FONDATION PALLIACCO DES SOMMETS

Palliative Home Accompaniment Services

Training program for palliative care volunteers

VOLUNTEER MANUAL

Family name: ______________________ First name: ______________________

Telephone number ________________________

Fall 2007

THE PRINTING OF THIS MANUAL HAS BEEN FINANCED BY

CLUB ROTARY MONT-TREMBLANT

A large portion of the didactic material in this manual has been taken from a document entitled « Programme de formation destiné à des bénévoles en soins palliatifs – Manuel des bénévoles » by Champagne, M., Foucault, C., Mongeau, S., Viau-Chagnon, M. (2006), a project financed by the PalliAmi Foundation, Hôpital Notre Dame de Montréal..

Note: The feminine gender has been used in a generic sense in this document to refer to the accompaniment volunteer in order to simplify the text.

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INTRODUCTION

OBJECTIVES

1. **Understand the objectives of the course.**
2. **Meet with other members of the group and learn the rules of the training course.**
3. **Explore the motivations and expectations of being a volunteer**.

OBJECTIVE 1

Understand the objectives of the course.

The goal of this training program is to give palliative care volunteers the knowledge, the ability and the approach to assist palliative care ill persons and their immediate family in a respectful, attentive and safe manner.

At the end of the training the participants will be able to:

- Apply the philosophy of palliative care and the policies of PALLIACCO when working as a volunteer.
- Respond to the emotional, physical, social and spiritual needs of the ill person and immediate family within the limits of a support role.
- Communicate adequately with the ill person and immediate family as well as with other care givers.
- Have a basic understanding of the illnesses most often fatal in adults and their effects.
- Apply strategies that can help comfort the ill person.
- Understand one's own attitudes and beliefs with respect to death and grief.
- Demonstrate a basic understanding of grief.
- Understand one's own motivations and needs as a volunteer.

OBJECTIVE 2

Meet with other members of the group and learn the rules of the training course.

Participant responsibility with respect to the training program:

- Inform those responsible of any delay or absence.
- Take any course missed in a later training program.
- Complete the readings to prepare for the training sessions.
- Participate actively in the group.

Rules of group activity:

These rules are very important and are designed to make every participant feel confident, safe and relaxed within the group. As well, these rules reflect the comportment that is essential in volunteers who assist people at the end of their life.

- Listen in an attentive manner.
- Respect the confidentiality of the information shared with others.
- Respect others and don't interrupt when others are speaking.
- Do not pass judgment on what others say.
- Ask questions of clarification to help other participants better express their ideas.
- Be ready to honestly engage in the training process and to examine one's life and question some decisions or orientations taken in the past.
- Have self-respect: if a participant is uncomfortable with a suggested activity, she does not have to participate.

OBJECTIVE 3

Explore the motivations and expectations of being a volunteer.

<u>Self description</u>: (write down 2 or 3 things that describe yourself)

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Motivations to become a volunteer

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My expectations with this type of volunteer activity

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CHAPTER 1 - PALLIATIVE CARE

OBJECTIVES

1. **Explain the origin and philosophy of palliative care.**
2. **Explain the two principle components of palliative care.**
3. **Outline the existing palliative care services in the Mont-Tremblant region.**

OBJECTIVE 1

Origin and philosophy of palliative care.

EXERCIZE

How would you like that a person dear to you be treated and accompanied if he/she became terminally ill?

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Palliative care services were introduced into Québec in the 1970s to assist people with incurable diseases. The concept of offering care, which stresses comfort and not cure, was started in England where Cicely Saunders opened the first institution offering palliative care at St. Christopher's Hospice. Dr. Balfour Mount who worked with Cicely Saunders brought the movement to Canada and has expanded the concept within Canada as the Chair of Palliative Medicine at McGill University in Montreal.

Definition and Goal of Palliative Care

Palliative care describes a combination of services offered to the terminally ill and immediate family to provide the best quality of life possible. The goal is to lessen the pain, control the symptoms of discomfort, and offer support, care and companionship.

A multidisciplinary team usually provides these services that include a physician, nurse, social worker, psychologist, pharmacist, respiratory therapist and music and art therapist among others.

Essential Values Attributed to Palliative Care

(Palliative Care Policy, Santé et Services sociaux, Québec 2004)

- Value of the person.
- Value of life.
- Death is inevitable.
- Confidentiality.
- Compassion.
- Respect for the ill and immediate family.

OBJECTIVE 2

The two principle components of palliative care.

1. **Medical component:** replace curative treatment with treatment to control and manage pain.
2. **Psychosocial component:** provide multidisciplinary services to reduce suffering and provide emotional, physical, psychological, social and spiritual support to the terminally ill and their caregivers.

Palliative care vs. palliative care residence.

