



*Reaching out at the **E**nd of life*

Palliative Care Manual

Extra-Mural Program



REACHING OUT AT THE END OF LIFE

The authors of this information manual are employees of the New Brunswick Extra-Mural Program (EMP), Regional Health Authority A. Together, they have shared their knowledge of palliative care in order to offer their patients, families and natural helpers a varied range of information that will facilitate the delivery of home care during the last phase of life.

Working Group—authors from zone 4

Armande Rousselle, EMP nurse

Astrid Pettigrew, EMP occupational therapist

France Bossé, EMP administrative support

Guylaine Bélanger Ouellette, EMP nurse

Karine Levesque, EMP social worker

Mariette Lafrance, EMP nurse manager

Olivine Desjardins, EMP nurse

Pauline Sirois Michaud, EMP social worker

Suzanne Beaulieu, EMP liaison nurse

Consultants:

Caroline Brutsch, EMP dietitian

Lise Fournier, EMP dietitian

Nathalie Nadeau, EMP respiratory therapist

AUTHORS—TABLE OF CONTENTS—DEDICATION—INTRODUCTION

CHAPTER 1

DEFINITION OF PALLIATIVE CARE9

CHAPTER 2

HOME CARE 13

CHAPTER 3

A PATH WALKED TOGETHER ... 17
— For the ill person 17
— For the natural caregiver 18
— The family ... 21

CHAPTER 4

CARE 25

CHAPTER 5

SPIRITUAL ASPECT... 45

CHAPTER 6

LAST WISHES... 49

CHAPTER 7

LAST MOMENTS ... 55

CHAPTER 8

GRIEVING ... 59

APPENDICES

Appendix 1—The Dying Person’s Bill Of Rights (Droits du mourant)

Appendix 2—Directory of services

Appendix 3—Personal record

Appendix 4—The rights of the bereaved

Dedication

This guide is dedicated to everyone who has
allowed us to accompany them on their last voyage.

Thanks to their generosity, courage and dignity,
we have grown as palliative care professionals.

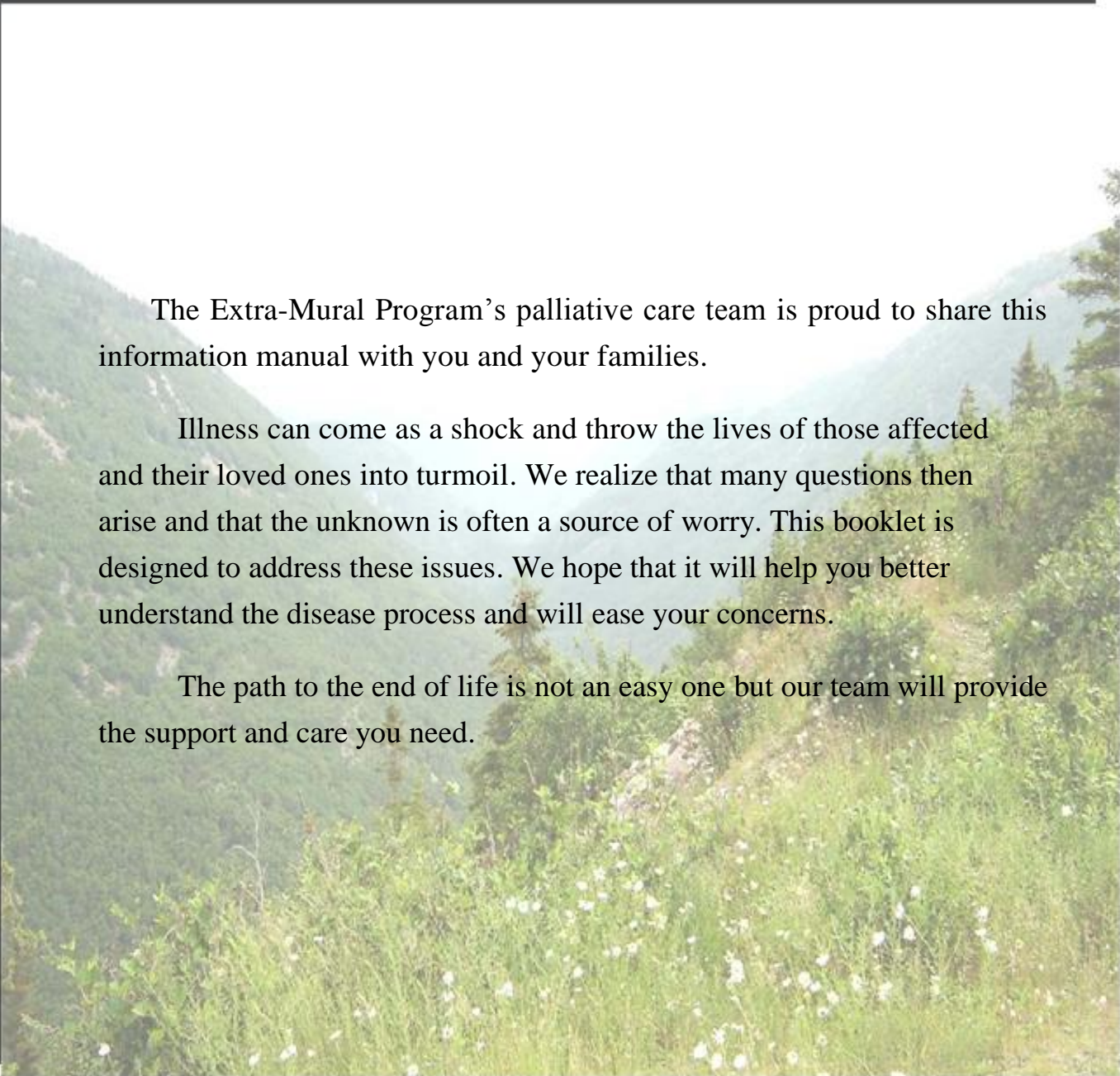
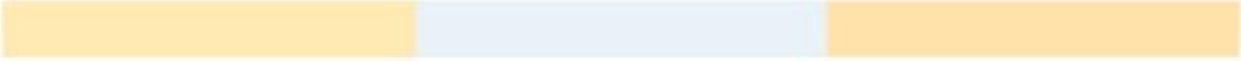
May this guide be a source of comfort and support for families
and natural helpers who are accompanying a loved one
whose days are drawing to a close.

We thank you all.

EMP Palliative Care Working Group
Regional Health Authority A

Introduction

Extending a hand at the end of life



The Extra-Mural Program's palliative care team is proud to share this information manual with you and your families.

Illness can come as a shock and throw the lives of those affected and their loved ones into turmoil. We realize that many questions then arise and that the unknown is often a source of worry. This booklet is designed to address these issues. We hope that it will help you better understand the disease process and will ease your concerns.

The path to the end of life is not an easy one but our team will provide the support and care you need.

CHAPTER 1

DEFINITION
OF
PALLIATIVE CARE

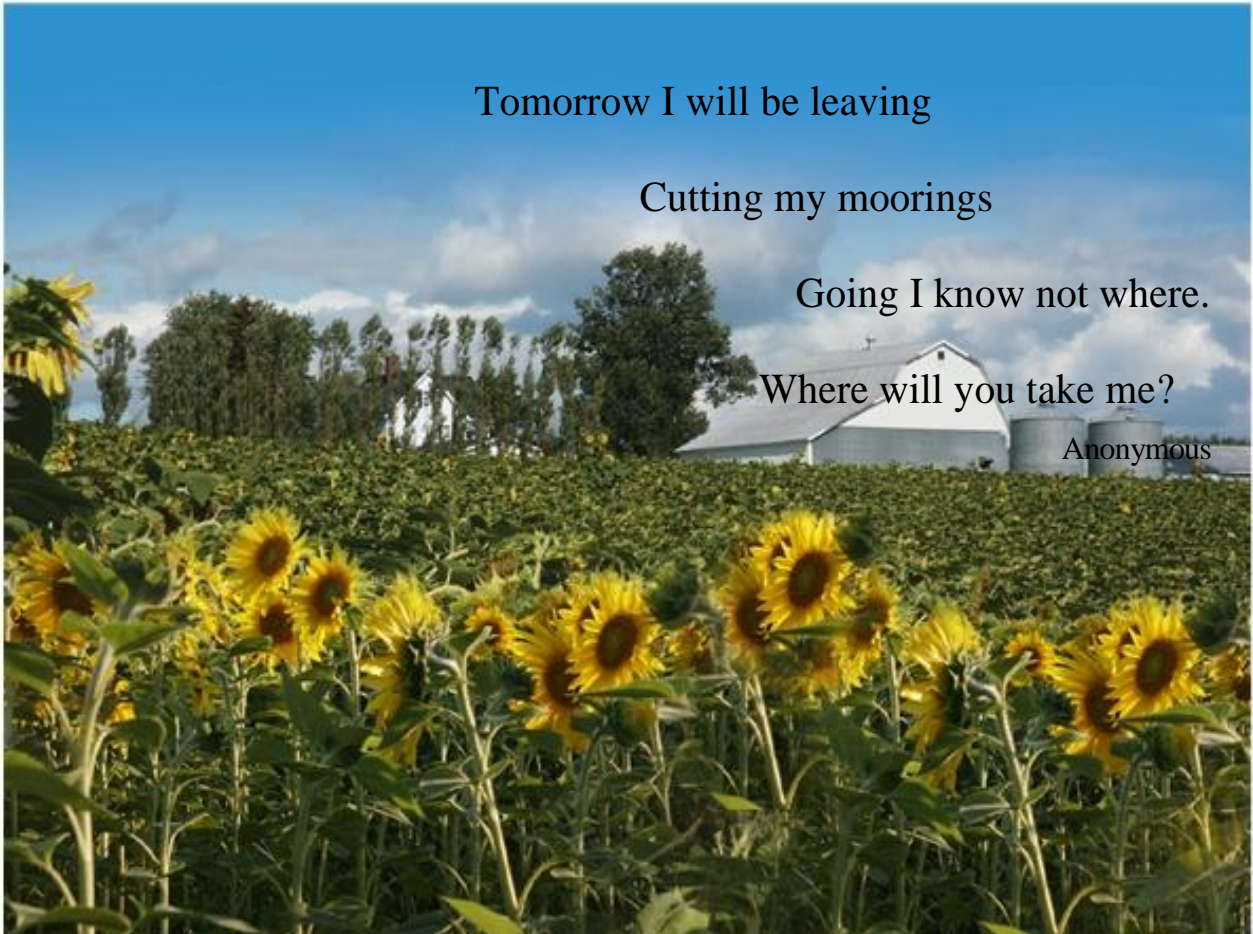
Tomorrow I will be leaving

Cutting my moorings

Going I know not where.

