



Guide for
PATIENTS
and **CAREGIVERS**



The Palliative Home-care Society of Greater Montreal
would like to thank those who contributed to the completion of this guide.

We would like to extend special thanks to Ms. Linda Saint-Germain who played a major role
in the completion of the first edition and initial funding of this guide.

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GUIDE FOR PATIENTS AND CAREGIVERS



Following the production of this guide, the Palliative Home-care Society of Greater Montreal was awarded the Derouin-Renaud grant from the Réseau de soins palliatifs du Québec in 2009.



With the care received by the Palliative Home-care Society of Greater Montreal, Ginette Hamel passed away with dignity, in her home.

This guide for patients and caregivers is a testament of our commitment to have a direct impact on the quality of care.

Linda Saint-Germain (LSTG), who accompanied Ginette Hamel as her caregiver, wanted to share this life experience. Her testimony aims to demystify palliative home-care.

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“Helping others in their journey towards death is just as important as preparing our own death.

We were all born helpless newborns and if we hadn’t received care and tenderness, we wouldn’t have survived. People at end-of-life are just as unable to care for themselves; we should also relieve them of their discomfort and anxiety and help them die as peacefully as possible.

What’s most important is putting their mind at ease; they’re already going through enough as it is. When helping the dying, the main goal is to bring them comfort. There are many ways to do this.”

Sogyal Rinpoche,
Tibetan Book of the Dead

1

**CARE and
SERVICES
PROVIDED**

by the Society



1. CARE AND SERVICES PROVIDED BY THE SOCIETY

1.1 PALLIATIVE HOME-CARE SOCIETY OF GREATER MONTREAL

The Palliative Home-care Society of Greater Montreal (formerly known as the Association d'Entraide Ville-Marie) is a non-profit organization, founded in 1973, which specializes in palliative home care for people who are in the advanced stages of cancer or other pathologies.

OBJECTIVES

- Ensure quality of life, at home, for patients and their families, living with cancer or other pathologies.
- Encourage and maintain the invaluable participation of loved ones in patient care by teaching, reinforcing, providing information and offering various resources.
- Take into account the situation in which the patient and his family are in as a whole by using a comprehensive integrated approach.

CLIENTELE

- We provide services to anyone in the last stages of cancer or other diseases as well as their loved ones.

NURSING CARE

- Nursing care to relieve pain and the other symptoms related to the disease
- Quick and easy access to the health network and social services
- A medical follow-up in collaboration with medical specialists, family doctors and palliative care specialists
- Training on the care to be provided by the patient and caregivers
- Support and spiritual care that is respectful of individual values and beliefs

The patient's health is monitored in collaboration with the attending physician and the specialists involved in their care.

1. CARE AND SERVICES PROVIDED BY THE SOCIETY (cont'd)

PSYCHOLOGICAL CARE

A psychologist from the Society provides psychological care to patients and their caregivers. Psychological support is provided during individual or family sessions at home, at the Society's office or by phone. Psychological care is aimed at introspection to deal with the symptoms related to the experience during this difficult time when various periods of distress may occur cognitively, emotionally or spiritually (anxiety, anguish, depression, anger, sadness, etc.).

HYGIENE AND COMFORT CARE

- Experienced personal care workers provide hygiene and comfort care.
The frequency of services is established according to the needs of the patient and the capacities of the caregivers.
- Personal care workers provide respite care services for caregivers during the day, evening and night.

FAMILY SUPPORT SERVICES

Family support services are complementary services to nursing and hygiene care. They are provided by volunteers and take into account the capacities and availabilities of caregivers. These services are meant to provide temporary support to caregivers to facilitate home support for patients, if possible until they pass away.

- A volunteer provides respite, active listening and psychological support. A maximum of six hours of at-home presence per week (1 x 6 h or 2 x 3 h) is offered.
- Transportation to appointments and to receive medical treatments, for laboratory samples or to deliver or collect assistive equipment on loan.
This service is provided when no other loved ones can provide it.

LOAN OF ASSISTIVE DEVICES

- Walker
- Cane
- Bath bench
- Raised Toilet seat

BEREAVEMENT SERVICES

- Themed conferences on grief with exchanges guided by a qualified professional
- Telephone monitoring by trained volunteers
- Referrals to specialized resources

TERRITORIES SERVICED

Montreal, Laval and South-Shore
Services are free; however, the transportation service is the only one for which we request minimal financial contribution.

*“It was a revelation for me, a privilege, to be able to accompany my friend during this ordeal. A spiritual revelation indeed, but also a revelation of strength that I didn’t know I could have in such a context.
I accompanied Ginette to the best of my knowledge; we helped each other out. We cried, laughed and grew. A year and a half later, I can say that it’s the best gift I’ve ever received. I learned that dying is also about learning to live.”*

LSTG

THE NEEDS OF A PERSON FACING IMMINENT DEATH

After having spent years listening to people living their last moments, Christine Longaker tries to talk on their behalf to express the emotional, practical and spiritual needs of someone confronted with imminent death.

“There are days and entire weeks that I feel sad or angry. If you could listen and accept me without trying to cheer me up, I might be able to relax and maybe even laugh with you again.”

“I’d really like it if my friends hugged me, squeezed my shoulder, held my hand or gently stroked my face. Please don’t repress your love and affection.”

“Talk to me directly and not above my head or as though I weren’t in the room. Ask me what medical care I want during these last moments while I’m still able to express my desires clearly.”

“Sometimes just thinking about death scares me, but at the same time, I feel strangely at peace and even a little curious to know what adventure lies ahead. It’s still probably a trip for which I’m not fully prepared. Don’t try imposing your beliefs and responses to death on me.”

“Please don’t worry and don’t be sad if you aren’t beside me when I die. Your presence is sometimes comforting, but at other times, it makes my departure that much harder. Remember that I’m thankful for everything that you’ve done”.

Christine Longaker
Facing Death and Finding Hope: A Guide to the Emotional and Spiritual Care of the Dying. 1997

1.2 NETWORK FOR PATIENTS AND THEIR CAREGIVERS

We want the following information to help alleviate concerns and answer the many questions that inevitably arise when a spouse, friend, loved one or significant other serves as attendant or caregiver.

The caregiver and the patient being accompanied are living a wide range of emotions: sadness, fear, rage, depression, hope acceptance...

Caregivers must take the time to listen to the patient without argument. The patient does not want to know what you think; he just wants to free himself of his thoughts. He is not a victim and even less a child: very much alive, he is capable of making decisions. He is independent and proud.

When accompanying someone, you must first acknowledge your limits and capacities and take the steps necessary to maintain your

mental and physical well-being. Any moment of respite, however brief, is essential. It is critical to share certain tasks with friends and loved ones.

A network is as helpful for caregivers as it is for patients. Sharing tasks gives caregivers time to listen, accompany and engage in activities with the patient. It is comforting and reassuring for caregivers to count on loved ones in such a challenging situation.

1.2 NETWORK FOR PATIENTS AND THEIR CAREGIVERS

(cont'd)

A caregiving network includes the participation of various contributors: specialists, family and friends. Patients and caregivers organize the implementation of this network. Here are a few suggestions to identify immediate needs. You should prepare a list of resources who can accomplish certain tasks that you deem essential as well as their availability.

PROFESSIONALS

List the phone number of all specialists indicating how and when to reach them. Medical service and night nurse: dedicated line for 24 h palliative care. Ask the nurse for the phone number.

Note emergency numbers for the evening and night.

LOVED ONES

- Hygiene care
- Medical appointments (doctor's office or hospital)
- Medication monitoring to make sure the patient does not run out
- Deposits and withdrawals at a financial institution, payments...

FRIENDS

- Babysitting
- Pet care
- Errands: groceries or various purchases
- Psychological support: a friend, loved one or volunteer with whom the patient or caregiver can talk
- Call centre: a person agrees to share any new developments with friends and loved ones

- Accompaniment: a loved one or volunteer keeps the patient company when the caregiver is absent
- Preparation of meals in advance (soup, muffins, stew, etc...)

OTHER RESOURCES

- CLSC
- Pharmacists
- Info-cancer line: 1 800 363-0063
- Info-caregiver line for loved ones: 1 855 852-7784
- Social enterprises that provide domestic care:
www.ramq.gouv.qc.ca/en/citizens/aid-programs/Pages/aid-programs.aspx
- Outside maintenance: grass, snow, windows...

“Accompanying actually means being there for the patient, by his side, with the utmost respect for his path and at his pace. Accompanying requires great availability and a sympathetic ear.”

Gauvin, Andrée and Roger Régnier (2004),
Translated from *Accompagnement au soir de la vie - Le rôle des proches et des bénévoles auprès des malades*



2

PSYCHOLOGICAL CARE *and* ACCOMPANIMENT

*“You taught me that everyone has strengths and resources.
My role is to support and accompany you throughout this
experience.*

*You have the strength and resources needed to transcend
what life brings you.”*

Manon Coulombe, Nurse, M.Sc.
Collective work by the Society, *Ce que vous m'avez appris*
Une qualité de vie jusqu'à la fin... des soins palliatifs à domicile, 2009

2.1 PSYCHOLOGICAL CARE AND ACCOMPANIMENT

The caregiver shares in the challenge of physical, emotional, cognitive and spiritual trials of the patient. Acknowledging what the patient is experiencing throughout his illness and on his trajectory towards death contributes to the quality of care being provided.