- Palliative care treatments may last days or years.
- In order to be accepted in most private palliative care residences in the Province of Quebec a ill person needs a medical prescription specifying that his/her life expectancy is less than three months. Ill persons' average stay in Quebec private palliative care residences varies between 16 and 21 days.

OBJECTIVE 3

Palliative care services in the Mont-Tremblant region.

Palliative care is not a place but a philosophy. Therefore, the approach can be offered in different places such as: the home, a hospital, residential centers for long-term care and palliative care centers.

Palliative care services in the region.

- Centre hospitalier de Ste-Agathe – 8 beds in a dedicated section and other beds in the hospital.
- Mont-Tremblant GMF offers office consultation and home visits by physicians from the medical center in St.Jovite for care and pain management.
- Ste-Agathe GMF.
- Physicians in private practice or as part of the CLSC network.
- St.Jovite CLSC offers office consultation and home visits in support of the GMF and physicians in private practice.
- Centre hospitalier de l'Annonciation – 2 beds and sitting room plus a department of geriatrics.

PALLIACCO works in concert with the above services.

Why services in the home?

1. A majority of people want to die at home or stay there as long as possible.

2. Government policy encourages home care.

CHAPTER 2 - PALLIACCO

Palliative Home Accompaniment Services

OBJECTIVES

1. Describe the history, the mission, the services and philosophy of care of PALLIACCO.
2. Provide information on the operation of PALLIACCO and on the role of the other palliative care providers in the health network in the region.

HISTORY

- The owner of the boutique Daniel Lachance, Daniel Lachance, dreams of a nine bed Palliative Care Center in Mont-Tremblant.
- Daniel equips skiers who count their vertical miles at Tremblant in order to raise funds, as is done in a walk-a-ton.
- A benchmarking study is conducted to assess the feasibility and the need for a nine bed Palliative Care Center in Mont-Tremblant.
- Conclusion of the study: what is needed is home accompaniment services.

OUR MISSION

To provide a better quality of life to people suffering from a fatal illness and their family caregivers.

OUR SERVICES

- Counseling for the terminally ill and their immediate family.
- Accompaniment in the home for the terminally ill and immediate family.
- Respite and support for the immediate family members.
- Referral services to help the terminally ill find the health professionals they need.
- Support groups for the terminally ill and their immediate family.
- Individual and group support for the immediate family experiencing grief.
- Training, education and leadership in palliative care.

Note 1. These services are offered in both French and English.
Note 2. These services are offered in concert with those provided by the CSSS, the physicians and pastoral services of the diverse religious communities in the region.

OUR VISION

In cooperation with our palliative care partners, our vision is to offer top quality palliative care services at home to ease the physical, emotional, moral and psychosocial suffering of those who have a terminal illness and help them live with their illness with serenity and dignity.

OUR VALUES AND PRINCIPLES

- **Priority given to the needs of the ill person and immediate family**
- **Compassion**
- **Reliability**
- **Confidentiality**
- **Competence and professionalism**
- **Ethical conduct**

EXPECTED BENEFITS FROM OUR SERVICES

1. Reliable emotional and social support for the terminally ill and immediate family.
2. Ill people and family caretakers being listened to.
3. Respite for the immediate family.
4. Greater serenity for the ill person and immediate family.
5. Possibility for a greater number to die at home.
6. Reduction of the time in hospital for the terminally ill, and reduction of curative medications.
7. Reduction of costs to the health system.

ADMISSION CRITERIA FOR OUR SUPPORT SERVICES

The ill person

1. Has been diagnosed with a terminal illness.
2. Understands the nature of his/her illness and the prognosis.
3. Accepts our support services.

Clients are referred to PALLIACCO by their physician or the CLSC.

The professionals and volunteers of PALLIACCO work in cooperation with a multi disciplinary team to assure homecare service: physicians from GMF, nurses, social workers and other care givers from the CLSC as well as pastoral support.

CHAPTER 3 - THE ROLE OF THE VOLUNTEER

OBJECTIVES

1. Define the role of a volunteer.
2. Define the meaning of the palliative care volunteer.
3. Identify the limitations of a volunteer's role.
4. Describe the responsibilities of a volunteer.
5. Describe the health and safety policy to follow as a volunteer.

OBJECTIVE 1

The role of a Volunteer

The role of a volunteer within a palliative care team is primarily to listen and to be available.

1. Volunteers are part of the palliative care team to help professionals provide the best quality of life for the terminally ill and their immediate family.
2. They come from different sectors of the community, and possess different talents and interests, just like the people they care for. This diversity of experience and ability is helpful in developing rapport with the dying, their immediate family and other members of the team.
3. They represent a link to the outside world, and in a way symbolize the support from the community.
4. Their contribution in supporting the terminally ill and their immediate family helps ease the work of the health professionals allowing them more time with ill persons who need more complex assistance.
5. They offer their presence and their time in a way which can rarely be offered by professionals.