Where will you take me?

Anonymous



DEFINITION OF PALLIATIVE CARE

According to the Canadian Hospice Palliative Care Association, palliative care is designed to ease suffering, improve quality of life, and accompany a person toward death.

The World Health Organization has declared that the objective of palliative care is to **provide the best possible quality of life for patients and their families.**

Based on this goal, palliative care:

- Treats death as an inevitable part of life;
- Neither hastens nor delays death;
- Eases pain and other distressing symptoms;
- Includes all aspects of care such as physical, psychological, social, emotional and spiritual care;
- Provides a support system that allows the patient to live as actively as possible until death;
- Supports families during the illness of their loved one and during the sorrowful period that follows;
- Respects the personal, cultural and religious values and the beliefs and lifestyle of the patient and their loved ones.

Palliative care is provided to help the patient and their loved ones to:

- Face the problems, expectations, fears and hopes associated with the end of life;
- Prepare to perform the end-of-life tasks determined by the patient and to face the patient's impending death;
- To overcome the losses and sadness that occur during illness and grieving.

Palliative care strives to:

Treat and prevent difficulties;

Promote a better quality of life.

The role of palliative care

Palliative care meets the needs of patients at the end of life. It should provide the care required by the patient and their loved ones through the illness, including during the grieving stage.

Palliative care is optimally provided by a team of professionals possessing knowledge and competencies related to all aspects of the care process.

Palliative care professionals

The Extra-Mural Program's palliative care team is made up of caregivers from the following professions:

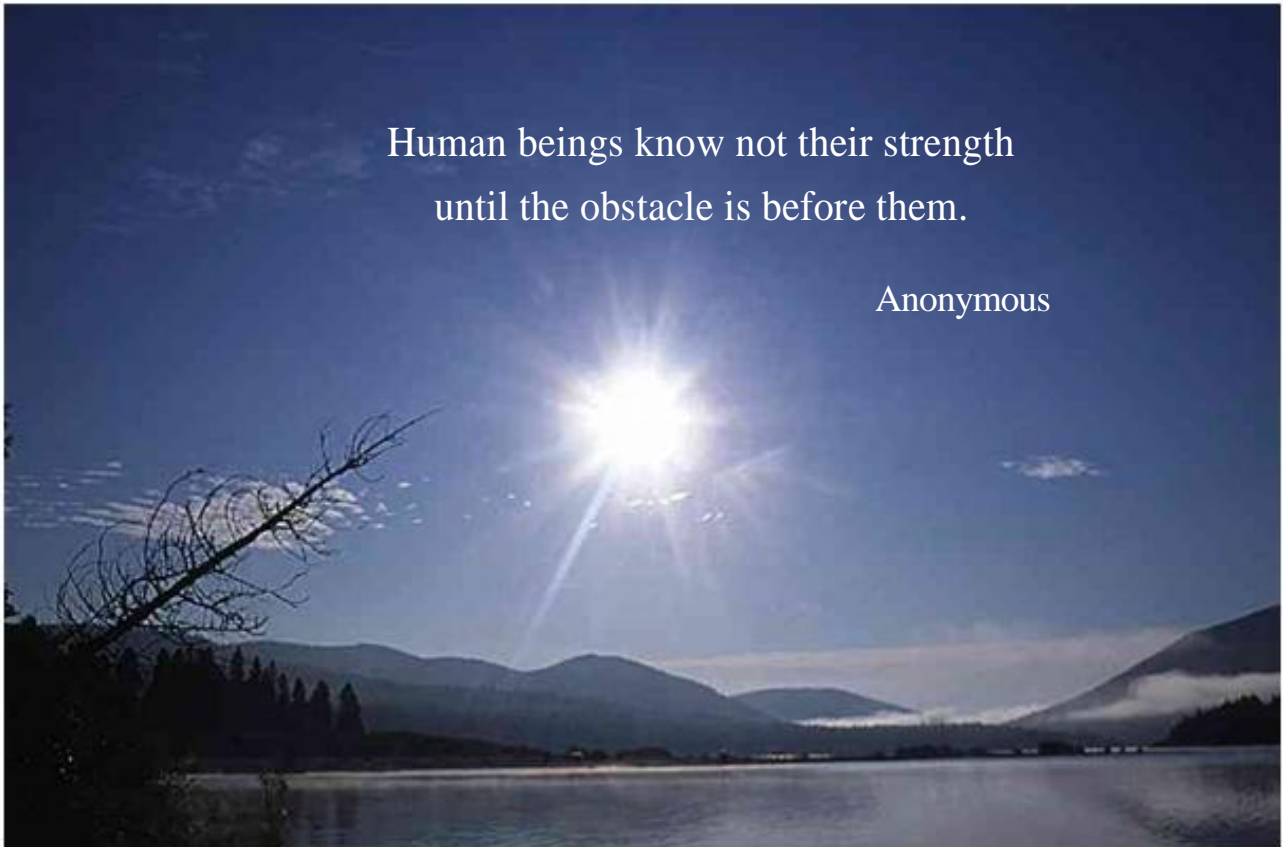
- Medicine;
- Nursing;
- Respiratory therapy;
- Dietetics;
- Occupational therapy;
- Physiotherapy;
- Speech-language pathology;
- Social work.

CHAPTER 2

HOME CARE

Human beings know not their strength
until the obstacle is before them.

Anonymous



HOME CARE

At the end of life, an ill person wishes to recover feelings of safety and wellness. They want to be with their loved ones in a familiar environment.

Carefully reflecting on the points below may aid your decision making related to home care. Do not hesitate to consult a health professional who will be able to guide you to an informed decision and advise you about available resources.

Certain points to be considered with respect to remaining in the home include:

- Can the home be adapted to different types of care (space and safe environment)?
- How available are family members in terms of time?
- Are there other more closely related or distantly related loved ones who are prepared to provide care and share tasks?
- Are the family members and the ill person prepared to accept outside help related to certain care with which they are less comfortable and/or familiar?

Caring for a gravely ill person at home can be a positive experience:

- The ill person is in a familiar setting with a familiar lifestyle (routine, meals, social network, etc.);
- Their loved ones together experience the losses brought about by the illness;
- Family bonds are strengthened.