Within the framework of palliative care, there is an encounter between the patient and caregiver who can experience the same sense of suffering and helplessness when faced with the inevitable. The goal is to foster relations between them so that they can develop the trust that will allow them to share this path until the time that they are separated by death.

Emotional, spiritual or existential representations are constantly present for the patient and caregiver. From the caregiver, the patient draws an essential trust which is necessary if he is to feel as though he can depart without being distressed or held back. The patient needs the assurance that his loved ones will follow their own life path.

Through conversation, silence, looks and touching, the patient nearing the end of his life can share with his caregiver their love, memories and experiences as they face the unknown. The goal is to provide the patient and caregivers with the psychological and spiritual resources necessary and appropriate for this situation.

Throughout the illness of the patient, in particular upon the announcement of the end of the curative phase, the patient and caregiver are faced with various stages of denial, anger, resignation, depression and acceptance. These are lived simultaneously through the emotional and spiritual representation of a shortened lifespan and inevitably, death.

To provide continuous psychological support for the patient and family, the clinical approach adopted is psycho-dynamic and humanistic. Based on a transfer of essential trust towards the caregiver and psychologist, this approach allows for some introspection to treat the symptoms related to this experience, such as: distress, depression, guilt, shame, anxiety, anguish, sadness, irritability, a feeling of helplessness, social and interpersonal withdrawal, anticipation of grief, the meaning of absence, reconstruction and reinstatement of life's humanistic and spiritual values. With this clinical approach, certain unconscious conflicts appearing during this period of accompaniment and grief are dealt with. This allows for the anticipation of emotional distress and depression and helps to mitigate the effects of eventual crises. Creating a sense of caring and trust connects us and is at the heart any accompaniment that respects the patients' needs.

The Palliative Home-care Society's psychologist offers individual or family sessions at home, at the Society's office, or by phone. Psychological monitoring is accessible throughout the patients' illness. In certain cases, caregivers can meet the psychologist individually to take the first steps towards mourning. Throughout the year, meetings are organized with the bereaved so that they can share and discuss their experience.

Speak to your nurse to benefit from psychological counselling.

2.2 HOME CARE FOR PATIENTS

“The thought of losing someone we care about forces us to surpass ourselves and through the cruelty of seeing this person wasting away, we’re thrust into unexplored territory. The privacy of the encounter, the vulnerability of one and generosity of the other are worth something, especially when life is coming to an end.”

Johanne de Montigny, Psychologist

Translated from *L'accompagnement : un engagement exigeant et tonifiant*

Une qualité de vie jusqu'à la fin... des soins palliatifs à domicile, 2009

LOSS AND GRIEVING DURING CARE

Mourning, living a loss and discovering its meaning can prevent depressive reactions and rekindle someone's desire to live, for those who may have otherwise dragged a burden of sadness with them for years. This sadness often prevents people from regaining motivation and finding new resources to continue without the person that used to give meaning to their life. The patient and his loved ones face increasing losses as the disease progresses.

Being familiar with our own avoidance behaviours towards the obstacle at hand, the stages leading towards death, and with the impact of loss is essential to be able to accompany someone efficiently and identify the means of support available.

After receiving a cancer diagnosis and an end-of-life prognosis, it is normal to be **shocked** and to want to deny a reality that is too difficult to contemplate. All we can do is accept this condition, which serves as a buffer during this terrible ordeal.

We can feel anger towards our own helplessness. This **anger** is often directed towards loved ones who have what the patient does not. It can be expressed as criticism, bad moods, refusal to cooperate, insults, accusations or unreasonable demands.

Bargaining is a step during which any attempt, promise or pact is meant to buy time. We would do anything to change the prognosis to be able to live and get better.

The period of **sorrow, sadness and depression**, expressed through withdrawal, is one of the crucial steps in the journey towards death. The patient lives in isolation, refuses to take part in normal activities and sleeps more. To avoid suffering caused by loss, they

2.2 HOMECARE FOR PATIENTS (cont'd)

sometimes avoid seeing people that they care about. It is an important step as it sets a unification process and internal dialogue into motion. It is important to recognize that it is quite normal to have moments of extreme sadness. The patient is slowly preparing themselves for the inevitable.

Acceptance, the last step, involves the patient organizing their death, drawing up a will and making funeral and financial arrangements. They can talk about their death. They talk very little and choose their words carefully. They are calm and enjoy silence. Some people may not experience this acceptance.

These non-mandatory and non-chronological steps can overlap in the journey towards death. They resemble those that his loved ones will have when he passes away. In his book entitled "Aimer, perdre et grandir", Jean Monbourquette talks about a sixth step, important for the loved ones, the legacy of the heart. This step involves accepting the loss of a loved one.

It is important that you recover the energy, love and qualities of your loved one. Remembering what you liked about this person such as his sense of humour or generosity and acknowledging this quality as being part of who you are now.

*It is essential that you make time for yourself and treat yourself to things
that make you feel good and let you heal from loss.*

A person in an advanced stage of cancer or at end-of-life and their loved ones are affected in various ways: physically, psychologically, cognitively, in their family life, socially and spiritually. The following table describes the global approach that staff at the Palliative Home-care Society of Greater Montreal use and the goals they pursue in their interventions with patients and their caregivers.

SUMMARY OF INTERVENTIONS OF CLINICAL STAFF AND GOALS PURSUED

DIMENSIONS OF THE HUMAN BEING	INTERVENTIONS FROM THE CLINICAL STAFF
PHYSICAL	Ensure the patient's overall well-being: prevention and control of pain and comfort by constantly adjusting the dosage with the attending physician, control of all symptoms linked to the diagnosis and comfort, monitoring of the medication and application of care techniques.
PSYCHOLOGICAL	Accompany the person in his journey towards death at his own pace. "Anyone who walks towards the truth of his own being will see the light."
COGNITIVE	Teach the care and treatments to give and provide information. Professionals must not manage patients and their loved ones. The latter maintain their ability to reason, judge and make decisions.
FAMILY	Facilitate the transfer of responsibilities and help the patient to adapt to the changes in his relationships and expectations towards his family. Provide home support for the patient.
SOCIAL	Stimulate people to open up to others while taking the situation into account to prevent the patient from becoming the only topic bringing them together.
SPIRITUAL	Listen to what the patient wants to share from his inner life. Respect his values, beliefs, hopes and quest for meaning. Make the patient feel safe in his beliefs. Acknowledge the importance of the spiritual sphere in care and accompaniment.

DIMENSIONS OF THE HUMAN BEING	GOALS WITH PATIENTS	GOALS WITH CAREGIVERS
PHYSICAL	Ensure physical well-being and promote independence.	Monitor the overall health of loved ones to avoid exhaustion, which may compromise home care.
PSYCHOLOGICAL	Listen and be present. Reduce anxiety by focusing the attention on the present moment rather than anticipating the future. Be compassionate, respectful, tolerant and open-minded.	Listen to and grasp causes of concern, which will help loved ones express the sadness or anger they feel at the thought of losing someone they care about.
COGNITIVE	Understand what the patient is going through. Encourage him to express his desires. Let him decide and take up his responsibilities.	Promote open communication between the loved ones and the patient. Inform on the patient's health and the evolution of the disease. Support caregivers and patients in the application of the proper physical care.
FAMILY	Enhance the patient's worth in his own eyes. Help him maintain or re-establish an activity pace with his loved ones. "There are still many things to live."	Raise the loved ones' awareness to the patient's need to keep on being connected or playing a role in the family dynamics.
SOCIAL	Promote expression and help to consider discussions as special moments that bring comfort, minimizing the feelings of guilt that a loved one can feel after the death.	Avoid isolation and escape. Encourage a social lifestyle that is suited to the requirements of the situation. Raise awareness about the reward of accompanying a loved one during their last moments. These can be full of infinite tenderness.
SPIRITUAL	Listen to what the patient wants to share from his inner life. Leave room for suffering, which is legitimate.	Listen to what the patient wants to share from his inner life: his anxiety, mental suffering, spiritual questioning, desperation, hope.

2.3 SPIRITUAL SUPPORT

“All this time spent with people so close to death is like a seed of life. I slowly came to terms, with a little less fear and more serenity, with the end of my own life. End-of-life remains a school of life for ourselves and others. It’s possible that as death nears, our own death and that of others, that we better understand the broadness of the cycle of life, the other side and the other dimension of life.”

Doctor Renée Pelletier
Collective work of the SSPAD,
Text: *De l'autre côté de la porte,*
Une qualité de vie jusqu'à la fin... des soins palliatifs à domicile,
Editor Richard Vézina, 2009

“Providing support during this time requires everyone’s acceptance of the inevitability of death. People must acknowledge their human limits.