OBJECTIVE 2

Description of volunteer care giving in palliative services

The notion of being present, listening, showing respect for another, and respect for the rhythm of life of another, are the key elements of palliative care.

The word " to accompany " refers to three of these elements: "to join with someone or to go where someone else goes and at the same time". At life's end it means: "to accompany a sick person, to cloak or envelop and provide him/her with the moral and physical support needed to face death". The word "to envelop" implies not only being present but also being empathetic, attentive, supportive. Another aspect of the definition is recognition of the terminally ill for what he/she has been and has accomplished in his/her life and also as a person who is a part of the community in spite of his/her illness. In summary "to accompany" is to be very attentive and supportive of the individual at life's end and to understand and respect his/her uniqueness.

OBJECTIVE 3

The limitations to the role of the volunteer

1. A volunteer is not to offer any form of intervention or therapy for the purpose of changing or converting the terminally ill person or members of his /her family.
2. The volunteer is not a therapist and she is not to propose or apply a plan of care for the ill person.
3. She is not a spiritual counselor. She is not to share her personal beliefs or try to convert people at the end of their lives.
4. She does not give advice except when acting within her role. For example advising the person to discuss a problem with their nurse.
5. She never provides medical care.

6. She is not a friend; otherwise she will not be objective or act with equanimity. One chooses one's friends but one does not choose the people one will accompany as they die. The volunteer must show great sensitivity and maintain a sense of detachment. This reserve will allow a certain rapport to develop, yet maintain emotional perspective.

The volunteer must act within these limitations to ensure that she can look and listen and make suggestions while not being part of the emotional bond of the family.

OBJECTIVE 4

The responsibilities of the volunteer.

Before visiting a home:

- Agree with the Nurse on the hours to visit and advise her as soon as possible if there will be a change.
- Make certain that your hands are washed and that you are clean and tidy and do not wear perfume, as people who are ill are sensitive to odors.
- Being dressed properly.

During the visit

- Be attentive and comforting to the ill person and immediate family, responding to their emotional, social and spiritual needs within your capabilities.
- Recommend possible changes to improve their comfort.
- When requested and if capable of, stay near an ill person needing close attention (agitation, anxiety, breathing difficulties, confusion.
- Be available to help the immediate family at the time of death.
- Keep the room clean and attractive and help with any tasks recommended by the Nurse.
- Make certain that the ill person and or family members are in agreement with any changes to the room environment.
- Address the family members by their family name unless asked to use their first name.
- Ensure that everything remains confidential.
- Do not make commitments or promises that cannot be kept.
- Make certain that all pertinent information is given to the Nurse.
- Do not hesitate to contact the Nurse whenever necessary.

OBJECTIVE 5

Describe the health and safety policy to follow as a volunteer .

Health and safety policy for volunteers.

- Telephone the center to cancel your appointment if you believe you have a communicable illness.
- Turn off your cellular phone before arriving at the home.

While in the home:

- Do not undertake any activity that is within the jurisdiction of a nurse or another professional.
- Know how to operate any electrical device, such as an adjustable chair or special chair for the elderly.
- Always check with the nurse before responding to requests for food or to be moved to another location.
- Ask the nurse about the procedures to follow when visiting a ill person who is in isolation.

Chapter 4 - THE ILL PERSON: PSYCHOSOCIAL CONSIDERATIONS

OBJECTIVE

To review the emotional, social and spiritual reactions that a person will go through when learning that they have a terminal illness.

- What would be the reaction of a person from the time of the diagnosis to his/her death when he/she learns that he/she has a terminal illness

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- What would this person need during the various phases leading to his/her death?

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SMALL GROUP DISCUSSION:

GRIEF: LETTING GO, MOVING ON

Each event implies a grief

- Health begins to deteriorate and energy is less.
- Loss of hair (cancer).
- Need to stop working.
- Less money available.
- Need to be helped for personal hygiene.
- Activities are restricted.
- Death is imminent.

Grief is a multi-faceted response to loss. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social and philosophical dimensions. Common to human experience is the death of a loved one, whether it be a friend, family, or other close companion. While the terms are often used interchangeably, bereavement often refers to the state of loss, and grief to the reaction to loss. Losses can range from loss of employment, pets, status, a sense of safety, order or possessions to the loss of the people nearest to us. Our response to loss is varied and researchers have moved away from conventional views of grief (that is, that people move through an orderly and predictable series of responses to loss) to one that considers the wide variety of responses that are influenced by personality, family, culture, and spiritual and religious beliefs and practices.