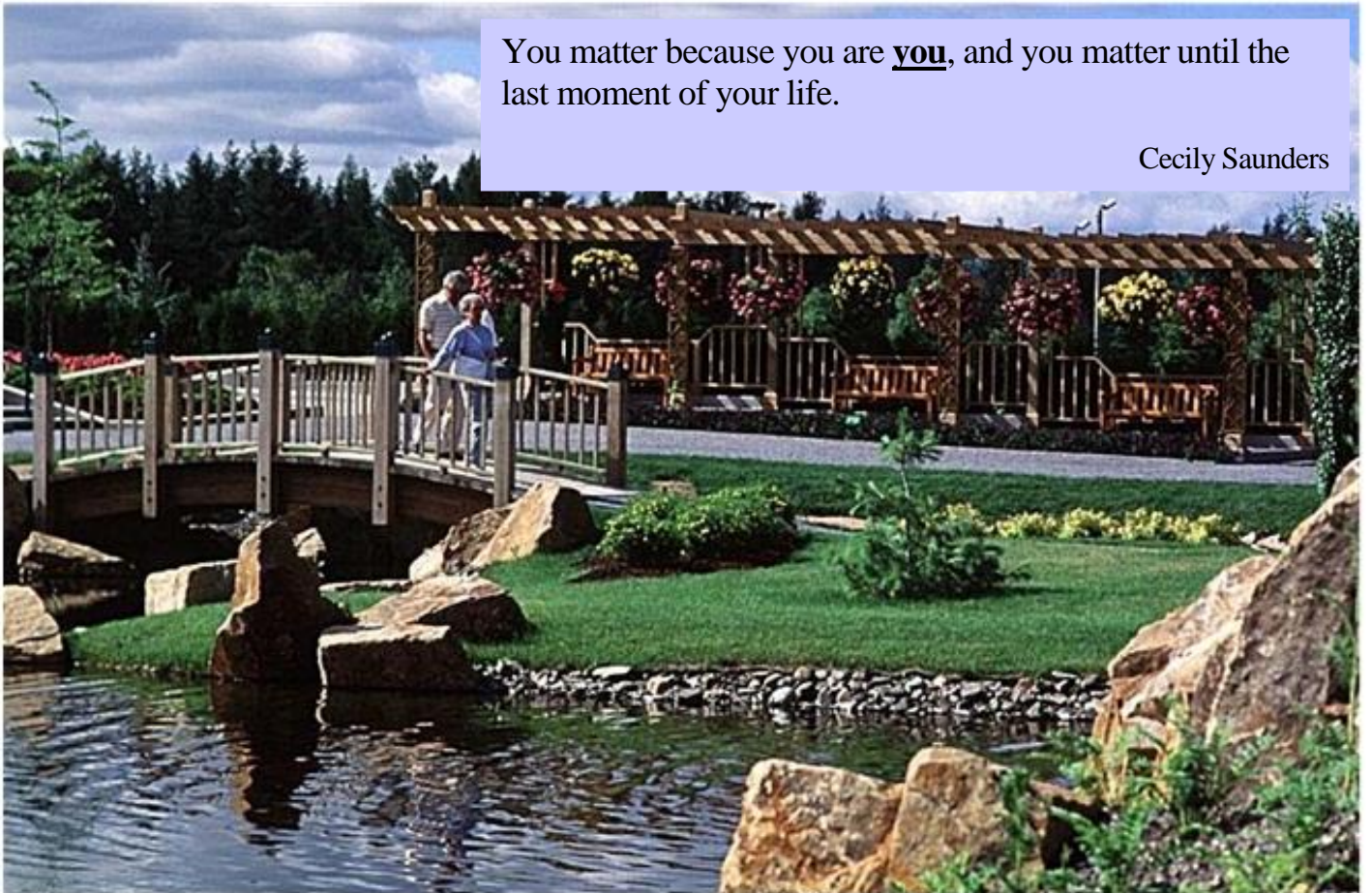
CHAPTER 3

A PATH WALKED

TOGETHER

You matter because you are you, and you matter until the last moment of your life.

Cecily Saunders



A PATH WALKED TOGETHER

With the diagnosis of a terminal illness, you and your loved ones will have to face a variety of reactions. This new reality will have an impact on your physical and emotional condition and your relationships. Everyone reacts differently for a variety of reasons. It is important to be familiar with the grieving process and the impact of associated losses (See Chapter 8 for details).

For the ill person

You have recently been told that your life expectancy is limited. You now find yourself in the final stage of your life and are feeling a tremendous sense of emptiness, loss and even sometimes distress. You are facing an as yet unfamiliar situation that is generating anxiety. The goal of palliative care is to ease your pain and provide you with as much comfort as possible so you can take maximum advantage of your remaining time.

Remember that despite your illness, the treatments you will undergo, and the impairments you may experience, you are no less a person than before. In other words, you are still YOU. You are still the same person you were, with the same personality, preferences, memories, etc. You are more than an illness, more than a body. It is your spirit, heart and soul that complete you and make you a UNIQUE person.

The following suggestions can help you through this stage of life:

- Talk to your loved ones about your desires and worries related to your care and to death;
- Meditate or pray, depending on your beliefs;
- Find things that give you pleasure;
- Recall good memories and share them (looking at a photo album can help you review your life);
- Allow yourself to feel emotions, even negative ones (anger, sadness, discouragement). These will help you along your path.

- Respect your body's limits and your physical capabilities;
- Remember that you remain an important person to those around you.

At the end of life, people may feel unhappy, desperate or sad at the thought of leaving their loved ones. It is never easy to think that one's life is ending. You may be angry or shocked or feel you are the victim of injustice. Fear is also a normal reaction, which may involve fear of losing control or fear of not being consulted about your care. We are especially fearful of the unknown, e.g. whether we will die a painful death or how the transition from life to death will occur. It is, however, very important to recognize the different emotions you are experiencing and to talk to a loved one or a palliative care team member about them.

In palliative care, one of our objectives is for you to be treated with dignity, i.e. for you to retain your full value as a human being, despite the losses you may experience, and to be treated with respect at all times.

There may be periods during which you will need help with personal care such as dressing and eating. This may seem degrading to you. However, ask for and accept people's help. Even if it is not always easy, these experiences will become cherished memories for those around you. Remember that although illness may change many things, it has no impact on your value as a human and the place you hold in your loved ones' hearts.

For the natural caregiver

Caring for a loved one at the end of life can prove physically and/or emotionally draining. However, these last moments are also a time of true love, intimacy, sharing and joy. When you provide care and accompany someone at the end of their life, you play a part in the important process they undergo in their final days.

The end of life gives a whole new significance to the “time” factor. It is not unusual to see a natural helper put themselves second and devote themselves full time to their ill family member. Making such a commitment involves reorganizing many areas of their lives, e.g. marital and family life, social life, work life, time and financial management, etc.

At the end of life, ill persons remain concerned about the well-being of their loved ones and especially of their primary natural helper. Given the increased risk of burnout during this period and the fact that ill persons fear becoming a burden to those around them, it is important for natural helpers to have a balanced routine so their needs are met and their lives remain balanced. Showing your loved one that you are taking care of yourself physically, emotionally and spiritually will ease their concerns.

Here are a few suggestions:

- Maintain a healthy diet;
- Take rests and get enough sleep;
- Listen to your body and respect its limits;
- Share your concerns;
- Continue your normal activities (e.g. walking, movies, seeing friends, reading, crafts, etc.);
- Keep a journal;
- Have a support network;
- Check into the resources available in your community;
- Accept help when it is offered.

The telltale signs of exhaustion to watch for include:

- Wanting to run away;
- Feeling overwhelmed and disorganized;
- Experiencing changes in your sleep and diet;
- Experiencing moodiness (irritability, anger, tears, sadness, etc.);
- Having difficulty concentrating;
- Experiencing a weight gain or loss;
- Losing interest (in yourself and others);
- Increasing your consumption of alcohol, medications or tobacco.

If you notice some of these symptoms, it is recommended that you speak to the care team to obtain appropriate follow-up.

To accompany someone at the end-of-life, it is necessary to:

- Have the ability to be genuine, i.e. frank, honest and respectful;
- Savour the present moment;
- Respect the decisions made by the person at the end of life;
- Share your life experience, memories, good times and bad times;
- Maintain family activities and allow the ill person to participate within their capabilities;
- Respect the feelings and emotions of the person at the end of life;
- Take the opportunity to resolve conflicts or misunderstandings;
- Share desires, wishes, plans and dreams.

The family

An ill person's "family" includes everyone that he or she says it does. It can include a spouse/partner, relatives and friends. (Palliative Care Info-Sheet for Seniors, Public Health Agency of Canada)

The family plays a role in the care that is provided and represents the natural, permanent community on which the ill person must rely. This makes it important for all family members to be respectful of the desires and choices of the person at the end of life.

News of the ill person's death may throw their loved ones into crisis and upset the family's balance.

It is not unusual to see the following difficulties arise within the family:

- **Emotional suffering:**
 - Broken relations, conflicts, guilty feelings, deferred of grieving;
 - Fear of physical or mental suffering;
 - Fear of not being up to the job of providing accompaniment.
- **Communication problems:**
 - Inability to communicate verbally;
 - Learning of new modes of communication, e.g. visual communication or touch.
- **Family burnout:**
 - Guilty feelings related to the length and intensity of the accompaniment or illness.
- **Changes in relationships**
 - Since every family member reacts differently, relationships may evolve (grow closer, grow more distant, etc.).

Remember that all family members are doing what they can under difficult circumstances. Their attitudes or behaviours may sometimes appear hurtful. Remember that these reactions are defence mechanisms.

It is quite normal for everyone's involvement to vary based on:

- Their prior relationship with the person at the end of life;
- Their ability to deal with a stressful situation;
- Their relationships and family ties;
- The acceptance (or lack thereof) by the person at the end of life of their situation;
- The willingness (or lack thereof) of the person at the end of life to accept help;
- The feelings and emotions unique to every person (fear, despair, denial, powerlessness);
- Everyone's openness and availability to provide care and accompaniment;
- Everyone's prior life experience;
- Everyone's communication modes and styles.