Whatever the love we feel for someone, we cannot prevent that person from dying, if that is his destiny. We can’t prevent a certain emotional and spiritual suffering either, as it’s part of the whole process of death.

We can only prevent this suffering from being lived in loneliness and abandonment, and surround it with humanity.”

Marie de Hennezel and Jean-Yves Leloup,

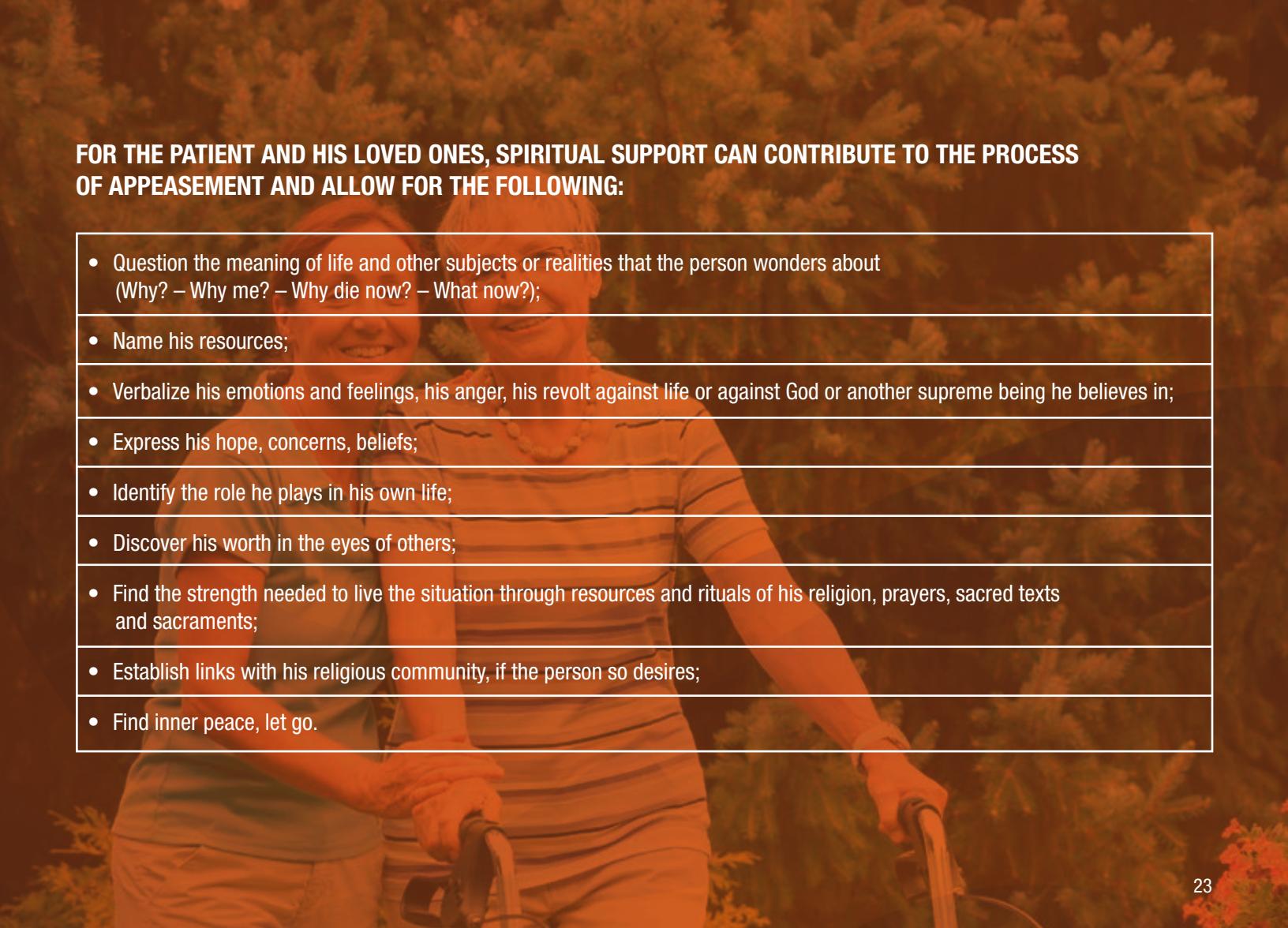
Translated from

L'art de mourir, Editor Robert Laffont, 1999

End-of-life often constitutes a soul-searching phase for the person. During this crucial phase, memories resurface and an assessment is made by the person who re-appropriates important moments of his life by giving them a new and healing meaning. This questioning of the meaning of the events of his life can help soothe his pain.

At end-of-life, existential questions are often asked, questions on the meaning of life, suffering and death. How can we support this questioning?

When providing spiritual support, the caregiver or person providing support must listen to what the patient wants to share about his inner life while respecting his values, beliefs, hopes, search for meaning and hope. The person providing support must leave space for the expression of spiritual suffering, which is legitimate.

A photograph of a woman with short brown hair smiling warmly at an elderly man. She is holding his right hand. The man, wearing a striped shirt and light-colored pants, is leaning forward with a walking cane in his left hand. They appear to be outdoors in a garden or park setting with greenery and flowers in the background.

FOR THE PATIENT AND HIS LOVED ONES, SPIRITUAL SUPPORT CAN CONTRIBUTE TO THE PROCESS OF APPEASEMENT AND ALLOW FOR THE FOLLOWING:

- Question the meaning of life and other subjects or realities that the person wonders about (Why? – Why me? – Why die now? – What now?);
- Name his resources;
- Verbalize his emotions and feelings, his anger, his revolt against life or against God or another supreme being he believes in;
- Express his hope, concerns, beliefs;
- Identify the role he plays in his own life;
- Discover his worth in the eyes of others;
- Find the strength needed to live the situation through resources and rituals of his religion, prayers, sacred texts and sacraments;
- Establish links with his religious community, if the person so desires;
- Find inner peace, let go.

Accompanying someone is offering our presence. This presence means “being with ...”. Accompanying is listening to the other person and being empathetic, compassionate, welcoming and open. Among the various needs of people at end-of-life, presence seems to be the essential one. At the very depth of their suffering, only quality presence can provide proper relief.

“During more difficult times in life, like an illness, failure, a break-up or death, the simple presence of someone is extremely important for the person who is suffering. This human presence is fundamental to comfort, support or help this person get through such ordeals; however, despite its stunning simplicity, it’s astonishing to see how difficult it is to really be present for someone who is suffering...”

Madeleine Saint-Michel, r.h.s.j.

Translated from

En soignant le corps, toucher l’âme

Une qualité de vie jusqu’à la fin... des soins palliatifs à domicile

Editor Richard Vézina, 2009

Caring for and accompanying someone who is suffering throughout his entire being is not simply a theory or technique. At the heart of this accompaniment there is an overall suffering. Physical suffering is often the easiest to relieve, but the suffering felt in the heart and soul is completely different. Everyone has their own way of promoting inner healing.

Spiritual support takes into account multicultural and multiconfessional considerations to meet the needs of the patient and his loved ones such as:

- The presence of a Palliative Home-care Society volunteer to support you and help you express what you are experiencing.
- The presence of a representative of your religious faith to talk to or participate in a religious ritual, for example:
 - receive communion, anointing the sick or another sacrament, etc.
 - read a prayer, sacred texts, etc.
 - seek a blessing
 - pray with a cult-specific object
 - light a candle or incense
 - accomplish specific customs or rites

You can also ask your nurse to provide you with a spiritual assistant.

“Although life expectancy is very much reduced, people can still live differently, awaken to the presence of others, trust, feel the love of others, feel grateful for having taken part in the evolution and development of humanity...”

Doctor Patrick Vinay
Collective work of the SSPAD,
Translated from
L'éloge de l'impuissance
Une qualité de vie jusqu'à la fin... des soins palliatifs à domicile,
Editor Richard Vézina, 2009

“My friend had a lot of trouble controlling her pain. She often took medication only to reduce the pain to a tolerable level. She’d stop her medication too fast. The pain would come back stronger and then she’d have trouble making it go away and be comfortable enough. Unfortunately, it’s common practice among the sick. They tend to make the same mistake. That’s the problem: people should never stop their basic medication.”

LSTG



3

PAIN RELIEF

3.1 PAIN INTENSITY RATING SCALE

Everyone has their own pain threshold. Only the patient can determine the true level of their pain. It is essential for the person to describe the exact intensity of their pain on a scale of 0 to 10. This scale allows the doctor to prescribe the proper medication for pain relief. This control is meant to relieve the patient during the night, at rest and when traveling.

Complete the monitoring form provided by the nurse of the Palliative Home-Care Society of Greater Montreal.

Suffering is unnecessary and never acceptable, especially now.

No pain 0



Mild pain 1-3



Arduous pain 4-6



Severe pain 7-9



Unbearable pain 10



PAIN SCHEDULE:

It is important to note when the pain starts, how long it lasts and when it occurs.