GRIEF PROCEEDS BY NON LINEAR STAGES

- Denial, negation.
- Bargaining, search for magical treatments.
- Depression, despair.
- Aggressiveness, anger, rebellion.
- Acceptance.
- Serenity, hope.

POSSIBLE REACTIONS FROM THE PERSON WITH A TERMINAL ILLNESS.
The first reaction is often one of shock and then denial or a refusal to believe it. This usually indicates that the person needs time to come to terms with the reality of the diagnosis and to address the associated emotions and fears. This reaction may return as additional diagnoses are given. Once the shock subsides, the person will have a series of emotions ranging from anxiety, fear, loneliness, aggression, anger, rebellion, sadness, impotence, to discouragement, concern for the family, guilt, feeling of helplessness, hope, the desire to live life to the fullest and a need to give new meaning to his life and death.
All these reactions are normal and allow a person gradually to adapt to the new reality.
To be able to talk about it can help enormously. On the other hand, family members and friends who are not sympathetic can cause enormous distress. The physical changes can also cause emotional difficulties when the person feels unattractive to look at. Relying on others for personal needs such as washing and eating can also cause emotional stress. Some people fall back into a state of denial and pretend there is a cure. It is not the role of a volunteer to confront the person when in denial.
One also has to be sensitive to the fact that the ill person may sometime say and repeat that he/she is accepting death even if down deep he/she would do anything to avoid it and is completely scared.
In the face of death, many people want to take stock of their lives, to show affection to their family and to give thanks or to ask for forgiveness for past mistakes. Most people want to put their affairs in order by writing a will or passing on possessions. In the days before death, many wish to keep words to a minimum and communicate by touch and silence.
Not all people can accept death with serenity, some die in a state of rebellion and great anxiety.

RESOLVED AND UNRESOLVED GRIEF.

- RESOLVED: The person remains in denial, depression or aggression. The person turns in on himself or herself, pulls away from everyone and slowly dies.
- UNRESOLVED: the person accepts to change, puts his/her financial and personal affairs in order; has feelings of serenity, wisdom, joy, tenderness and gentleness with others.

Needs of the terminally ill
Bio-physical needs:

- To be informed on a regular basis and in a comprehensible manner (some prefer not to hear the whole truth).
- To participate in decisions with regard to care.
- To be relieved of pain and discomfort.
- To remain autonomous as long as possible in respect of mobility, body hygiene, eating, etc.

Psycho-physical needs:
Security and safety needs

- To feel well cared for; not left alone.
- To have faith in the competence of professionals, caregivers and family members.

Identity needs:
- To maintain a sense of one's identity and uniqueness (interests, skills, strengths, etc.).
- To keep playing his/her role in the family and the society. To maintain a good appearance and have physical contact with loved ones.
- To maintain a positive of his/her physical appearance (cleanliness, hairstyle, make-up, shaving, etc.).
- To maintain a sense of intimacy with spouse.

Needs for love and belonging:
- To feel loved and to be able to express love and affection.
- To reconcile oneself, to thank, to pardon and be pardoned, to say goodbye.

Need for esteem and consideration:
- To be treated like a human being until the end.
- To be able to speak openly and to feel understood.

Achievement and spiritual needs:
- To find meaning in life, in sufferance and death.
- To clarify one's true values and beliefs.
- To maintain a sense of hope (may take different forms as the illness progresses).

Unfinished business needs
- To reconcile oneself
- To clarify situations
- To put order in one's affairs
- To undo harm done

Sometimes the ill person may not perceive the need for certain situations to be clarified, but family members do. Examples: no will, need to appoint a power of attorney or to specify bereavement rituals to be followed.

Chapter 5 - THE ILL PERSON AND IMMEDIATE FAMILY: PSYCHOSOCIAL ISSUES

OBJECTIVES
1. To identify the reactions and needs of the immediate family when a loved one is terminally ill, be they adults, adolescents or children. Give a brief definition of anticipated grief.
2. Describe the appropriate way to help the ill person and all members of the immediate family.
3. Outline the things that volunteers should not do.

OBJECTIVE 1

To identify the reactions and needs of the immediate family when a loved one is terminally ill, be they adults, adolescents or children. Give a brief definition of anticipated grief.

Discussion in small groups of 2-4:
What can have an effect on the way a family reacts to a terminally ill loved one?

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How would the different members of the immediate family react?

What would the needs of the immediate family members be?

EXPERIENCES OF THE IMMEDIATE FAMILY
1. Overwork and exhaustion.
2. Feeling of helplessness.
3. Distress.
4. Denial and aggression.
5. Grief.
6. Ignorance of resources available.
7. Fear or reticence to use these resources.