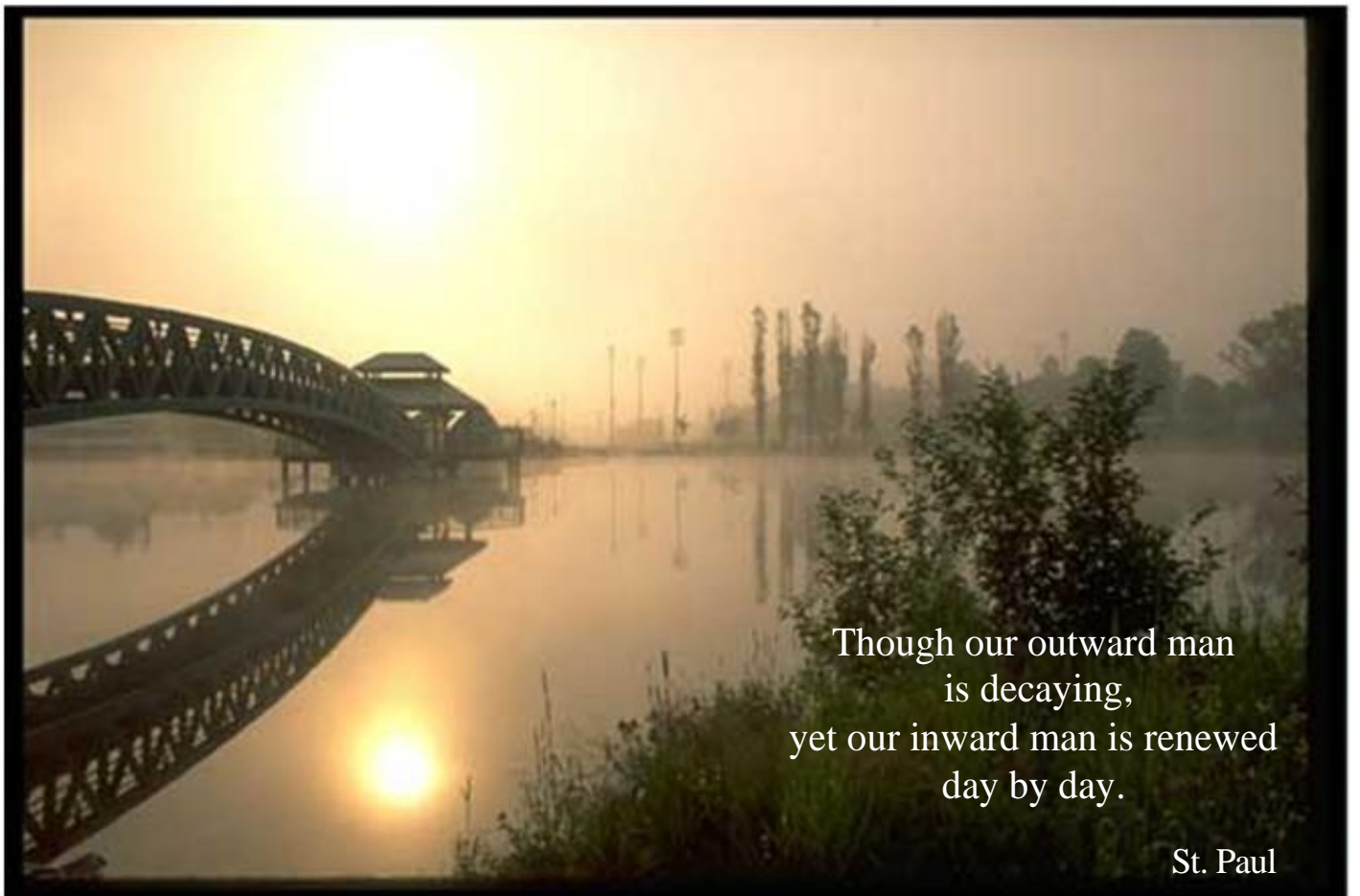
Every person is unique, as is every family. This means that the functioning of the immediate or extended family will not necessarily change when one of the family members is at the end of life.

The treatment team remains at your disposal to accompany family members along this path.

Please note that it is also important to consider the circumstances of the ill person's children (however old they are) during this stage of life.

CHAPTER 4

CARE



Though our outward man
is decaying,
yet our inward man is renewed
day by day.

St. Paul

CARE

The ill person and their loved ones are key members of the team. This makes it important for them to share their desires, fears and concerns, so that the comfort and quality of life of the ill person can be enhanced.

By comfort, we are referring to:

- A. Pain control;
- B. Breathing;
- C. Nutrition;
- D. Mobility;
- E. Hygiene;
- F. Sleep;
- G. Elimination;
- H. Controlling nausea and vomiting;
- I. Positioning and the prevention of sores;
- J. Managing confusion.

A. PAIN CONTROL

It is important to see the ill person from an overall physical, social, moral and spiritual perspective. The treatment team's objective is to ease pain at all times while showing the ill person dignity and respect.

The telltale signs of pain to watch for include:

- Clenched hands;
- Tense shoulders;
- Frowning (forehead and eyebrows);
- Constant agitation;
- Biting lips and fingernails;
- Becoming withdrawn;
- Having a different tone of voice;
- Moaning or crying;
- Other.

The team members must identify the source of the pain and the factors that may be triggering or intensifying it. In other words, it is very important to locate the site, type, intensity and duration of the pain as well as the triggers, where applicable.

Many medications may be used to ease moderate to severe pain. These medications are reliable and effective when correctly administered and may be prescribed on a regular or “as needed” basis.

Pain medications can cause certain side effects such as:

- Nausea;
- Vomiting;
- Constipation;
- Drowsiness;
- Confusion;
- Agitation;
- Disorientation;
- Hallucinations;
- Tremors;
- Other.

These symptoms are not always present, however, and are not always related to medications. They may instead be caused by the person's evolving illness. It is important to advise the nurse and/or physician about such symptoms. Some side effects of new medications can diminish within the first 24 to 72 hours. In addition, it is essential to follow the instructions on how to take the medications, to ensure they are effective and safe. It is strongly recommended to have a medication box.

Pain medications are available in different forms and may be administered:

- Orally (capsules, tablets or liquids by mouth);
- Transbuccally (between the gums and lower lip);

- Sublingually (tablets or liquids placed under the tongue);
- Intra-nasally (in the nostrils);
- Transdermally (skin patch);
- Rectally (suppositories, capsules or liquids via the rectum);
- Subcutaneously (injected under the skin);
- Subcutaneously by perfusion (continuously administered by pump).

Pain may have different causes. This is why the nurse must correctly assess every situation and request help from other interdisciplinary team professionals.

All medications or medicinal herbs not prescribed by a physician must be discussed with the medical team since these can cause certain reactions or side effects.

Some therapies and alternative techniques can reduce pain, such as:

- Massage therapy;
- Controlled breathing;
- Music therapy;
- Visualization;
- TENS and acupuncture.

It is preferable to talk to the treatment team so the therapy best tailored to the circumstances can be chosen.

B. BREATHING

What you need to know:

Breathing enhances quality of life. The following signs may indicate that someone is having difficulty breathing:

- Bluish lips;
- Excessive secretions (sputum), which are coloured and/or thick;
- Noisy, moist breathing (rales);
- Difficult or rapid breathing at rest and/or with effort;
- Discomfort or pain.

To make the person more comfortable:

- Create a calm relaxed atmosphere;
- Position the person to facilitate deep breathing;
- Encourage a second person being present to reduce anxiety;
- Plan rest periods between activities;
- Ensure that medications are taken as prescribed;
- Open a window or use a fan;
- Have the person drink hot water to make coughing up easier.

In some situations, oxygen may be prescribed.

If you note a change in the ill person's condition, contact an Extra Mural Program team member.

Respiratory therapy can suggest different techniques to ease the person's breathing and make them more comfortable.

C. NUTRITION

Eating is usually one of life's pleasures.

When a person is sick, it is normal to have less appetite because the body cannot digest foods as before. At this stage of life, the goal of eating is to provide enough nourishment to maintain wellness without causing discomfort.

Often, a person at the end of life will eat less than usual. As a helper, do not worry about this, since it is rare for them to feel hunger. Even if portions are very small, the ill person will be satisfied. It is important to encourage them to eat, without, however, forcing them.

Food presentation, i.e. decoration, atmosphere and colour, can help make food more appealing.

It is often easier to eat several small meals per day rather than three large meals. Fluids and nutritional supplements are sometimes better tolerated than solids.

Foods that the person used to like may not taste the same as before. Plastic utensils can be used when foods take on a metallic taste.

Cooking odours from some foods can cause nausea. If this occurs, it is preferable to serve cold foods (sandwiches, salads, fresh vegetable snacks).

Even if the person is eating well, they may lose weight.

Feel free to ask the dietician for advice.

D. MOBILITY

Mobility refers to all movement from one place to another, transfers, or changes of position. The objectives are to make the ill person as independent as possible and to ensure their comfort and safety, as well as the safety of caregivers. Also, in some cases, doing light movements or exercises may increase comfort.

To prevent falls, we recommend the following:

- Wearing non-slip shoes or slippers;
- Avoiding clothing that is too large;
- Removing objects (furniture, rugs, etc.) that can hinder walking;
- Ensuring the living area is well lit;
- Using a cane or walker as needed;
- Using a walking belt if the ill person needs assistance from another person;
- Using a wheelchair if the ill person can no longer walk;
- Ensuring that surfaces are stable (apply wheelchair brakes, lock bed wheels, etc.) when transferring the ill person from the bed or wheelchair.

The occupational therapist and physiotherapist can teach safe ways of changing position and moving. These professionals can also suggest technical aids and specialized equipment tailored to the person's needs.

E. PERSONAL HYGIENE

It is essential to thoroughly wash your hands and fingernails with soap before and after providing care. Gloves are sometimes required for certain types of care.

With respect to hygiene, it is strongly recommended that you:

- Encourage the ill person to do their own hygiene if they are able to;
- Schedule hygiene at the person's preferred time of day;
- Ensure the bathroom is safe and adapted to the person.

If the ill person can no longer take a bath or shower alone, you can help them get set up and then wash their back and hair, help them dry off, and apply a moisturizer. It is also possible to do only part of the hygiene process, depending on the person's condition.