DURATION OF THE PAIN: Is the pain: sudden / constant / intermittent / periodic / brief paroxysms (by peaks) / persistent – How long has it been lasting?

THE CONTEXT OF THE PAIN:

- does it occur after being in a certain position for a lengthy period of time?
- does it occur immediately after a meal?
- does it occur upon waking up?
- when does it begin?
- are there factors that relieve it (rest, positioning)?
- are there factors that aggravate it (movement, posture)?

It is not necessary to suffer:

- 90% of pain can be controlled. Don't fear increasing pain. There is a dosage that can control it.
- 7.5% of pain is difficult to control and requires dosage adjustments.
- 2.5% of pain is refractive to medication.

CONSISTENCY

- Indispensable to pain management.
- Even though some pain medication is prescribed every 4, 6 or 8 hours, do not hesitate to administer or take an extra dose to relieve pain.

3.2 TYPES OF PAIN

IT IS SOMETIMES HARD TO DESCRIBE THE TYPE OF PAIN FELT.
THESE EXAMPLES CAN HELP THE PATIENT TO BETTER IDENTIFY WHAT THEY FEEL.

PAIN:

- stabbing (throbbing)
- shooting (lightning)
- lacerating (tearing)
- pulsating (pulses)
- penetrating (spikes)
- burning (like a match)



- dull
- tingling
- widespread
- knotted
- hammering
- neuralgic (affecting a nerve)



Nociceptive pain = Visceral
Neuropathic pain = Nerve pain

To treat it effectively, it is important to understand what pain is and communicate this information to the doctor and nurse.

In case of serious or progressive diseases such as cancer, we can speak of total pain; the patient experiences psychological suffering that is both physical and emotional.

WHAT TO DO?



3.3 RELAXING MEASURES

CERTAIN APPROACHES SEEM TO HAVE A BENEFICIAL IMPACT ON EMOTIONAL AND RATIONAL ASPECTS AND CONSEQUENTLY ON PAIN:

- Light massages
- Touch
- Music
- Relaxation
- Distractions and leisure
- The presence of someone calm and soothing
- Noise reduction
- Dim lighting

The nurse can suggest other approaches depending on the type of pain.

WHAT TO DO?



3.4 MEDICATION

Used as prescribed, pain medication does not shorten someone's life or create addiction. If the pain subsides following chemotherapy or radiotherapy treatments, the dosage can be reduced progressively under the supervision of the doctor/nurse team.

! Do not stop taking the medication even when the pain is well controlled.

SIDE EFFECTS

Pain medication can cause side effects: nausea, vomiting, constipation, muscular cramps, spasms, drowsiness, dry mouth. The nurse can help you control these effects.

IN-BETWEEN AND RESCUE DOSES

For the patient to be comfortable during this period, the pain intensity scale and types of pain are an easy and efficient way to indicate exactly the kind of pain felt. Between the regular doses of pain medication, small doses called "in-between doses" or "rescue doses" can be prescribed to control the pain felt between the regular doses.

These in-between doses should be given without hesitation. This is a recognized approach in this type of situation. They ensure the person's well-being. That being said, it is important to note the number of such doses given over a 24-hour period and to share this information with the nurse or doctor. This information should be written on the monitoring form provided by the nurse.

WHAT TO DO?



3.4 MEDICATION (cont'd)

RENEWAL OF MEDICATION

1. Plan for the renewal of the medication five to six days before its depletion.
2. Before calling the pharmacy to renew any medication, check to see if other medication also needs to be renewed.
3. Check to see how many renewals are allowed on the container:
 - If the medication can be renewed, call the pharmacist and ask for a renewal.
 - **If the number "0" appears**, this means that the medication cannot be renewed.
You must obtain a new prescription as follows:
 - A. If the doctor practices at the hospital, call the nurse
(Refer to the phone number on the "Identification of the patient and caregivers" sheet;
 - B. If the doctor practices in a clinic, call his office.
4. If it is the pain medication that needs to be renewed, plan on going to get the prescription yourself (narcotics-analgesics) or ask if the medication can be delivered. Certain pharmacies agree to pick-up the prescription while others agree to have it be sent by fax and have the original be sent by mail within a reasonable period of time.
5. If you have any doubts or concerns, contact the nurse at the Palliative Home-Care Society of Greater Montreal.

WHAT TO DO?



3.4 MEDICATION (cont'd)

STORAGE OF PAIN MEDICATION

Remember that pain medication is a powerful drug that must be kept out of sight and reach of children and teenagers and any other person at risk of using them.

It is important to return the medication to the pharmacy once it is no longer used. This precaution is crucial to prevent any incidents/accidents caused by the inappropriate use of medication.

“In the palliative home care universe, there’s still room for independence. Decisions can be made, even small ones, to ensure the patient’s comfort. When the dosage of medication does not alleviate the pain and the suffering becomes increasingly apparent, we can act quickly and ensure a follow-up with a palliative care specialist.”

Palliative Home-care Society nurses
Collective work

Translated from *Une qualité de vie jusqu'à la fin ... des soins palliatifs à domicile*
Editor Richard Vézina, 2009

USE OF MEDICATION AND INSTRUMENTS

WASTE CATEGORY	PACKAGING METHOD	STORAGE AREA	DISPOSAL METHOD
Sharp instruments: <ul style="list-style-type: none">• Needles• Butterfly needles• Ampules• Vials• Glass tubes• Vacutainers	1. Place the instruments in a rigid plastic puncture-resistant container with screw lid provided by the patient or his family.	In the patient's home, in a closed area, out of reach of children, the cognitively impaired or people who risk using it. E.g.: cupboard, drawer. The lid of the container must be closed at all times.	For each of these situations: Once these containers are full or the person stops receiving care by the Society, the nurse brings all the containers (well closed) back to the office.
	2. Limited use of such instruments: The nurse places these instruments in the needle container provided by the Palliative Home-care Society and brings it with her.	The needle container is well closed and always kept in the nurse's kit.	
	3. If the patient has HIV or Hepatitis B: the nurse brings the needle container provided by the Society and leaves it at the patient's home until the end of the treatment or until it is full. She uses the device on the container to remove the needle from the syringe; she never uses her fingers during this operation.	At the patient's home, in a closed area, out of reach of children, cognitively impaired or people at risk of using it. E.g.: cupboard, drawer. The lid of the container must be closed at all times.	



WASTE CATEGORY	PACKAGING METHOD	STORAGE AREA	DISPOSAL METHOD
<p>Material that is soiled or impregnated with blood or secretions:</p> <ul style="list-style-type: none"> • Syringes without needle • Catheters • Bandages • Compresses • Cotton swabs • Sponges • Gowns 	<p>Soiled material is placed in a sealed plastic or double bag provided by the patient or caregiver.</p>	<p>In the patient's home, in a closed area. E.g.: cupboard.</p> <p>The bags must be closed at all times.</p>	<ul style="list-style-type: none"> • Place the bags in a rigid garbage can. • Close the lid of the garbage can properly. • Take out the garbage at the appropriate time.
	<p>The medication is kept:</p> <ul style="list-style-type: none"> • in its original container or • in a dispenser or • in the refrigerator depending on the pharmacy's instructions (on a shelf and not in the refrigerator door). 	<p>At the patient's home, in a closed area, out of the reach of children, cognitively impaired or people at risk of using it. E.g.: cupboard, drawer.</p> <p>The lid of the container must be closed at all times.</p>	<p>Return to the pharmacy according to the instructions on the container or bottle. The medication should never be disposed of in a garbage can or toilet.</p>



“It’s been said so many times that we need to eat to stay healthy, but when you’re in palliative care, nutrition takes on a whole new meaning. Sometimes my friend had sugar cravings, especially when she was on cortisone, and at other times she wouldn’t eat at all. At first, I insisted that she eat, but then I learned to respect her needs.”

LSTG



4

NUTRITION



4. NUTRITION

IT IS PREFERABLE TO ENCOURAGE THE PATIENT TO EAT FOR AS LONG AS POSSIBLE BY:

- respecting his preferences and eating habits;
- changing the texture and consistency of foods if necessary;
- serving home cooked meals.

Actually, the ultimate goal of nutrition and hydration is to improve the patient's comfort and overall well-being. Swallowing difficulties or pain, digestive occlusion and loss of appetite are the main nutritional problems encountered.

4.1. SWALLOWING PROBLEMS

WHAT TO DO WHEN SWALLOWING BECOMES PAINFUL?

- Check to see if there are white plaques in the mouth. If so, inform the nurse.
- Continue preparing small meals.
- Cut the food into bite-size pieces to avoid foods whose consistency is too hard.
- Avoid dry foods. Add sauces and puree and thicken liquids.
- Make sure that the patient is well positioned during meals.

WHAT TO DO?

4.2 LOSS OF APPETITE

WHAT TO DO WHEN THE PATIENT LOSES THEIR APPETITE OR IS FULL QUICKLY?