THE WAY FAMILY MEMBERS REACT TO THE TERMINALLY ILL DEPENDS ON SEVERAL FACTORS:

- Family experiences,
- Coping skills,
- Role within the family of the dying member,
- Length of illness,
- Access or not to social support,
- Culture, values and beliefs,
- Communication skills and patterns within the family,
- Financial situation.

POSSIBLE REACTIONS OF THE ADULTS:
Recognizing that all family adults will not react the same way and may go through several stages the following may happen.

Immediately after the diagnosis:
The family could react with shock and become quite disoriented.
The most common reactions are fear and denial.
Family members may blame others, or the one who is ill, in response to their own anger.

As the illness progresses:

- Family members tend to adjust, some better than others, by taking on different duties and roles.
- Some are afraid and want to express it.
- Family members become tired, and sometimes imill person or frustrated looking after their loved one.
- Some feel guilty if they don't have the time and energy to look after others in the family.

As death approaches:

- Family members can again be in shock and disorganized.
- Some can feel useless that they can no longer help.
- Family members can have a sense of frustration or anger.
- Family members may start to grieve and this can cause anxiety, depression or pain or even a desire to be alone and deal with the grief.
- Some members of the family may overcompensate and never leave the dying person.
- All family members do not accept death in the same way, or at the same time.

NEEDS OF THE ADULT FAMILY MEMBERS

- To be considered important by the terminally ill and caregivers.
- To be kept informed on a regular basis of the condition and prognosis.
- To be able to react and express themselves without judgment.
- To be listened to, reassured and comforted that the reactions are normal.
- To feel the support and solidarity from the caregivers.
- To know how to find additional support.
- To be able to speak with other family members and feel their support.

Some family members may feel the need to have time off to regain their strength through exercise, hobbies, or just sleep.

POSSIBLE REACTIONS OF ADOLESCENTS AND CHILDREN

When a parent is ill, children sense there is a problem even when they have not been told. Sometimes they come to horrible conclusions that may be more damaging than if they had been told the truth. It is important, therefore, that parents tell their children the truth in a way that they can understand and answer their questions honestly. This will ensure a sense of trust.

Children should not be kept away from the ill family member for fear that possible changes in the physical appearance will upset them. Children can create images in their imagination that are worse than the reality. Children should be allowed to see the ill family member after being told that they will see changes in the physical appearance or additional equipment in the room.

The same is true for adolescents. It is not a given that they will understand what is really happening. It is important that they be told the truth. Some adolescents may wish to escape the home environment; others may become too involved. Adolescents should help the family but not be given adult responsibilities. If that happens, it may be a sign that the family needs additional resources.

Children and adolescents who have been told the truth may feel conflicted emotions, just like adults, such as sadness, worry, anger or guilt. They may feel insecure because the routine at home has changed. They may fear that they will become ill. These emotions may affect their appetite, their sleep pattern and their behavior at school. Therefore, the teachers at the schools should be told of the situation at home.

Needs of children and adolescents:

- To feel that their parents are receptive to their questions and feelings.

- To be told the truth in a manner that is sensitive and easy to understand.
- To understand that everyone is doing everything they can to care for the ill person.
- To know what their daily routine will be.
- To help the ill person as best they can the ill person.
- To have an outlet for their emotions in activities such as drawing, games, music, dance, etc.

OBJECTIVE 2

The appropriate way to help the ill person and immediate family members, be they adults, adolescents or children.

Helping the ill person:

- listen,
- talk,
- look at photos or videos of happy memories,
- read to the person,
- help with correspondence,
- listen to music,
- play games,
- watch a film,
- walk outside,
- share a meal,
- help with personal appearance,
- celebrate important occasions,
- tidy the room or bed,
- pray together if appropriate,
- visit a chapel,
- **or just remain silent.**

Helping the adults:

- Help them in their day today tasks.
- Stay close to the ill person to give the adult some respite.
- Stay close to the ill person in the company of family members if they so wish.
- Do errands.

When family members want to stay close to the ill person many things can be done to help them.

- Help with meals.
- Make beds.
- Play with the children.
- Answer the phone.
- Transmit messages to the CLSC, to a physician or to other family members or friends.
- Inform them of resources in the community.

Helping children and adolescents

- Listen.
- Play with them.
- Prepare their meals.

- Help them with homework.

OBJECTIVE 3

Outline the things that volunteers should not do.

CONDUCT THAT IS NOT PERMITTED:

1. Never accept or give money or expensive gifts.
2. Never bring friends or family members when accompanying.
3. Never take or make personal calls during accompaniment.
4. Never do heavy house cleaning.
5. Never take a key to the residence.
6. Never provide transportation. A volunteer can accompany and even drive the car of an ill person or of a family member.
7. Never prolong the accompaniment over the period of time specified by the Nurse. If it had to be done to deal with an emergency, the nurse should be notified.
8. Never sell services or products.
9. Never smoke, especially when in a non smoking home.
10. Obtain favors in exchange for accompanying.