If a sponge bath must be given:

- Adjust the bed to prevent back strain (if the patient is in a hospital bed);
- Get a basin of hot water, soap and towels as well as a light blanket so the person does not get cold;
- Gently wash their skin with a mild soap; work from their face down to their feet and remember to wash their back. Rinse, wipe and apply moisturizer;
- End with their private parts, making sure to change the water beforehand. If there is redness, apply a protective lotion;
- Change the drawsheets (protective sheet or piqué) and bed sheet as often as necessary;

- Watch for the appearance of redness or lesions that may develop into pressure sores (bed sores). If this occurs, advise the nurse;
- Suggest that the person choose sleepwear (pyjamas or nightgown) that is easy to put on;
- Respect the person's habits (makeup, hair style, shaving, etc.).

F. SLEEP

Insomnia is defined as the “inability to obtain adequate sleep.” *Merriam Webster*

Most people who are near death note a change in their sleep. They either have difficulty falling asleep or sleeping well. Sleep difficulties may be caused by anxiety, worry, fear, sadness, pain, coughing, nausea, vomiting, etc.

The sleep patterns of a person with a terminal illness are often disturbed. They may sleep a great deal during the day and then have insomnia once night falls. Here are a few suggestions to help the person sleep better:

- Offer them a hot, caffeine-free drink such as warm milk with honey;
- Choose a calm location for sleeping;
- Keep the bed clean and comfortable;
- Spend some quiet time with the ill person to calm their worries.

Massage and relaxation techniques can also help, but if the insomnia persists, it would be preferable to discuss it with an EMP team member.

G. ELIMINATION

When a person is in the process of losing their independence, elimination may become embarrassing and stressful, especially if the person is bedridden.

- Give the ill person as much privacy as possible and let them take their time going to the toilet.
- Use an adapted toilet seat, a commode chair or a bedpan. Install grab bars if necessary. Consult an occupational therapist as needed.
- Keep bedding clean (pique and drawsheet).

Urination

Some people lose their bladder control. Towels, incontinence briefs or diapers may be used in such cases. Good hygiene of the person's private parts is important. To prevent sores from appearing, keep the bedding clean and dry and apply protective lotion as needed. If the ill person is producing little or no urine, the nurse must be advised.

Diarrhea

Intestinal infections and some medications can cause stomach cramps and diarrhea (frequent and fairly liquid stools). Note how often the person goes to the toilet and advise the nurse so she can determine the cause and can provide an appropriate treatment as soon as possible.

Bowel movements can be difficult to predict and control, which sometimes makes it necessary to get to the toilet or chamber pot quickly. To avoid embarrassing situations, diapers may be used. These must be changed whenever they are soiled. The person's private parts must be cleaned with water and a mild soap. Then dry the skin well and protect it with a moisturizer.

Ensure that the drawsheet and bed sheets are clean and dry at all times, to maintain hygiene and prevent bed sores.

With diarrhea comes the risk of dehydration, so it is very important for the nurse to be advised from the outset. The nurse and dietitian will be able to suggest broths and liquids to take or avoid, depending on the seriousness of the condition.

Constipation

Constipation is the absence of a person's normal bowel movements; this may cause bloating, stomach pain or flatulence. If constipation is not treated, the person may become agitated or confused.

Here are a few factors that can cause constipation:

- Some medications, especially pain medications;
- Tumours or conditions related to the illness;
- Weakness and lack of exercise;
- Diet low in fibre and/or fluids;
- Fear of soiling oneself;
- Hard stools blocking the intestines.

H. CONTROLLING NAUSEA AND VOMITING

Nausea (feeling sick to your stomach) is the sensation of wanting to vomit, even if no vomiting actually ensues. This sensation is often more difficult to stand than the vomiting itself, which eases nausea. As soon as the ill person experiences nausea and vomiting, inform an EMP professional. The dietitian will be able to advise you.

Nausea may be caused by:

- The illness, poorly controlled pain;
- Problems related to the stomach and intestines (intestinal blockage, constipation, etc.);
- Some medications;
- Lack of movement;
- Odours;
- Anxiety, fear and emotional problems;
- Fatigue.

We suggest the following ways for preventing or reducing nausea:

- Create a relaxed atmosphere;
- Move the person slowly;
- Take them outside for fresh air if their condition allows;
- Keep the room at a cool, comfortable temperature;
- Avoid strong odours (perfumes, tobacco, coffee, etc.);
- Serve cold or room temperature foods, since hot foods give off more odours;
- Offer water or other fluids, as tolerated;
- Avoid having the person drink while they are eating;
- Give them crushed ice to refresh their mouth;

- Encourage the person to regularly take prescribed nausea medication, such as Gravol;
- Have them use a non-alcohol mouthwash after vomiting;
- Encourage the person to rest in a sitting position for 30 minutes after a meal;
- Ensure that the ill person's bedding and environment are clean at all times.

Important: When a bedridden person vomits, they must be placed on their side to prevent them from choking or aspirating their vomit.

Mouth care

Good mouth care is very important in improving the ill person's appetite and preventing nausea, infections and dry mouth. Ensure that mouth care is performed after every meal and as needed (at least twice a day).

If the ill person cannot perform mouth care on their own:

- Wash your hands well;
- Raise their head and then their body into a half-sitting position, so they do not choke;
- Give them a sip of water to moisten their mouth. Then use a soft brush to delicately brush their teeth and tongue;
- Have them spit into a towel, then rinse their mouth out with cold water (they may use a flexible straw to expend less energy taking in and spitting out the water).

- Have them freshen their mouth regularly during the day using an alcohol-free mouthwash.

Home recipe:

1 teaspoon of bicarbonate of soda in half a cup of warm water

or

1 soup spoon of salt in 1 cup of boiled water; let cool

If the person cannot lift their head:

- Place a towel on their chest;
- Clean their teeth, the inside of their mouth, and their tongue using a soft brush or a sponge stick.

Advise the nurse if you notice lesions or any other change to their mouth, gums or teeth.

I. POSITIONING AND THE PREVENTION OF SORES

POSITIONING

The goal of positioning is to place the person so they are as comfortable as possible. This may involve positioning in bed, in a chair, on the toilet, or even in a car. Good positioning can improve sleep, breathing and digestion. It helps protect their joints and skin, which may in turn allow them to participate in some family or social activities. A few of the most common things that can be done are explained below.

In bed:

- Pillows, cushions, rolled-up towels or a hospital bed can increase comfort and improve breathing;
- A gel pad can prevent heel irritation;
- A special mattress can be useful in some cases;
- Regularly changing position (every 2 to 4 hours) is recommended.

In a chair or wheelchair:

Special cushions and chair backs can allow the person to continue sitting when they are very weak or in pain.

In the bathroom:

Using a padded seat, toilet cushion or shower chair can increase comfort.

In a car:

Adding a cushion or chair back can make car trips more pleasant.

Whether you have questions about learning or experimenting with new positions, adding specialized equipment, or inventing homemade adaptations, the occupational therapist can help you. Feel free to contact them.

PREVENTION OF SORES

There is a risk of bed sores developing (redness, soreness, pain) when the person remains in the same position too long.

Here are a few factors that can increase the risk of sores:

- Remaining immobile;
- The positions taken;
- Folds in the bedding and clothing;
- Incontinence;
- Heavy sweating;
- Skin fragility.

It is important to pay attention to pressure sites and to advise a treatment team member if redness appears.

J. MANAGING CONFUSION

A “confused person” is defined as a person who has difficulty thinking and acting appropriately.

Signs and symptoms of confusion include:

- Memory and concentration disorders;
- Disorientation (person, place, time);
- Behavioural issues (agitation, aggressiveness, etc.);
- Hallucinations;
- Nightmares;
- Difficulty expressing themselves.

Causes:

