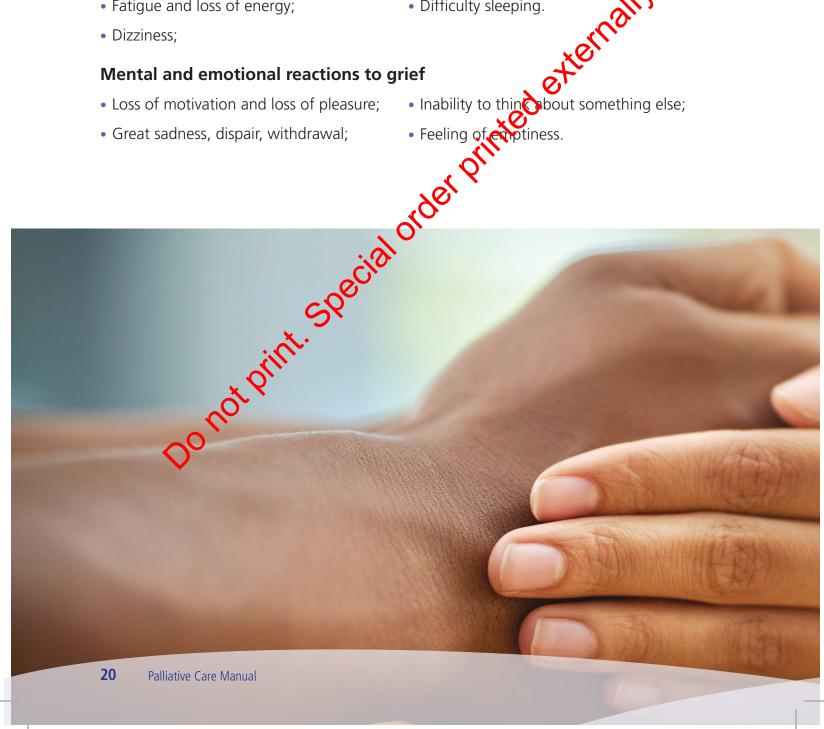
Physical reactions to grief

- Increase or loss or appetite;
- Fatigue and loss of energy;
- Dizziness;

- Digestive issues;
- Difficulty sleeping.

Mental and emotional reactions to grief

- Loss of motivation and loss of pleasure;
- Great sadness, dispair, withdrawal;
- Inability to thin bout something else;



Spiritual reactions to grief

- Blaming a higher power;
- Loss of meaning of life;

- Desire to die and join the deceased;
- Existential pondering.

Tips to make grieving easier

- Accept taking the time you need to grieve;



AFTER DEATH

After death, several things need to be done. To this end, the deceased's personal information is required:

- Copy of the death certificate;
- Copy of the marriage certificate;
- Copy of the birth certificate;

- Medicare number;
- Social insurance number.

scial order printed externally Checklist (things to check, to cancel, etc.)

- Will:
- Funeral arrangements contract;
- Employer (inform them of the death);
- Services, licences, etc.
 - Government of Canada:
 - » Canada Pension Plan
 - » Old Age Security Pension
 - » Employment Insurance
 - » Canada Revenue Agency
 - » Social Insurance Card
 - » Passport
 - » Citizenship or Permanent Resident Card
 - » Secure Certificate Indian Status
 - Government of New Brunswick:

>>	Medicai	re	sard	
			•	

- » Driver's licence
- » Vehièle registration
- » Student loans
- » Property tax
- » Social assistance program
- » Public Safety compensation
- » Firearms licence

- 1-800-567-6868
- 1-888-242-2100
- 1-800-567-9604
- 1-888-762-8600
- 506-453-2410
- 506-453-2410
- 1-800-667-5626
- 506-453-2264
- 1-833-733-7835
- 506-453-2410
- 1-800-731-4000



- Public services:
 - Residential and cell phone;
 - Electricity;
 - Gas;
- Insurance companies:
 - Life insurance;
 - Disability insumice;
 - Private bealth insurance;
- Mortgage:
- Banking institutions;
- Credit cards;
- Investments and other loans;
- Social clubs, associations and subscriptions/memberships.

- Cable, Internet;
- Post office.
- Home insurance;
- Automobile insurance.