Chapter 6 - COMMUNICATIONS WITH THE ILL PERSON AND IMMEDIATE FAMILY

OBJECTIVES

1. Briefly describe the communication process with the ill person and immediate family.
2. Learn the value and uses of silence.
3. Learn the use of touching as a communication means
4. Learn the pitfalls of palliative accompaniment and how to avoid them.

OBJECTIVE 1

Communications with the ill person and immediate family.

IMPORTANCE OF NON-VERBAL COMMUNICATION AND BODY LANGUAGE FOR LISTENING:
Non-verbal communication is 80% of the communication message. For example, the following are all actions that put ill persons at ease.

1. smiling,
2. approaching gently,
3. staying in their line of sight,
4. speaking calmly,
5. adjusting to their pace,
6. being relaxed and attentive.

Certain communication techniques can help when speaking with the ill person such as:

1. take time to introduce yourself to the ill person and members of the immediate family,
2. nod your head and use words like yes, I see, hum,
3. repeat the words you have just heard to show you understand and help the ill person stay on subject,
4. ask questions to help ill person clarify his/her feelings and talk about what he/she is experiencing; simple and open ended questions are preferable,
5. reflect the feelings of the person.

CARL ROGERS- Empathic Understanding

"...the therapist senses accurately the feelings and personal meanings that the client is experiencing and communicates this understanding to the client. When functioning best, the therapist is so much inside the private world of the other that he or she can clarify not only the meanings of which the client is aware but even those just below the level of awareness. This kind of sensitive, active listening is exceedingly rare in our lives. We think we listen, but very rarely do we listen with real understanding, true empathy. " *(from Carl R. Rogers. Way of Being. Boston: Houghton Mifflin, 1980, p.115-116)*

Two processes foster empathic understanding: **reflection and clarification**. Reflection occurs when the therapist repeats fragments of what the client has said with little change, conveying to the client a nonjudgmental understanding of his/her statements. Clarification occurs when the therapist abstracts the core or the essence of a set of remarks by the client.

COMMUNICATIONS WITH PEOPLE WHOSE COMMUNICATIONS SKILLS ARE LIMITED- problems with hearing or speaking, mother tongue other than English.

1. Reduce or eliminate all sources of distraction (radio, television, etc.).

2. Speak in a normal way with a reasonable intensity. Loud speaking can be perceived as aggressive by the ill person. Do not speak to the ill person as if he/she was an adult not a kid.
3. Unless it is the only way to communicate with the ill person, do not speak in his/her ear. It can be painful and be perceived as a territory invasion.
4. Pronounce your words clearly.
5. Use short and simple sentences. Be expressive.
6. Introduce one thought at the same time. Repeat it if necessary.
7. Use gestures if necessary.
8. Give the person some time to respond. Observe her/him : facial and eyes expression, non verbal behaviour, gestures.
9. In some situations it may be appropriate to write down what you want to say or even to resort to a drawing.

Dealing with ill persons whose hearing ability is reduced.

1. Eliminate any other source of noise.
2. Speak in a normal adult voice, not too loud as it may aggress the person. Do not treat the person as a child.
3. Do not speak into the ear of the person as it may threaten their personal space.
4. Articulate well.
5. Use short simple sentences. Be expressive.
6. Bring one subject at a time.
7. Use gestures that the person understands.
8. Give the person adequate time for a response and observes his/her body language (gestures, facial expression, the look of his/her eyes).
9. It may sometimes be appropriate to put in writing or in the form of a drawing what you want to say.

OBJECTIVE 2

The value and uses of silence.

Volunteers must be able to remain silent but stay attentive at the same time. Silence is often a very effective means of communications. Often an ill person needs silence around her/him. As an accompaniment volunteer, you have to expect to spend long periods of silence just sitting in presence of the ill person. The ill person will come to appreciate the calm and silence and will not feel rejected or alone. Often, times of silence allow the ill person to have the necessary physical and psychological rest and to have time for reflection.
Active listening does not necessarily means that you have to answer with words to all questions. Often a smile, a gesture, a human presence is worth more than words.

OBJECTIVE 3

Touching

Most people want to be touched when dying. At birth we need to be held and touched in a loving way. The same is true at the end of life. The feeling of isolation brought by dying can be immense. Touching the ill person can help fill a great need for contact.

- Always ask for permission before touching.
- Approach your hand gently from the ill person’s hand. If she/he does not want to be touched, he/she will withdraw his/her hand.
- Touch his/her hand or lower arm without moving or by massaging lightly.
- When the ill person is sitting in a chair or sofa, approach a chair and sit directly in front of him/her. Look at him/her in his/her eyes. It may then be possible to establish a contact with his/her knees and

to touch his/her hands. This position can be appropriate to establish a climate of trust when important issues are at stake

OBJECTIVE 4

Behavior to avoid as a palliative accompaniment volunteer.