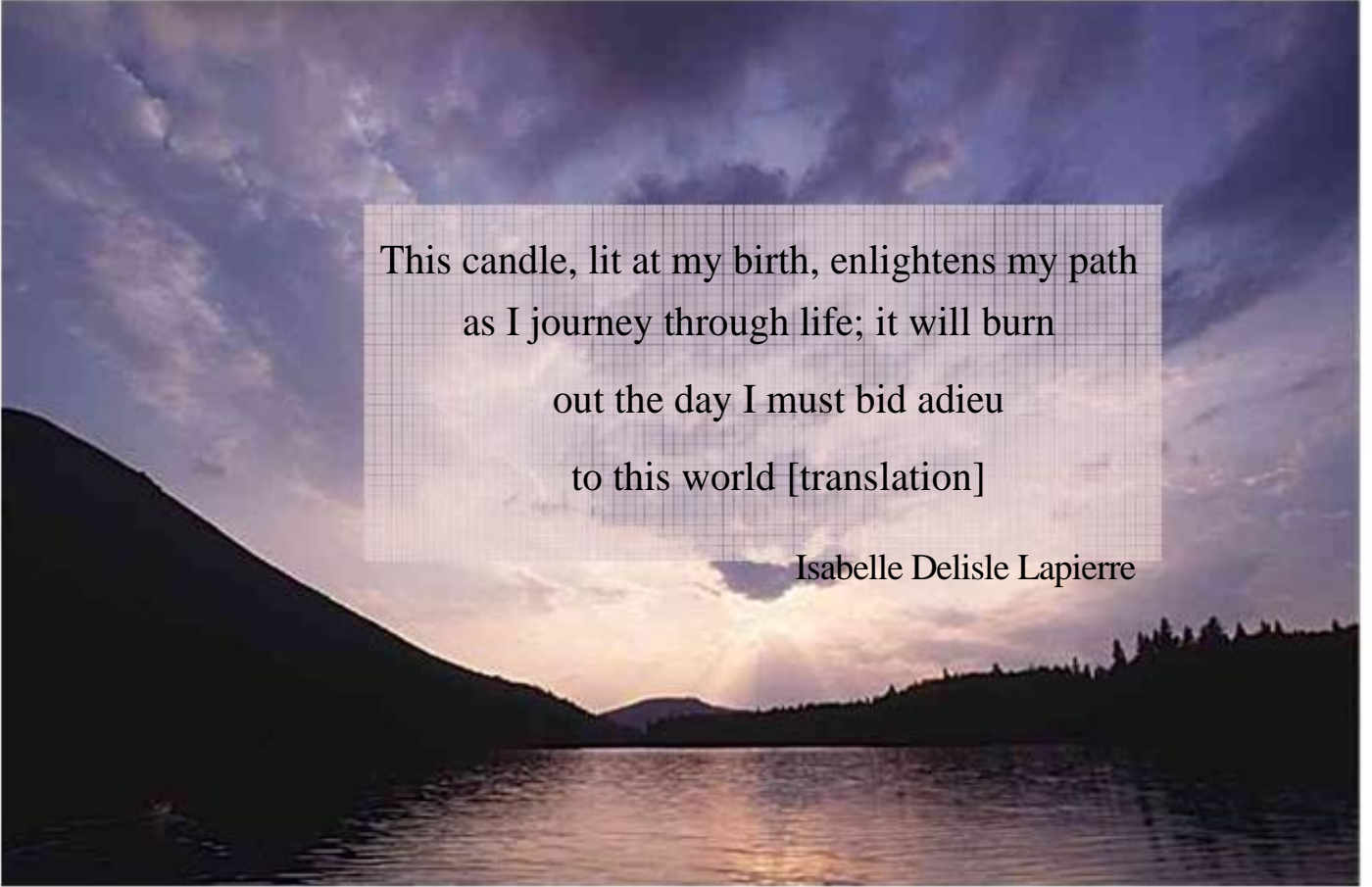
- Side effects of some medications;
- Discomfort, e.g. too hot, too cold, wet bedding, folds in bedding, pain, itching, fatigue, constipation, urinary retention;
- Changes in the environment;
- Infection;
- Neurological problems such as brain tumours or withdrawal/overdose of alcohol, tobacco or medications.

What can be done:

- Consult the treatment team as soon as signs and symptoms of confusion appear so the causes can be identified and the risk factors modified;
- Maintain a calm environment. It may be necessary to limit visits;
- Keep the living area properly lit, i.e. brighter during the day, dark at night;
- Hold the person's hand and identify yourself;
- Use simple phrases and speak calmly;
- Maintain a routine and explain everything you are doing;
- Orient the person as needed;
- Avoid upsetting the person;
- Administer medication as prescribed.

CHAPTER 5

SPIRITUAL ASPECT

A landscape photograph of a lake at sunset or sunrise. The sky is filled with dark, dramatic clouds, with a bright glow of light breaking through near the horizon. The water in the foreground is dark, reflecting the light from the sky. The silhouettes of hills and trees are visible along the shoreline. A semi-transparent grid overlay is centered on the image, containing text.

This candle, lit at my birth, enlightens my path
as I journey through life; it will burn
out the day I must bid adieu
to this world [translation]

Isabelle Delisle Lapierre

SPIRITUAL ASPECT

Spiritual needs are important to a person at the end of life and their loved ones, and are just as important as physical, psychological and social needs. The spiritual dimension involves returning to the past, attempting to make sense of the present, and looking forward to an unknown future. For a person at the end of life, it may be important to conduct a life review and find meaning in their life and death. They may feel a need for pardon, reconciliation and hope.

The life review

As death approaches, returning to the past is a common phenomenon. This process of reflection serves to identify what the person has done well during their life and also to acknowledge their errors or weaknesses. This exercise allows the person to see that their life has a significance (meaning), to repair their mistakes, to ask for forgiveness—in short, to find peace as their life draws to a close. The person will choose when and with whom they share their spiritual desires and thoughts.

Some life reviews cannot be performed because certain issues, such as family conflicts, remain unresolved. A life review can be done verbally or in writing, as the person prefers.

In some cases, the person at the end of life attempts to find meaning in illness and suffering. Good communication and non-judgmental listening will allow the person to share their spiritual dimension.

The future

The nature of the transition they are about to experience is difficult to ascertain. For some people, everything ends at death, nothing follows. For others, there is a next life, a continuation. Quite apart from any religious belief, a person may harbour a perception or intuition that life continues and feel the need to believe this. For this reason, spirituality cannot be limited to religion.

In conclusion, the spiritual aspect elicits the following behaviours from people at the end of life:

- Wishing to re-establish contact with their religion and its rituals (e.g. last rites);
- Wishing to establish a link to an unknown superior being;
- Expressing the desire to ask for forgiveness in order to obtain peace of mind and/or peace with others;
- Asking the question “Why?” to a spiritual power or to the universe;
- Experiencing a variation (increase or decrease) in their need to pray;
- Looking back on their life and forward to an unknown future.

The great challenge during this step involves finding the interior strength to talk about death and allowing the person to remain “alive” until their last breath. Talking about death often raises the fear that it will occur sooner. However, talking represents one way of reaching the person, whatever point they are at in the process.

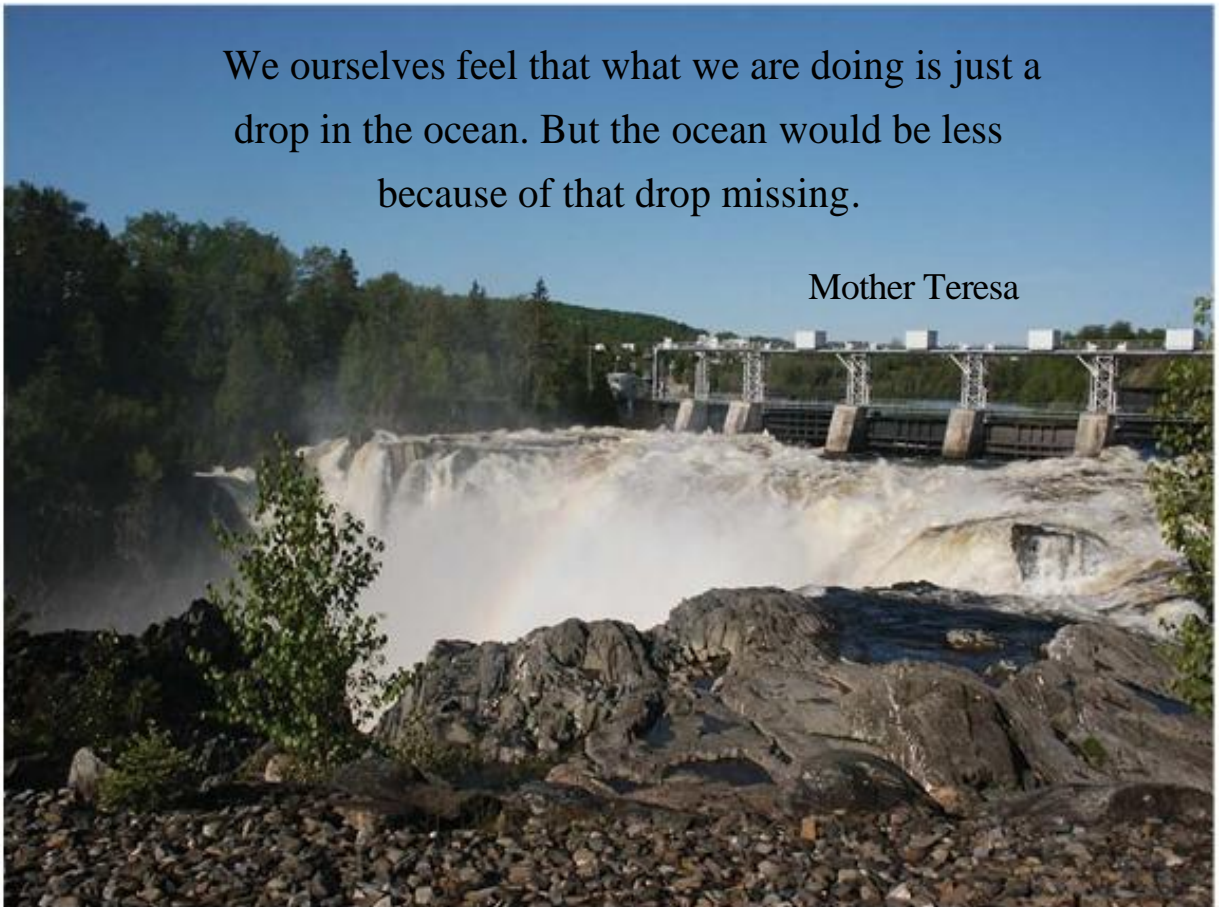
More and more material on spirituality is becoming available. You may contact the treatment team for more information.

CHAPTER 6

LAST WISHES

We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that drop missing.

Mother Teresa



LAST WISHES

When all hope of a cure appears lost, the ill person must make choices, express their last wishes, and help their family carry these out. Financial and legal issues are difficult ones to address.

To ensure that everything is done legally, it is always recommended to retain the services of a lawyer.