- Serve small portions to avoid discouraging the patient.
- Encourage them to eat their favourite foods and start the meal with foods containing the most calories.
- Prepare small light meals and encourage him to eat slowly.
- Plan meals according to the patient's fluctuations in appetite. Mornings are often best.
- Recommend nutritional liquids between meals such as milkshakes or Ensure.
- Avoid consumption of fatty or fermented foods.
- Prepare foods that smell good or favour microwave cooking to reduce the smell of foods.
- Offer a glass of wine to stimulate the patient's appetite.
- Offer appetizing snacks such as: cheese, crackers, muffins, nuts...
- Offer dietary supplements in small amounts and in various forms such as: granola bars, puddings, energy drinks...



4.3 SORENESS OF THE MOUTH AND THROAT

WHAT TO DO?



WHAT TO DO WHEN THE MOUTH AND THROAT ARE SORE?

- Check to see if there are white plaques in the mouth. If so, inform the nurse.
- Increase the consumption of liquids, if possible.
- Choose soft and moist foods. If necessary, add some sauce, meat juices, butter or other liquids.
- Avoid alcohol, tobacco and irritating foods (i.e. popcorn).
- Take a sip of liquid with each bite to ease the chewing and swallowing process
- Stimulate the secretion of saliva with sugar-free gum, oral gel, water spray (short-term relief).
- Examine the condition of the patient's mouth regularly to detect any change.
Use a soft bristle toothbrush or soften it under lukewarm water if necessary.
- Because of the dryness of the tongue, after having taken Ensure or a dairy product, the patient should rinse his mouth preferably with a mouth wash with little or no alcohol or glycerine.

WHAT TO DO?

4.4 ORAL CARE

To prevent the numerous consequences linked to oral problems, it is essential to take precautions to avoid discomfort and unnecessary suffering. In an end-of-life context, many patients will eventually suffer from an oral problem: alteration of taste, subjective feeling of oral dryness and problems swallowing and communicating, which interferes in interpersonal relationships with loved ones and/or lowers self-confidence.

Oral hygiene is essential. Good oral care increases comfort and helps to prevent the dryness of mucous membranes and the loss or change of taste.

WHAT TO DO WHEN THE SALIVA IS THICK AND THE MOUTH IS DRY?

- Drink liquids that are hot or slightly acid such as tea, citrus juices or pineapple juice with less sugar and offer popsicles.
- Rinse the mouth frequently.
- Encourage the patient to brush his teeth or rinse his mouth four times a day.
- Change the toothbrush every three months.

MOUTHWASH RECIPE

30 ml of non-sterile water

30 ml of mineral water

30 ml of a commercial mouthwash without alcohol or phenol

P.S. : If debris sticks to the mucous membranes of the mouth, add 30 ml of peroxide to the preparation. Rinse the mouth again with water.

WHAT TO DO?

4.4 ORAL CARE (cont'd)

WHAT TO DO WHEN THE MOUTH IS DRY AND THE TONGUE IS CRACKED OR CRUSTY?

- Increase hydration by offering ice cubes, juice or any other favorite drink.
- Make sure that the patient's environment is well humidified.
- Offer honey, maple syrup, butterscotch or barley sugar candy. To stimulate the production of saliva, provide sugar-free chewing gum while avoiding cough drops and mint candy.
- If the inside of the mouth is sensitive, use a moist cloth dipped in mouthwash instead of a toothbrush.
When this technique is no longer possible, use a sponge on a stick sold in pharmacies or distributed by the nurse from the Palliative Home-Care Society of Greater Montreal.
- Apply a lip moisturizer with aqueous products or a balm such as Nyaderm cream, two to three times a day if necessary.
Avoid Vaseline for patients who require oxygen. Avoid glycerine or lemon swabs that dry out lips.
- Use an oral gel (Oral Balance^{MD}) and/or spray to create artificial saliva.

The doctor can prescribe medication to relieve oral pain from: ulcers, white plaques, gingivitis, cracks in the tongue...

4.4 ORAL CARE (cont'd)

WHAT TO DO?



HOMEMADE MOUTHWASH RECIPE

**1/3 cup of water
1/3 cup of alcohol-free mouthwash
A few drops of glycerine (liquid)**

Use 3 teaspoons of this mix to gargle, three to four times a day.

P.S.: If there are crusts in the mouth, add 2 teaspoons of peroxide (3%)
to 6 teaspoons of the homemade mouthwash before use.

RECIPE FOR WHITE PLAQUES IN THE MOUTH (Oral Moniliasis/Thrush):

Use this mix as soon as the patient receives an oral moniliasis diagnosis.

Add it to the antifungal medication prescribed by the doctor.

**1 teaspoon of baking soda solution (baking soda)
2 cups of water**

Refrigerate (can be kept for one month)

Take 2 teaspoons three to four times a day.

Continue as a preventive measure.

“When came time for grooming, it was as if part of the disease was washed away with the bath water. It did her so much good. I applied an oat based cream that nourished her skin. It’s as if she was reborn every time. And, with a nice clean pyjama, the smell of the medication disappeared.”

LSTG



5

**HYGIENE
and COMFORT CARE**

5. HYGIENE AND COMFORT CARE

**WHAT
TO DO?**



Hygiene and comfort care, such as bathing, can be especially tiring for someone at an advanced stage of a disease. It may not be necessary to groom extensively each day, but it is important for the patient to feel clean and comfortable. The eyes, mouth and genitals must be kept clean. If a bath cannot be given, the patient can be refreshed with a moist cloth or by applying a hydrating lotion. So, in one single application, the patient's skin is refreshed and hydrated.

It is preferable to groom the patient half an hour after he has taken his pain medication. This way, the pain felt due to handling and movements is relieved.

Care attendants can also provide respite services for patients and caregivers during the day, evening and night if necessary. This service is provided to caregivers to ease homecare for the person at end-of-life and to prevent the exhaustion of loved ones.

Always let the patient guide you

5.1 PREVENTION OF BED SORES

WHAT TO DO?



HOW TO PREVENT BED SORES (PRESSURE SORES)

- It is important to prevent bed or pressure sores as no medication can relieve them and heal them readily at an advanced stage of the disease.
- Alternate the patient's positions in the bed regularly. The nurse or care attendant can teach you the proper handling techniques to do this.
- **Refer to the handling table on the following pages.**
- When the patient is in a sitting or half-sitting position, in bed or in a chair, stabilize his position with pillows for his back, knees and feet to prevent numbness.
- Softly apply hydrating cream to the pressure points regularly: elbow, heel, hip, seat, shoulder blades and ears. Support them with cushions and protectors.
- Clean the sheets and pillowcases with a very soft detergent. Make sure they are always clean and dry. Avoid pleats and pay attention to anything that could harm or irritate the patient: crumbs, rosaries, medals, probe tubes, pump tubes...
- Place the patient on a egg-shell mattress or therapeutic mattress, if necessary. A sheep-skin placed on the mattress protects against moisture.

A TRICK

If the ears are red, cut the shape of the ear in a sponge and put it on the sensitive ear.

WHAT TO DO?



5.2 INCONTINENCE

WHAT TO DO IN CASE OF INCONTINENCE?

- Make sure to clean and dry the genitals properly.
- To protect the skin and prevent irritations, apply a zinc-based hydrating cream such as Zincofax, Ihle paste, Barriere cream or Critic-Aid® Clear ointment.
Warning: underwear elastics, bladder drain tubes and ostomy bag ties can cause irritation.
- If the patient accepts, suggest that he wear incontinence briefs (available at the pharmacy).
- To reduce the risks of incontinence, place a commode chair (portable toilet) or bedpan right next to the bed. These can be provided by the Palliative Home-Care Society of Greater Montreal.
- To ease movements, provide the patient with a cane, walker, wheelchair or call bell. These can be provided by the Palliative Home-Care Society of Greater Montreal.
- Suggest functional aids suited to the patient's condition.

A TRICK

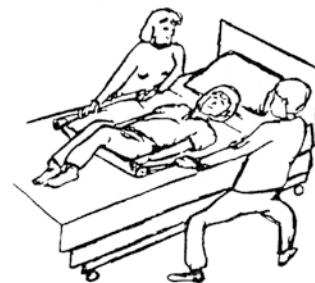
Sitting the patient in a chair with wheels like an office chair can also work well.

WHAT TO DO?

5.3 HANDLING TECHNIQUES

MOVING A BEDRIDDEN PERSON

- Make sure to place a spare sheet, folded in four, underneath the person, from mid-thigh to the shoulder, to help you carry him.
- If the person has tubes or a urine collection bag on him, make sure to clear them out of the way to avoid injuring the person.
- With the help of a second person placed on the other side of the bed, grab the drawsheet at the waist and shoulder level.
- Ask the patient to bend his knees, if he can, and to lift his head.
On three, lightly lift the person with the drawsheet.