RESOURCES AND CONTACT INFORMATION

Canadian Hospice Palliative Care Association: chpca.ca

New Brunswick Hospice Palliative Care Association: nbhpca-aspnb.ca

Canadian Virtual Hospice: <u>virtualhospice.ca</u>

Canadian Virtual Hospice: My Grief (mygrief.ca) and Kids Grief (kidsgrief.ca)

Government of Canada: www.canada.ca Government of New Brunswick: gnb.ca

Vitalité Health Network: vitalitenb.ca

Social Supports NB: socialsupportsnb.ca

Advance Care Planning Canada: <u>advancecareplanning.ca</u>

Heart and Stroke Foundation of Canada: heartandstroke Palliative Care phone numbers of Voncton: 506-862-4000 ainte-Anne-de-Kor

Zone 4

Edmundston: 506-739-2544 Grand Falls: 506-473-7553

Saint-Quentin: 506-235-7110

Campbellton: 506-789-5014

Zone 6

Bathurst: 506-544-2004

Caraquet: 506-726-2110

Lamèque: 506-344-3416

Tracadie: 506-394-3037

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APPENDICES

APPENDICES

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APPENDIX A

WHAT MATTERS TO PATIENTS AT THE END OF LIFE

What matters to patients during their final days?

- 1. Having their family by their side.
- 2. Being able to talk about death.
- ied externally 3. Meeting a member of the clergy or a spiritual care practitioner.
- 4. Talking about their fears.
- 5. Being at peace with their higher power.
- 6. Not being connected to machines.
- 7. Not being a burden to their family.
- 8. Having completed preparations for their funeral frances.
 9. Being of sound mind until the end.
 10. Being able to trust the care team.
 11. Not dying alone.
 12. Having their loved ones visit.

- 13. Keeping their sense of humo
- 14. Maintaining their dignit
- 15. Being treated the waythey wish, in accordance with their values and priorities.
- 16. Remembering their personal achievements.
- 17. Being able to you goodbye to their loved ones.
- 18. Being informed of how their body will change.
- 19. Being able to prepare their family for their death.
- 20. Dying at home.
- 21. Not suffering physically or mentally.
- 22. Keeping good bodily hygiene.
- 23. Having a feeling of peace.

APPENDIX B HEALTH CARE DIRECTIVES

•		RÉ	seau de santé Vitalité
	٠	•	HEALTH NETWORK

réseau de santé Vitalité HEALTH NETWORK	Name:	
Current state of health: I am healthy I have an illness. Specify:		Sally.

Take the time to reflect before completing this form. In each of the boxes write.

• "Yes" for treatments that you wish to receive:

- "No" for treatments that you do not wish to receive.

Rest assured that, whatever decisions you make, you will always receip comfort care (to ease pain and discomfort or provide psychological and spiritual support)

	Illness Mentioned	Termin al	Cognitive I Alzheimer	mpelkment (s, Stroke, etc	dementia, c.)	Permanent
	Above	Illness	Mild	Moderate	Severe	Coma
Intravenous (IV) Hydration			ofor			
Artificial Feeding		3				
Dialysis	~ (S				
Cardiopulmonary Resuscitation (CPR)	×.					
Artificial Respirator	IL.					
Blood Transfusion						
Life-saving Surgery						
Life-saving Antibiotics						
Other						

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RÉSEAU DE SANTÉ	HEALTH CARE DIRECTIVES
Vitalite	Name:
HEALTH NETWORK	Date of Birth:
•	
Additional directives:	
	700
Signature of patient or third party ¹ :	
Signature of first witness ² :	ate:
Signature of second witness ² :	Date:
1. Third parties:	
 Cannot be the attorney for per attorney for personal care; 	ersonal care or the spouse, common-law partner or child of the
Must be at least 19 years old	ı. , 0'
2. Witnesses:	
Must be present when the part of the	Cent or third party signs and dates the directives;
 Cannot be the attorney for personal care; 	ersonal care or the spouse, common law partner or child of the
Must be at least 10 years old	l.
**********	*****************
Give the hospital lealth Records De	partment a copy of this document and keep the original.
Also give capies to your doctor and fan	nily.
Think about and revise your health car	e directives at least once a year.
If you change them, replace all outdate remain valid until they are revised.	ed copies with the new version. Your health care directives
************	*****************

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DEFINITIONS

Health problems

Terminal illness: Incurable illness involving a life expectancy under six months.

Cognitive impairment: Gradual and irreversible loss of mental functions. The illness may progress over the course of months or years.

- Mild impairment: The person can do most of their daily activities without help.
- Moderate impairment: The person can live in their home but needs a few hours of help day.
- Severe impairment: The person cannot do their daily activities and needs help day and night

Permanent coma: The person is unconscious and will always remain so.

TREATMENT CHOICES

Intravenous (IV) hydration: A small tube is inserted into the article hydrate the person with an intravenous.