Here are different points:

Living will

This document contains the person's wishes concerning the treatments and care that they agree or refuse to receive, in the eventuality they are no longer able to give the necessary consent. The document must be signed and dated. Note that a document of this type has no legal status. The ill person should discuss it with their physician and a significant other.

Power of attorney

This is a document through which a person gives another individual the power to act on their behalf with respect to financial matters, belongings, or personal care needs.

Do Not Resuscitate Order

This is a form signed by the attending physician confirming that a person at the end of life is not to be resuscitated. The Extra-Mural Program staff will provide you with a copy.

Will

A will is a document that allows a person to distribute their belongings to individuals of their choice after death.

Funeral arrangements

Pre-need funeral arrangements are becoming increasingly common. They guarantee that things will be carried out according to your wishes and they allow you to make your own choices without any pressure.

If the deceased person has not left prior instructions or made pre-need funeral arrangements, the executor of the will or any other person designated by the estate or the survivors are responsible for making the funeral arrangements with the funeral home management.

Personal record

To facilitate the executor's task, it would be very useful for the ill person to provide certain information in writing (personal record document). If they are unable to complete this document themselves, you could help them. Some people experience strong emotions dealing with these legal and financial issues. The completed personal record contains confidential information. It should be kept in a safe place before being given to the person responsible for the estate.

(See Appendix 3—Personal Record)

COMPASSIONATE CARE BENEFIT

In January 2004, the federal government added the Compassion Care Benefit to the Employment Insurance Program. Under this benefit:

- Special benefits are paid to recipients who are providing care or support to a seriously ill family member;
- Recipients are entitled to this special employment insurance benefit if they have worked 600 insurable hours during the qualification period (i.e. the same rules as apply to the existing EI special benefit programs such as illness or maternity/paternity leave);
- Leave of this type may be granted to family members or any other person chosen by the ill person;
- A waiting period is involved but when eligible members of an eligible family or other designated persons share the benefits, the waiting period is required for the first person who is providing support to a family member at the end of life;
- Recipients must obtain a medical certificate from a physician indicating that the family member is seriously ill and at risk of dying within the next 26 weeks (six months) and that it is necessary for one or more family members to provide the patient with care and support.

The government also made a related modification to the *Canada Labour Code* to create eligibility for a period of up to eight weeks of job-protected leave during a 26-week period for the provision of compassionate care to a family member or other person. This means that an employee cannot be terminated for taking up to eight weeks of leave to care for a family member or other person.

Additional information and some updates are posted on the Human Resources and Social Development Canada (HRSDC) Website at:

<http://www.hrdc.gc.ca> (English)

<http://www.drhc.gc.ca> (French)

Some information may also be obtained from your region's employment insurance office at 1-800-808-6352 or by contacting the treatment team members.

CHAPTER 7

LAST MOMENTS



Shedding tears is the normal way of expressing sadness and freeing yourself from it. Do not fear crying.

Author unknown

LAST MOMENTS

During the last days of life, the ill person's condition gradually declines. This end-of-life period is one of the difficult times for the family. It is impossible to accurately predict when death will occur.

The ill person is starting to gradually withdraw when they:

- Are no longer hungry and have stopped drinking;
- No longer get up;
- Sleep more and more;
- Become more withdrawn but do not like being alone;
- Are afraid of the night and of the unknown.

As the end approaches, some physical signs may appear:

- Their blood pressure drops;
- Their pulse varies;
- Their body temperature may rise;
- They sweat more;
- Their arms and legs become cold and bluish;
- Their often half-open eyes are glassy and teary;
- Their breathing changes, becoming faster or slower. There may even be a pause between each breath;
- Their sputum thickens, accumulates, and may trigger noisy breathing (rales).
This noise does not necessarily mean the person is in pain;
- The person no longer wishes to drink;
- Their urine changes in colour and volume.

Whatever the situation, it is normal to be worried and feel great sadness in these last moments. The Extra-Mural Program nurse will accompany you during this time.

Lack of breathing and heart beat marks the end of life. The person's last sigh is often accompanied by a few spaced out breaths. Sometimes, the person's mouth and eyes remain open. You may close their eyelids.

In the minutes following death, the loved ones may take the time they need to collect themselves.

If the death occurs at home without the EMP nurse being present, the nurse should be contacted. They will go to the home to confirm the death and advise the attending physician.

DO NOT CALL 9-1-1

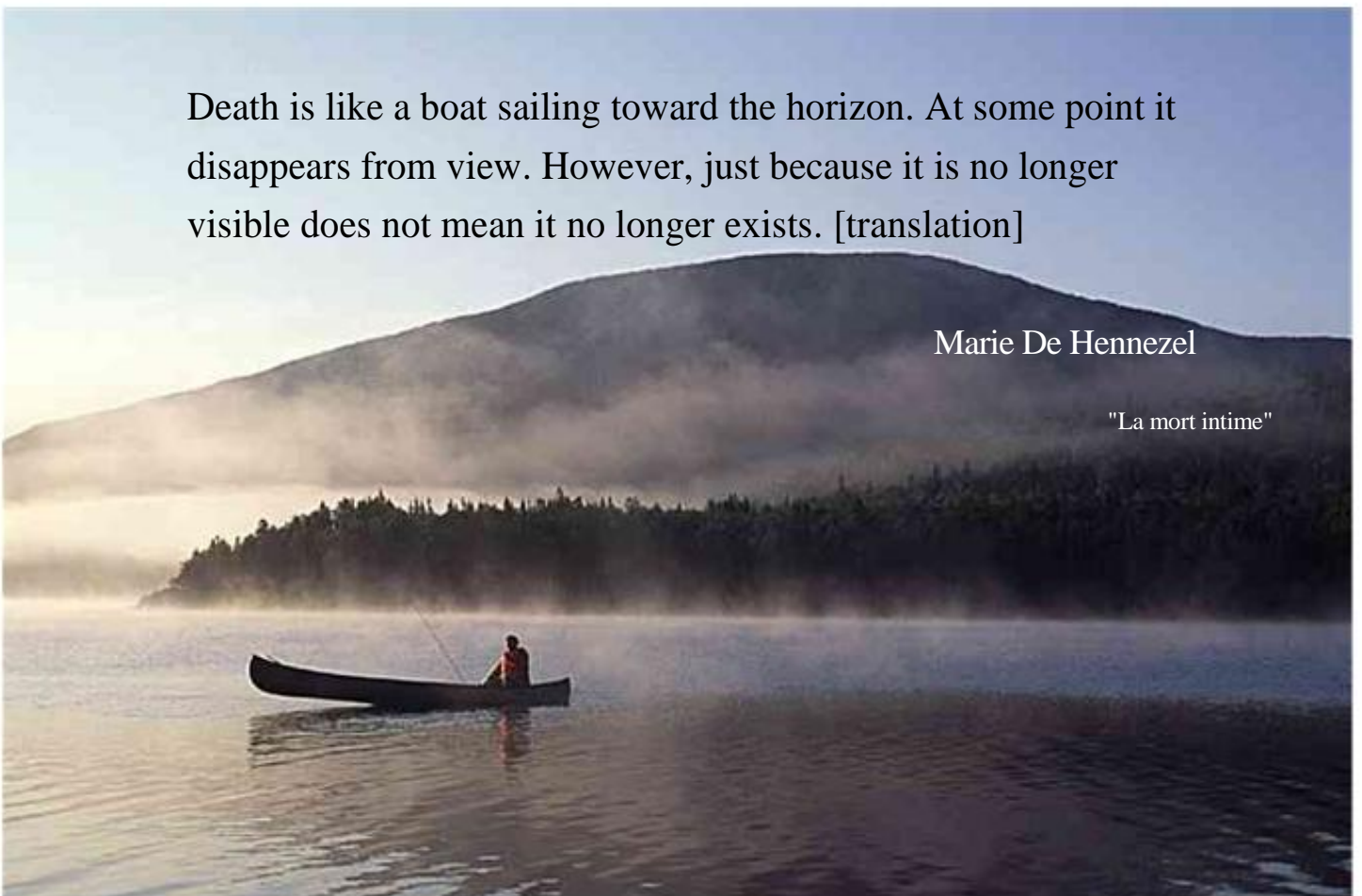
CHAPTER 8

GRIEVING

Death is like a boat sailing toward the horizon. At some point it disappears from view. However, just because it is no longer visible does not mean it no longer exists. [translation]

Marie De Hennezel

"La mort intime"



GRIEVING

The death of a loved one is among the most difficult of life's experiences.

The suffering that follows death is not only normal but also part of a process called grieving. Grieving is not an illness, even if it changes you forever. Instead, it is a life learning process, i.e. learning to accept the loss of a loved one.

Every case of grieving is unique, i.e. everyone experiences it differently. The intensity and duration of grieving depends on different factors:

- The grieving person's relationship with the deceased person;
- The circumstances surrounding the death;
- The grieving person's support network;
- The grieving person's physical and psychological condition;
- The grieving person's ability to move on.

The grieving process consists of three main steps:

1. Shock

This is the initial step following the death of a loved one. It is not unusual to feel as if you are in a dream. This step is generally of short duration.

2. Disorganization

The painful absence of the loved one is now part of the survivor's reality. The survivor feels lost. It is during this period that the loss is most keenly felt, at the individual, family and/or social levels. This is the longest and most painful period.