CHANGING THE BED SHEETS WITH A BEDRIDDEN PERSON IN IT

- To make the bed more comfortable, install a foam or eggshell mattress.
- Place a plastic sheet (a large open garbage bag can also work) directly on the mattress before installing the sheets.
- Place a drawsheet, folded in four, in the middle, on top of the bottom sheet, at the hip and shoulder level.
Use this sheet to lift the bedridden patient.

A TRICK

*As a last resort, use a large
but very soft towel... just out of the drier!*

5.3 HANDLING TECHNIQUES (cont'd)

MOVING THE PATIENT FROM THE BED TO THE CHAIR

- Help the patient to sit, their legs hanging on the side of the bed and their buttocks as close to the edge of the bed as possible, as the distance between these two positions must be minimal. If possible, ask the patient to rest their feet on the floor.
- Stand in front of the patient, one foot between theirs. Use your feet or knees to block those of the patient and prevent any falls.
- With your back straight, bend your knees and bend toward the patient. Place your arms under their kidneys and take their waist or use a drawsheet or towel as a transfer support.
- Ask the patient to wrap their arms around your back and not your neck.
- If the patient is too weak to do this, place the sheets on your shoulders and place their head on your shoulder.
- Rock them gently to get some momentum and count to three.
- In one motion, get up, pivot toward the chair and place the patient gently in it while flexing your knees.



WHAT TO DO?

5.3 HANDLING TECHNIQUES (cont'd)

MOVING A PATIENT FROM A CHAIR TO ANOTHER CHAIR OR A BED

Adopt a good starting position:

- Spread your feet and place them in the direction you are headed.
- Bend your knees.
- Keep your back straight.
- Bring the person as close to you as possible.
- Make sure to have a firm grip.
- Ask the patient to wrap their arms around your back and not your neck.
- Use your feet and knees to block those of the patient and thus prevent any falls.
- Use your thigh muscles (not your back muscles) to a maximum.
- Slide the patient rather than lifting them.
- Always apply the brakes if you are using a wheelchair.



WHAT TO DO?



5.3 HANDLING TECHNIQUES (cont'd)

HELP WALKING

- Free the path of any obstacle. Have a wheelchair or chair closeby in case the patient needs to rest while walking from one room to another. Make sure they are wearing slippers or non-slip footwear.
- Always offer to help the patient on their weaker side so that they can use their stronger side more often.
- If the patient uses a cane, make sure they are holding the cane on their strong side, which will help keep the weight on the side that can support it.
- Stand beside the patient to help him walk, remaining slightly behind, facing the same direction as them. If necessary, remind them to stand straight and to look ahead rather than down.
- Use your arm closest to them to support their back at the waist. Your other hand can be used to stabilize their shoulder or armpit for added support..
- Do not let the patient hold your hand or hold onto you. This will prevent you from having to support them should their knees buckle.

WHAT TO DO?



5.3 HANDLING TECHNIQUES (cont'd)

ACCESSORIES

- A commode or portable toilet placed near the bed for patients who cannot stand or who are too weak to walk to the bathroom.
- A bicycle horn or call bell tied to a string beside the bed to allow the patient to ask for help if necessary.
- A bath bench placed in the bath helps patients who have trouble standing for a long period of time.
- A hand-held shower nozzle allows the patient to take a shower sitting down while being able to control the water flow.
- Solid grab bars attached firmly to the wall and bathtub to ease access to the tub.
- A raised toilet seat and handrails as armrests attached to the toilet to help the patient sit down and get back up.
- The wheelchair allows patients who are very weak to get around. It also allows them to go outside; however, an office chair on wheels can also work well.
- A patient who is weak or has problems keeping their balance can use a functional aid, such as a walker, for added support.
- Certain patients need oxygen. Electrical concentrators can be rented and are serviced by the rental company.

“It’s already painful enough to have this disease, do they need to be constipated and feel nauseous too? Do they really need that? I would encourage my friend to eat foods containing fibre. She also drank prune juice and took stool softeners as prescribed on a daily basis, which helped to regulate her system.”

LSTG



**DISCOMFORT
and SYMPTOMS** **6**

WHAT TO DO?



6.1 CONSTIPATION

Sleeping more and more and being gradually confined to his chair, the patient becomes sedentary.

Constipation is a universal problem that comes about with the evolution of a disease, when taking painkillers and with a reduction in activities. Constipation is a direct result of the pain medication.

- Always keep taking the amount of medication prescribed to relieve the pain efficiently although it can have side effects such as constipation, dryness of the mouth, etc.
- Even though the patient is barely eating, they will feel better if their intestines are functioning. As a preventive measure, take a stool softener daily (such as Colace or a laxative like Sennoside or Senokot that have a softening and laxative effect).
- Promote foods that activate the intestines: prune juice, bran bread or muffin, 1 to 3 tablespoons of bran cereal (All Bran), applesauce, yogurt... And drink lots of water.
- If the constipation lasts more than three days, use glycerine suppositories. In some cases, the nurse or doctor can recommend an enema.

LAXATIVE RECIPE

1 cup of All-Bran
1 cup of prune juice
1 cup of applesauce

Take 2-3 tablespoons, two or three times a day.
Refrigerate in a glass container.

WHAT TO DO?

6.2 DIARRHEA

Diarrhea can be chronic but can also occur suddenly in the hours or days following certain treatments or after taking certain medications.

- To avoid dehydration, drink fruit juices or soft drinks such as Seven-up, club soda or ginger ale. It is advisable to remove the gas from these drinks by transferring the contents several times. Drink these liquids at room temperature. By drinking in small gulps, many times a day, it will be easier for the patient to take in at least 125 ml of liquid.
- Avoid fermented, fried or very sugary foods and all stimulants like caffeine, alcohol or prune juice.
- Promote the consumption of foods rich in potassium and soluble fibres that bulk stools such as applesauce, pears, peaches, bananas, pearl barley, oat bran and cooked carrots.
- If the diarrhea is continuous, stick to strict liquid diet for 12 to 24 hours.
- If the diarrhea persists, stop using all laxatives until the situation returns to normal and avoid all diarrhea medication that is not prescribed by the doctor or before consulting the nurse.
- We can suggest that the patient wear incontinence briefs. Applying zinc-based protective creams such as Barrière cream is recommended to prevent and relieve skin irritation.

NOTE

Diarrhea can indicate fecal impaction (plug of stool in the rectum), which is referred to as an overflow diarrhea. This problem must be flagged to the attending nurse or physician who will determine whether enema or manual extraction should be performed.

HYDRATION RECIPE

2 cups of unsweetened pulp-free orange juice
6 cups of water boiled for 5 minutes
1 teaspoon of salt

Mix and refrigerate.

WHAT TO DO?



6.3 NAUSEA AND VOMITING

The disease itself, the medication or an empty stomach can cause nausea and vomiting, as well as radiotherapy, chemotherapy, anxiety, certain smells...

- Plan nausea medication (antiemetic) such as Gravol, in pill or suppository form, available without a prescription at the pharmacy.
- If the nausea is intermittent, we recommend taking nausea medication (Gravol) half an hour before taking a painkiller.
- If the nausea is constant, it is important that the nausea medication be taken regularly, without stopping it, even if the symptoms subside.
- If the nausea or vomiting is predictable (relatively set moments), take the nausea medication approximately one hour before the usual appearance of the symptoms.
- If the patient has vomited or has an accumulation of foods or liquids in their stomach, it is useless to give them nausea medication.

WHAT TO DO?

6.3 NAUSEA AND VOMITING (cont'd)

- Daily oral hygiene helps to prevent nausea.
- Rest before eating, promote calm after meals and avoid rapid head movements.
- Fasting is not recommended: hypoglycemia (low blood sugar) can increase nausea. If the patient tolerates them, small meals will help to control the nausea. Promote salty foods rather than sugary ones.
Eating crackers or pieces of toast absorbs acidity and fills the stomach.
- Provide a calm environment and aerate living spaces.
- Avoid foods with strong smells. Good options include: chicken soup, rice, pasta, cottage cheese and fruits, hard-boiled eggs, meat/tuna/egg sandwiches, pancakes, crackers and light cheese, canned pears/peaches.

“My friend experienced nausea and vomiting regularly. She tended to avoid eating. I encouraged her to take nausea medication regularly and to eat, first and foremost, even if it was only crackers.”

WHAT TO DO?

6.4 FEVER

Normal body temperature is 37.2 °C in the morning and 37.7 °C at night. Anal temperature (in the rectum) is usually 0.6 °C higher.

When the patient's oral temperature exceeds 38 °C (100 °F) and anal temperature exceeds 38.5 °C, they have a fever. At first, the person starts shivering and then their skin becomes hot and humid.

It is important to take the temperature and to note the degree, time of day and whether the temperature was taken orally or anally. It is important to rinse the thermometer under cold water and to shake it gently for the mercury to return to 35 °C (95 °F).

“She'd always have to start over. My friend never jotted down the temperature and the time at which it was taken, which didn't help the nurse to identify the cause of these fevers.”

WHAT TO DO?