1. Systematically reassure.
2. Change the subject of conversation or use humor to change the mood in the room without taking into account the needs of other people.
3. Judge or interpret the conduct or words of the ill person and immediate family members.
4. Interpret what the ill person and immediate family members say or do.
5. Give advice on issues outside your role.
6. Issue diagnoses.
7. Confront the person and immediate family members.
8. React aggressively to the anger or violence of the ill person and immediate family members. In such circumstances it is preferable to simply listen or to discretely move away.
9. Talk about yourself at length and frequently.

Chapter 7 - THE ILL PERSON AND IMMEDIATE FAMILY: PHYSICAL ASPECTS

OBJECTIVES

1. Describe the illnesses that ill persons using the services often have.
2. Explain how certain illnesses and their treatment can physically affect the ill person and their immediate family.
3. Identify some remedies to ease the physical effects.
4. Identify some cultural aspects

OBJECTIVE 1

Some illnesses of the terminally ill

1. Cancer.
2. Aids.
3. Degenerative diseases such as multiple sclerosis, Parkinson's, ALS.
4. Alzheimer's or other illnesses of cognitive deterioration.
5. Heart diseases.
6. Respiratory diseases such as emphysema or cystic fibrosis.

OBJECTIVE 2

Possible physical effects from terminally ill diseases and their treatments.

1. Overall weakness and an inability to walk or move on one's own.
2. Irregular or difficult/painful breathing.
3. Loss of appetite and weight, dehydration, nausea, vomiting, mouth sores, bedsores, difficulty swallowing, intestinal problems, edema, constipation, incontinence.
4. Wounds of bed.
5. Ascites (accumulation of fluid in the peritoneal cavity), edema (swelling).
6. Fragile immune system and a sensitivity to infections.
7. Angst, confusion, insomnia, fatigue, lethargy.
8. Confusion in respect of time, location, people, etc.
9. Convulsions. The person may remain conscious or lose consciousness.
10. Hemorrhaging can occur although rare.
11. Pain : may be due to various reasons. Bone cancer, compression of nerves attributable to the growth of a tumour, lesions in the mouth, headache caused by a cerebral tumour, muscular spasms, etc.

Members of the family may react physically with:

1. Loss of appetite and weight loss.
2. Weight gain.
3. Back problems.
4. Insomnia.
5. Angst.
6. Fatigue.
7. Irritability.
8. Sensitivity to infections.

OBJECTIVE 3

Identify some remedies to ease the physical effects.

1. Medications by mouth, suppository or skin surface are offered to relieve discomfort and pain.
2. When medication is administered intravenously a small needle is inserted in the skin and maintained in place with an adhesive. A pump which is fixed to the needle may be used by the ill person or members of the immediate family to inject the medicament at set intervals.
3. Injections may also be used as required between set intervals when pain becomes intolerable.
4. Oxygen therapy. Oxygen is brought by face mask or nasal tube.
5. Tracheotomy by incision in the trachea to permit or improve breathing.
6. Catheter inserted in the bladder to permit urination in a pouch.
7. Colostomy through surgery on the colon to permit the stools to collect in a pouch.
8. Nasal tube connected to the stomach to nourish or eliminate liquids.
9. Feeding tube (Levine) inserted in the wall of the stomach.
10. Re-hydratation administered intravenously through a small needle inserted in the skin and connected to a water bag.

OBJECTIVE 4

Identify some cultural aspects

1. Distrust of physicians and/or medical system
2. Unrealistic expectations of physicians and/or medical system
3. Any life is worth living, no matter how compromised
4. Belief in miracles
5. Death is the "enemy"
6. Death should not be discussed openly
7. The ill person should not be told what his/her problem really is.

Chapter 8 - APPROACHES TO RELIEVE PAIN AND IMPROVE COMFORT

OBJECTIVES

1. Identify signs or symptoms of pain in the terminally ill.
2. Outline precautions for volunteers providing comfort.
3. Describe approaches for improving comfort.
4. Identify practices that volunteers should not undertake.

OBJECTIVE 1

Signs or symptoms of pain in the terminally ill.

INDIVIDUAL WRITTEN EXERCISES:

1. Take five minutes and think about your reactions and behavior when you have pain.
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   ____
   ____
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2. Think about a specific pain you felt: describe it in your own words.
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   ____
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3. Describe your physical and psychological reactions.
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4. Describe what medications or actions help you make the pain more endurable.
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PAIN IS VERY SUBJECTIVE

Only the person feeling it can experience its intensity and nature.