3. Reorganization

This step marks a gradual return to life. The survivor is once again interested in their activities, plans and loved ones. The emotional and physical pain related to their loss gradually becomes less intense. The end of grief work does not indicate that the loved one has been forgotten but rather that the survivor is returning to life without that person.

During these steps, you may experience different reactions in different areas—physical, cognitive or mental, emotional, and behavioural.

Physical: lack of energy, appetite changes, sleep changes, racing heart rate, diarrhea/constipation, vomiting, high blood pressure, stomach problems, tremors. If these symptoms persist, discuss them with your physician.

Cognitive or mental: difficulty concentrating, confusion, sense that the deceased person is present, and thinking about them obsessively.

Emotional: dejection, discouragement, anger, anxiety, relief, guilt, sadness, despair, solitude, feeling numb.

Behavioural: becoming withdrawn, losing interest, becoming isolated, functioning more slowly or in an automatic and agitated manner.

Here are a few suggestions that may help you through this difficult process:

- Take the time you need. Grieving is not a race against the clock;
- Surround yourself with people who are respectful of your pain and with whom you are comfortable talking about your loss. Avoid becoming isolated;
- Express your feelings, either verbally or in writing;
- Take care of your physical health. It is important to maintain healthy eating and sleeping habits;

- Respect your limits and accept that your life is going to be different;
- Defer major decisions and changes to later;
- Seek help. Join a support group;
- Get informed about grieving. Some very good books are available on this subject;
- Feel free to contact a member of the treatment team, who will be able to direct you to appropriate resources.

A grieving child

Like adults, children react to losing a loved one but they do so differently. Their understanding of the death and their reactions to it can vary depending on their age.

Here are a few suggestions during this difficult period:

- Involve the child in what is happening;
- Tell them the truth, support them, and listen to them attentively;
- Be honest and use language they will understand;
- Reassure the child about illness. Explain that illness does not always lead to death;
- Demonstrate that their thoughts and emotions are normal;
- Encourage them to express themselves by drawing or writing a letter;
- Attempt to maintain a certain routine.

References

- *Pratiques privilégiées en thérapie respiratoire du N.-B.* and free translation; RRRI, Benoit Tremblay.
- *Guide des aidants naturels.*
- *Accompagner ceux qu'on aime en fin de vie.*
- *A Model to Guide Hospice Palliative Care, Based on National Principles and Norms of Practice.* Canadian Hospice Palliative Care Association, March 2002.
- *The Dying Person's Bill of Rights,* American Journal of Nursing, January 1985.
- Héту, Jean-Luc. *Psychologie du mourir et du deuil.* Édition du Méridien, 1989.
- Beaulieu, Hélène. *Guide de soutien pour les proches - Accompagner ceux qu'on aime en fin de vie.* Association du cancer de l'Est du Québec.
- Bouchard-Picard, Rosa. *Recueil d'animation, Le cheminement d'un deuil.* Édition FPR, 2003.
- Callanan, Maggie and Kelley, Patricia. *Final Gifts; Understanding the Special Awareness, Needs and Communications of the Dying.* Bantam Edition, 1993.
- Ferris D., Frank (et al.). *A Model to Guide Hospice Palliative Care.* Ottawa, Ontario Canadian Hospice Palliative Care Association, 2002.
- Hycha, Dennie, Hopkinson, Jane, MacMillan, Karen and Peden, Jacquie. *A Caregiver's Guide: A Handbook about End-of-Life Care.* Canadian Hospice Palliative Care Association and the Military and Hospitaller Order of St. Lazarus of Jerusalem, 2004.
- MacMillan, Karen (et al.) *A Handbook about End-of-Life Care—A Caregiver's Guide.* Co-published by the Canadian Hospice Palliative Care Association, 2004.
- Parry, Joan K. *A Handbook about End-of-Life Care—A Caregiver's Guide.* Co-published by the Canadian Hospice Palliative Care Association, 2004.

References (continued)

- Rivoire, Bénédicte. *Celui que tu aimes va mourir, fais-le vivre!*
Éditions des Béatitudes, “Bonheur chrétien” series, April 2006.
- Workman, Karen (et al.)
“Caring at home”
Web article.
- Wright, M. Lorraine and Leahey, Maureen. *Families and Chronic Illness*.
Spring House Corporation, 1987.

Photos—contributors:

City of Edmundston

City of Grand Falls and FallODesign

City of Saint-Quentin

France Bossé

Gérald Cyr

The DYING PERSON'S BILL OF RIGHTS

Rabbi Earl A. Grollman

I have the right to be treated as a living human being until I die.

I have the right to maintain a sense of hopefulness, however unchanging its focus may be.

I have the right to express my feelings and emotions about my approaching death in my own way.

I have the right not to be deceived—to be told the truth.

I have the right to die in the most conducive setting for me.

I have the right to be free from pain—so "cure" goals may be changed to "comfort" goals.

I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

I have the right to allow children to visit me during my illness.

I have the right not to die alone.

I have the right to expect that the sanctity of the human body will be respected after death.

*A. J. Barbus "The Dying Person's Bill of Rights"
American Journal of Nursing, January 1985*



NAME	TELEPHONE NUMBER
Extra-Mural Program	
Physician	
Pharmacy	
Family aid	
Volunteer(s)	
Family and friend(s)	

Other information

Living will Yes No

Will Yes No

Funeral arrangements Yes No

Name of funeral home: _____

Tel.: _____

PERSONAL RECORD

3-page document

IDENTIFICATION

NAME:

Birth certificate (Number and where it is found):

Citizenship:

Marital status:	Married	date:	Widowed
	Divorced	date:	Single
	Separated	date:	
	Nun/monk		

Marriage contract (may contain testamentary provisions useful to the executor):

- Yes
- No

Where it is found:

Name and contact information of the person in possession of it:

Name of spouse:

Date of birth:

Social insurance number:

Name(s) and contact information of children:

Names and contact information of parents and friends to be advised:

WILL

If one exists, where it is found:

Name and contact information of the person in possession of it:

LIVING WILL

If one exists, where it is found:

POWER OF ATTORNEY (IN CASE OF INCOMPETENCY)

If one exists, where it is found:

ORGAN DONATION

If organ donation is authorized, indicate where your health insurance card or other document attesting to this fact is found:

CARD, LICENCE AND CERTIFICATE NUMBERS		
Health insurance:		
Social insurance (SIN):		
Driver's licence:		
Registration certificate:		
Car insurance:		
Life insurance:		
Private health insurance:		
House insurance:		
Other insurance (individual or group):		
Pension / old age security:		
Income security (file number):		
Compensation (work accident):	Yes	No
If compensation is being provided, what the conditions are:		
Annuities (retirement / survivor):		
Private pensions / name of employer:		
BANKING INSTITUTIONS		
Name of banking institution:		
Bank account:		
Safety deposit box:	Yes	No
(If so, box number, where it is located and where the key is found):		
Credit cards (numbers):		
INVESTMENTS AND BANK CERTIFICATES		
Type of investment (savings bonds, term deposits, stocks, RRSP, etc.):		
Name of banking institution:		
Name of broker:		
Telephone number:		
COMMERCIAL PAPER AND SECURITIES		
Companies, number of shares, certificate numbers, dates, locations, etc. / purchase of properties (note the name and contact information of all owners if purchased jointly):		
LOANS, MORTGAGES, ACCOUNTS PAYABLE		
Original copies of loans (company, finance or personal) and where they are found:		
NAME AND CONTACT INFORMATION OF BROKER:		
MORTGAGE LENDERS:		
(date of end of lease and other):		
THE FOLLOWING PEOPLE OWE ME MONEY:		
Names and contact information:		

LAST INCOME TAX RETURNS

Where they are found:

Name of person who completed them:

OTHER DOCUMENTS:

FUNERAL ARRANGEMENTS:

Pre-need arrangements

Yes

No

Contract date:

Contract number:

Where contract is found:

Name and contact information of funeral home or cooperative:

IF ARRANGEMENTS HAVE NOT BEEN MADE

Specify your wishes [i.e. with respect to viewing, cremation, disposal of ashes (if applicable), a service (religious or other), and any other instructions]:

If you have a cemetery plot, specify where it is located:

LIST OF PERSONAL BELONGINGS (may help in writing your will)

Family heirlooms, clothing, jewellery, furniture, collections, etc.:

THE RIGHTS
OF THE
BEREAVED

[TRANSLATION]

1. **A bereaved person has the right** to expect that the dying person will be cared for with compassion.
2. **A bereaved person has the right** to be informed of the death gently and to expect that the deceased's body will be treated with respect.
3. **A bereaved person has the right** to see the deceased's body and to make their initial expressions of grief at that time, if they wish to do so.
4. **A bereaved person has the right** to expect that this emotional experience will be made easier for them.
5. **A bereaved person has the right** to know the exact cause of death as well as the nature of the treatments that were administered and the reason they failed, if applicable.
6. **A bereaved person has the right** to make funeral arrangements of their choosing, without being manipulated.
7. **A bereaved person has the right** to grieve according to the rituals of their religion and culture.
8. **A bereaved person has the right** to grieve, whatever the cause of death may be (suicide or other) and to be helped in understanding their own reactions.
9. **A bereaved person has the right** to expect that caregivers themselves will understand the dynamic around grieving.

Hétu, Jean-Luc, *Psychologie du mourir et du deuil*, Édition du Méridien, 1989.

Extra-Mural Program

Regional Health Authority A

Zone 4