6.4 FEVER (cont'd)

- Soothe the chills by covering the patient. Once soothed, remove the covers. Avoid rubbing alcohol and wash the person with lukewarm water.
- Ensure proper air circulation by opening the window or placing a fan.
- Offer the patient something to drink as often as possible if they can tolerate it.
- Clean and dry clothes and sheets will make them more comfortable.
- Give Tylenol (tablet) or Abenol (suppository) every four hours. They are available at the pharmacy.
- Re-take the temperature one or two hours after having given the medication.
- The patient at end-of-life may never have a normal temperature. It is then important to monitor the person's comfort level and not the temperature curve.

*Complete the monitoring form provided by the nurse from the
Palliative Home-Care Society of Greater Montreal.*

6.5 FATIGUE AND REDUCED ENERGY

WHAT TO DO?

Fatigue is a feeling of weariness and exhaustion accompanied by a sense of physical weakness and a lack of energy. The main causes of fatigue felt by the cancer patient include:

- The anemia resulting from the effects of the cancer or its treatment
- Inadequate intake of proteins and calories in the person's diet
- Change in sleep and rest habits
- Inactivity, discouragement, anxiety and fear
- Certain cancer treatments: chemotherapy – radiotherapy



“Reduced energy levels were cyclical. They would often occur after chemotherapy treatments. But certain drugs, like cortisone, would actually make her very energetic, even preventing her from sleeping. She had a good attitude about her changing energy levels. She would lie down willingly when she felt she had less energy.”

LSTG

NOTE

It is important for the patient not to overexert themselves.

WHAT TO DO?

6.6 LYMPHOEDEMA (edema of the upper and lower limbs)

Edema is caused by an obstruction of the lymphatic vessels (lymphatic circulation). Localized clogged areas appear in certain parts (feet, hands...) of the body. The skin becomes stretched and swollen because of the excess liquid in the subcutaneous tissues.

- A gentle massage on the surface of the skin works very well. It circulates the liquid that has accumulated while promoting the movement of the proteins contained in this liquid.
- Support hose and elastic bandages have the same effect. They must, however, be taken off before going to bed and be put back on before getting out of bed in the morning. This technique is not more efficient than gentle massages
- Activate the limb affected as often as possible, one to three times a day. Rest with the swollen limb elevated.
- Diuretics (medication to reduce swelling) can sometimes help. In case of heart or venous complications, inform the nurse or doctor.
- Avoid all activities that can cause injuries.

Applying a hydrating cream overnight helps to improve the skin's elasticity.

Example: Keri Lotion or Aveeno, but avoid scented creams.

“My God did she have this often! She'd lie in the lazy boy with her legs up in the air. She used to say that she had the feet of a cabbage patch doll!”

WHAT TO DO?



6.7 CONFUSION

This confusion can stem from the effects of the medication or be a symptom of the disease's progression. The nurse can ask the attending physician to re-adjust the medication. If the confusion persists, increased presence by the patient's side may be necessary. It then becomes the caregiver's decision to: keep the patient at home or have them admitted to the hospital if the responsibility becomes too great or if the patient so desires.

- Being gentle is always beneficial.
- It is useless to want to correct confused statements: simply accommodate the verbal and physical behaviour, speak calmly while staying beside the person and help them get to where they seem to want to go: room, bathroom...
- Gently bring back the person to reality when deemed appropriate.
- And take whatever time is needed...

“The first time I came face to face with her confusion I was caught off guard. Standing next to the bed, my friend seemed lost, not knowing where to go in the house. She felt attacked by any move I made. What can I do or say? At first, I thought that this irritation was directed towards me. The nurse from the Palliative Home-Care Society of Greater Montreal told me not to take it personally; confused patients often react this way.”

WHAT TO DO?

6.8 AGITATION

Agitation is not necessarily a symptom of confusion. This disruption can occur especially at the end-of-life. There are several possible causes:

- lack of oxygen
- breathing difficulties
- pain
- anxiety
- urinary retention or constipation
- reaction to a medication
- fear towards death

What to do:

- Increase the medication to relieve the patient.
- Promote a calm environment by reducing noises and the volume of music, dimming lights and reducing the ringer on the phone.
- Reassure the patient by telling them that you are there to support and accompany them.
- Ask the person if they wants a friend or family member to come visit.

"At one point, my friend seemed very uncomfortable. I thought she was resisting the fact that I had put incontinence briefs on her. She was actually displaying suffering rather than discomfort. By rectifying the dosage of her medication, she felt better within minutes."

“Haunted by the thought of having breathing problems, my friend was reassured as soon as an oxygen machine entered the house, even though she only used it for a few hours. She never used the machine again, but knew that in case of emergency, there was oxygen in the house.”

LSTG

WHAT TO DO?



6.9 BREATHING DIFFICULTIES

For the patient and their loved ones, pain and respiratory difficulties are great sources of concern and anxiety. Shortness of breath can be caused by the disease, anxiety or the patient's extreme weakness.

Two types of respiratory problems can occur:

DYSPNEA: This feeling of oppression can cause rapid breathing, coughing, anxiety, panic and paleness. Functional limitations can eventually lead to a loss of independence.

APNEA: This occurs when someone stops breathing for 10, 15 and even 35 seconds and then starts breathing again

- Ask the patient to choose the most comfortable position to help them breathe more easily: sitting position, elevation of the headboard or slight inclination, back resting on pillows, elevation of the arms supported by pillows...
- Encourage the person to move more slowly to conserve energy. If possible, limit or eliminate the use of stairs and place them near a window to enjoy the fresh air.
- Install a fan to promote air circulation in the room and a humidifier if necessary, if the room is too dry.
- If the patient's breathing difficulties seem to increase, inform the doctor or nurse. Administering oxygen (O₂) or certain medications can clear the respiratory tract and reduce anxiety related to shortness of breath.

"Choose the most comfortable position"

“You come to know your body. From one treatment to the next, she knew the cycles of the side effects, which reassured her. She’d learned to tame the side effects of these treatments; they weren’t a surprise to her anymore.

For all the treatments, my friend would always tell me that I didn’t need to come with her. She didn’t want to bother me. Once home, it was incredible how she could appreciate the fact that I’d come with her. It was a privilege for me to be able to support her through this ordeal.”

LSTG

7

TREATMENTS



7.1 RADIOTHERAPY

The word radiotherapy usually means “x-ray therapy”. By knowing, in advance, what the general side effects are such as fatigue, skin problems and loss of appetite, the patient can easily overcome them.

- Fatigue: the human body consumes more energy than usual during radiotherapy treatments. It is important that the patient not overexert themselves.
- Skin problems: the skin tends to redden, peel or scale. It is important not to rub or scratch the affected areas and to cover them with cotton, loose and soft clothing. Avoid soaps, perfumes, medications or other substances that can reduce the efficiency of the treatment. If the skin tends to crack or become humid or if dark blisters start to form, inform the doctor. Avoid exposing the treated areas to sun and wind as they are sensitive.
- Loss of appetite: a patient's appetite can diminish during radiotherapy treatments.

CHECKLIST DURING THE TREATMENT PERIOD:

- Do not erase the pencil marks indicating the areas of the body to treat with radiotherapy.
- Do not wash the treated area with soap; instead blot lightly with lukewarm water only.
- Do not apply cream, ointment, powder or Vaseline without the prescription of the radio-oncologist.
- Do not shave the area treated except with an electric razor.

CHECKLIST AFTER THE TREATMENT PERIOD:

- Do not wash the treated area with soap; instead blot lightly with lukewarm water for fifteen (15) days.
- Do not wear a bra for up to three (3) weeks after radiotherapy of the breast area and do not shave the armpit area prior to the post-treatment visit.

7.2 CHEMOTHERAPY

The word “chemotherapy” comes from the words “chemistry” and “therapy”. Medications are used to fight the cancer.

A normal diet helps to stabilize the patient’s weight and fight fatigue. Foods rich in protein help the body to regain its strength quickly.

Chemotherapy affects each person differently. Some people may only feel some side effects or none at all. The treatment’s efficiency is not at all related to the side effects felt by the patient.

If the following side effects appear, call the doctor or nurse:

- A fever of more than 38 °C (100.4 °F) or shaking chills
- Unusual bruises and bleeding
- Pain at the point of injection or near it
- Shortness of breath
- Ulcers or inflammation of the mouth (rinse the mouth often with baking soda)
- Irritation of the mouth or throat
- A metallic or different taste in the mouth

The effects of chemotherapy and radiotherapy are noticeable. Some people may only feel mild side effects and may not have to change their daily activities. Others may be more affected and have to change their activities significantly. Whatever the case, it is important to know that the adverse effects almost always disappear at the end of the treatment.

Caution: Never give patients aspirin or medications containing aspirin during chemotherapy treatments.

They can affect blood platelets; however, Tylenol can be taken to relieve some of the pain. For more information, contact the nurse at the Society.