Artificial feeding: A tube is inserted into the stomach through the nose or mouth or through a small hole in the abdomen to nourish the person.

Dialysis (artificial kidney): Treatment given when he kidneys no longer work. The person is hooked up to a machine for several hours at a time, several times a week, by a tube that enters the abdomen or a vein.

Cardiopulmonary resuscitation (CP) Technique used to restart a heart that has stopped beating. The person may then need to be kept alive artificially with machines, without being able to speak, and may have to receive pedications keeping them "asleep" while they are hooked up.

Artificial respirator (breathing machine): Machine used when a person can no longer breathe on their own.

Blood transfusion: Brood introduced into a vein through a needle or small tube.

Life-saving survery: Surgery to prevent death, without which the person would only survive a few hours or days.

Life-saying antibiotics: Medications used to treat infections that may be fatal (pneumonia, meningitis, etc.). These medications are sometimes given through a small tube inserted into a vein.

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APPENDIX C ENDURING POWER OF ATTORNEY FOR PERSONAL CARE

RÉSEAU DE SAN	alité
	HEALTH NETWORK

ENDURING POWER OF ATTORNEY FOR PERSONAL CARE

Take the time to reflect before completing this form.

An enduring power of attorney for personal care allows you to name one or more for personal care to act on your behalf concerning your personal care when you are no longer able to do so. If you have more than one attorney for personal care, they must act gether.

Attorney(s) for personal care

If I am no longer able to make decisions about my care and treatments, I ask that my wishes (expressed verbally or in my advance health care directives) be respected.

If other directives are needed, I authorize my attorney of personal care to make decisions about my care and treatments.

Name of attorney for personal care ¹ :	Telephone:	
Relationship to patient:	Cell:	
Signature of patient or third party:	Date:	
**************************************	************	***
Name of attorney for personal care ¹ :	Telephone:	
Relationship to patient.	Cell:	
Signature of patient or third party:	Date:	
Name of first witness ² :		***
Signature of first witness ² :		_
Name of second witness ² :		
Signature of second witness ²	Date:	

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ENDURING POWER OF ATTORNEY FOR PERSONAL CARE

1. Attorney(s) for personal care:

• Must be at least 19 years old.

2. Witnesses:

- Must be present when the patient or third party signs and dates the directives;
- Cannot be the patient's attorney for personal care or the spiller, common-law partner or child
 of the patient's attorney for personal care;
- Must be at least 19 years old.

Give the hospital's Health Records Department a copy of this document and keep the original.

Also give copies to your attorney(s) for personal care, doctor and family.

Think about and revise your enduring porter of attorney for personal care at least once a year.

If you change your attorney(s) for personal care, you must complete a new form and distribute new copies. Your enduring power of attorney for personal care remains valid until it is revised.

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ANNEXE D IDENTIFICATION OF SUBSTITUTE DECISION MAKER FOR INCOMPETENT PATIENT

réseau de santé Vitalité HEALTH NETWORK				
IDENTIFICATION OF SUBSTITUTE MAKER FOR INCOMPETENT PATIS			-	ally.
☑ Vitalité Zone : ☐ 1B ☐ 4 ☐ 5	☐ 6 Facili	ty :		•
*Any court order or power of attorney fo	r personal care	takes precedenc	ce over this form.	
The purpose of this form is to facilitate personal care on behalf of the above-m Declarant's full name:	the identification	on of a person to grapetent patient.	give or refuse cons	ent to
Address and phone number: Relationship with the incom				
 Guardian appointed by a court of co Attorney under a power of attorney f *For choices 1 to 3, provide a copy of Person appointed by the patient who Spouse or common-law partner Custodial parent Other family member: 	or personal car of the court or en the latter Child Siblin	s competent who has reached who has reached	I the age of 16 ☐ ed the age of 16 ☐	
For choices 4 to 9, you may act as sobstatements: 1. I have reached the age of 19 or Thathe incompetent patient.				owing ☐ Yes ☐ No
2. I believe that if the patien had been objection to me making a decision a to his or her personal health information.	bout his or her			□ Yes
3. I wish to take esponsibility for giving for the patient.	_			☐ Yes ☐ No
 I believe that no one at a higher rank rank as its available, willing, and cla patient's personal care. 				☐ Yes ☐ No
Name of substitute decision maker	Signatu	ure of substitute d	ecision maker	
Name of witness	Signature of	of witness	Date (yyyy-mr	 n-dd)
Note: Place the original in the patient's record				,
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