A close-up photograph of a man lying in a hospital bed, wearing a blue and white patterned gown. He has an oxygen tube inserted into his nose. A woman with dark hair, wearing a light-colored top, is leaning over him, holding his hands. The background is blurred.

8

ADVANCED STAGE *of the* DISEASE

8. ADVANCED STAGE OF THE DISEASE

It is important to know and understand the changes that occur during the weeks or days prior to death. This knowledge does not prevent the caregiver from feeling doubt and helplessness and to wonder what the best ways to help the patient are. The nurses of the Palliative Home-Care Society of Greater Montreal can support the caregiver throughout the care trajectory.

Main warning signs

- Lower blood pressure
- Cold extremities
- Rapid, slow or irregular breathing
- Noisy bronchial gasps (the patient's weakness prevents him from coughing)
- Rapid pulse
- Major weakness
- Drowsiness, lethargy (deep and continuous sleep)
- Increasing lack of interest towards loved ones
- Very reduced mobility
- Premonitions and dreams about death

8. ADVANCED STAGE OF THE DISEASE (cont'd)

WHAT TO DO?

- At this stage of the disease, the patient often does not feel hunger. They are sometimes even unable to swallow liquids.
- Moisten the mouth with water every 10 to 15 minutes with a very fine spray, a syringe (without needle) or sponge sticks to provide the patient with a feeling of well-being.
- If the patient makes hoarse sounds suggesting that he is choking, inform the nurse, who can administer subcutaneous medication. The doctor can also be reached at all times if necessary.
- Providing a soothing atmosphere: the softness of touch and voice, non-verbal communication takes on greater meaning in this context.
- Avoid fatigue caused by numerous and lengthy visits.
- Avoid talking about the patient as though they are not there.



8.1 JOURNEY TOWARDS DEATH

The Palliative Home-Care Society of Greater Montreal team that completed this guide was inspired by a text on the journey towards death completed by the palliative care consulting team at the Montreal Jewish General Hospital, namely Nurse Barbara Karnes and Doctor Michael Dworkind.

When death becomes imminent, the person usually falls into a coma and stops responding to the stimuli from the environment. How we deal with death depends on the fears we had during our lifetime, the intensity of what we lived and our willingness to let go. Fear and the feeling of not having finished what we started are two factors that have a significant bearing on our reluctance to welcome death.

The separation of the body becomes complete when the patient stops breathing. What seems to be the last breath is often followed by one or two long spaced out breaths.

The person has entered a new world and a new life.

8.1 JOURNEY TOWARDS DEATH (cont'd)

SUMMARY OF THE JOURNEY TOWARDS DEATH

One to three months before the patient's death

- Withdrawal from loved ones and the rest of the world
- Less communication

One to two weeks before the patient's death

Behavioural changes

- Disorientation – agitation
- Imaginary conversations – confusion
- Tugging at clothes and sheets

Physical changes

- Lower blood pressure, faster or slower pulse
- Change in skin colour (pale or blue tinge)
- Increased sweating and fluctuations in body temperature (fever/hypothermia)
- Irregular breathing and congestion
- Sleep (with response to stimulation)
- Fatigue and heaviness
- Refusal of food, minimal absorption of liquids

Days or hours before the patient's death

- Intensification of the signs observed over the last week or two
- Renewed energy
- Lower blood pressure
- Glazed, watery and semi-closed eyes
- Irregular breathing (stops and starts over)
- Agitation or inertia
- Purplish knees, rosacea-prone hands and feet
- Weak pulse or pulse that is hard to evaluate
- Decreased urination
- Wet or soiled bed

Minutes before the patient's death

- Laboured breathing or periods of apnea

“While heading to the room to check on Ginette, a great silence surprised me. As if she’d waited for me to leave, she’s increasingly short of breath. She passes away as softly and slowly as a candle blowing out. I don’t see any sign of suffering on her face. There’s only silence. Time stops.

I look at her and take her hands in mine to say goodbye. I’m extremely relieved, for both of us. She’s at peace. I take the time to tell her that I love her and not to worry about me: everything will be fine. I stay beside her for quite some time. I can enjoy this time now that it’s mine. As I say goodbye, I tell myself that it’s crucial for me to let her go. I feel her presence so much in the room: her soul is palpable.”

LSTG

A photograph showing a woman with blonde hair, wearing a light-colored ribbed sweater, gently holding the head of a man with a beard and mustache who is lying in bed. The man is resting his head on a white pillow. The scene conveys a sense of care and intimacy.

DYING AT HOME

9

9.1 DYING AT HOME

Death can occur gently, so gently in fact that family and friends may not notice it right away. When the patient stops breathing and his death is confirmed, certain things must be done. These actions will be much easier if the attending physician has already made arrangements with the immediate loved ones.

- The loved ones or patient at end-of-life must make arrangements with the doctor. For example, the patient and doctor must sign a non-resuscitation form, which must be kept in the patient's home to prevent any person called during the passing of the patient to perform resuscitation if not so desired by the patient or his family.
- Once the patient has passed, family and friends can come together, without prejudice or danger, to say goodbye and call any missing relative to spend a few last intimate moments with the patient.
- Once the family has mourned together, call the attending physician or his replacement with whom the agreement was previously made to advise him of the patient's death. A doctor must go to the patient's home to confirm the death legally and medically and complete the death certificate (SP.3). The doctor, a nurse or a member of the patient's family or caregiver removes the catheters and butterfly needles.
- If the doctor cannot come to the patient's home, dial 911 and mention that a palliative care patient has died.
- Once the doctor has confirmed the death, the loved ones ask the funeral parlour to have the body transferred.
- The members of the family can groom the deceased patient.

9.1 DYING AT HOME (cont'd)

Shortly after the death of a loved one, some people may still feel their presence and feel the need to stay in the room, recall certain memories, express the affection they felt for the deceased or come together in silence.

When the time comes, you will know that it is time to let your loved one go and to move forward, take care of yourself and grieve in your own way for the loss of your loved one.

During the grieving period, you will learn to live with the memory of the deceased. Be empathetic and patient with yourself. It takes time and courage to get over the death of a loved one.

To help you get through this period, we can provide you with bereavement services for you or a family member. These services include:

- Meeting with the psychologist from the Palliative Home-care Society
- Support groups on grief with exchanges hosted by a professional grief counsellor
- Monitoring, in person and over the phone, by trained volunteers
- Referrals to specialized resources

Our thoughts are with you!

Do not hesitate to ask for the help you need and to contact our
Family Support Service at 514-272-7200 ext. 225

SPECIALIZED RESSOURCES FOR GRIEF

MAISON MONBOURQUETTE

Help for grieving families, facilitate access to bereavement monitoring services
150 De L'Épée Street
Outremont, Quebec H2V 3T2
Telephone: 514 523-3596 Toll-free: 1 888 423-3596
infos@maisonmonbourquette.com

ORDRE DES PSYCHOLOGUES

1100 Beaumont Avenue, Suite 510
Mont-Royal, Quebec H3P 3H5
Telephone: 514 738-1881 Toll-free: 1 800 363-2644
info@ordrepsy.qc.ca | <https://www.ordrepsy.qc.ca>

TEL-JEUNES

P.O. Box 186, Place d'Armes Branch
Montreal, Quebec H2Y 3G7
Telephone: 514 288-1444 Toll-free: 1 800 263-2266
teljeunes@generations-familles.com

ORDRE PROFESSIONNEL DES TRAVAILLEURS SOCIAUX DU QUÉBEC

255 Crémazie Boulevard East, Suite 520 (CRÉMAZIE METRO)
Montreal, Quebec H2M 1M2
Telephone: 514 731-3925 Toll-free: 1 888 731-9420
info.general@optsq.org | <http://www.optsq.org>

LINE ASSELIN, PSYCHOTHERAPIST/GRIEF COUNSELLING

École de vie et de ses deuils
Telephone: 450 446-5419
info@lineasselin.com | www.lineasselin.com

SERVICE PSYCHO-POP

Service Psycho-Pop is a non-profit organization that offers counselling services whose prices are established according to the person's family income. These services are provided by quality and experienced professionals who are members of a recognized professional body (CITRAC). The services provided include individual, couple and children/teenager meetings.
Telephone: 514 990-9306 | <http://servicepsychopop.com>

ALFRED DALLAIRE MEMORIA

Bereavement service
<http://www.memoria.ca/funeralles/deuil.html>
Telephone: 514 277-7778

JOHANNE DE MONTIGNY

Psychologist in the Palliative Care Unit at the Montreal Jewish General Hospital, McGill University Health Centre.
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*People are like stained glass windows.
They sparkle and shine when the sun is out,
But when the darkness sets in,
Their true beauty shines through.*

*The most beautiful people are those
Who have known suffering,
Known struggle, known loss,
And have found their way out of the depths.*

*These persons have an appreciation,
A sensitivity and an understanding of life
That fills them with compassion, gentleness
And a deep loving of their fellow man.*

Quotes from Elizabeth Kubler-Ross



**Taking care
of families
since 1855.**

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