However there are signs that caregivers can notice for ill persons in pain who may not want or be able to express it verbally.

1. Facial expressions such as tensing of the face, grimacing or a hurt look.
2. Agitation, placing a hand on the sore area or
3. Tense posture.
4. Difficulty moving or inability to move.

Some people are very stoic when faced with pain; others are very verbal or agitated or become almost paralyzed.

Many factors influence a person's reaction to pain:

- Type of pain.
- Past experiences.
- Temperament.
- Support given.
- Culture. Certain cultures encourage the expression of feelings others not.

Factors which may aggravate pain:

1. Certain moves.
2. Solitude.
3. Being overwhelmed by pain.
4. Noise, light.
5. Fear, anxiety.
6. Insomnia.
7. Fatigue.

Strategies for volunteers to improve physical comfort of the ill person.

Some strategies may not work with certain pains:

1. Medication.
2. Changing position.
3. Adjustment of light and sound.
4. Attentive and gentle presence.
5. Encourage him/her to think of other things.
6. Humor.
7. Hot or cold applications.
8. Light massage to help relaxing.

OBJECTIVE 2

Outline precautions for volunteers providing comfort

These measures are applied universally to avoid the transmission of infection.

1. Wash hands in warm soapy water on arrival, departure or use antibacterial lotion.
2. Always wear gloves when dealing with blood, urine and excessive saliva and vomiting
3. Volunteers must always wear gloves if their hand has a cut or a sore and the gloves must be disposed of immediately after use.
4. Volunteers must never look after the terminally ill if they are sick with a cold or any other contagious illness.
5. Volunteers must never touch intravenous needles and if they do by accident, the area touched must be washed.
6. Volunteers must follow the instructions of the house when assisting those placed in isolation, i.e. wear gloves, mask, jacket, etc.

OBJECTIVE 3

Dealing with comfort

It is important that the volunteer be sensitive to the sick person's pain.

1. Be delicate when approaching the sick person.
2. On arrival inform yourself of the state of the sick person.
3. Be attentive to the sick person's complaints. Listen to him/her without passing judgment or minimizing the importance/intensity of pain.
4. Be attentive to the sick person's facial expressions, gestures, posture and moves.
5. Inform the nurse of the sick person's signs of pain and discomfort.
6. Encourage the sick person to verbalize his/her pains and discomforts to the nurses and physicians.
7. Encourage the sick person to take his/her medication as prescribed.
8. Inform the nurse if he/she does not.

Assisting a person in pain. It is important to adapt yourself to his/her rhythm and to ask him/her what could help him/her.

1. Reduce light or noise.
2. Help him get busy with something else: music, reading, conversation, etc.
3. Help him/her with relaxation techniques.
4. Light massaging or touches.
5. Change position. Note. In some cases it may be necessary to consult with the nurse before doing so.
6. Let him/her rest/sleep but stay with him/her.

ASSISTANCE WITH ALIMENTATION

Drinking and eating can be a challenge for the terminally ill and a nurse should advise on the level of assistance from the volunteer.

Preparation

- Always consult with the nurse about the sick person's ability to swallow before feeding him/her.
- Ill persons should have their head raised or in a sitting position for food or drink.
- Place a serviette or bib to keep clothing clean.

While eating

- Make certain the food is cut in small portions to assist with chewing and await swallowing before adding another portion. It most circumstances avoid getting involved in a conversation in order not to interfere with eating.
- Spoons rather than forks should be used for food.
- Make certain the food is cut in small portions to assist with chewing and await swallowing before adding another portion.
- Liquid and solid should be offered separately.
- Encourage the ill person to drink slowly and to take little sips.
- Offer a straw if it can help.
- Lightly stroking the throat can help swallowing.

After the meal

Advise the nurse or family member if the ill person has trouble swallowing or is choking.

SPECIFIC STRATEGIES TO REDUCE DISCOMFORT

These measures should be discussed with the ill person before implementation.

1. Mouth: assist with dental and mouth cleaning; apply lubricants on the lips as recommended, offer a drink or something cool to suck.
2. Nausea: encourage the ill person to breath deeply, apply a wet cloth to the head or nape of the neck, reduce disagreeable odors and cleanse mouth.
3. Vomiting: keep the ill person in a sitting position or semi sitting position on his side, hold the receptacle, clean it and help the ill person rinse his mouth, ensure bed linen are clean.
4. Breathing problems: depending on the person's mobility, assist with movements to improve breathing, encourage rest, open window or offer ventilator.
5. Confusion: look the ill person in the face and take his/her hand or arm, speak softly and remain calm and explain who you are, reassure them, eliminate other noises. Do not argue or contradict him/her.
6. Convulsions: stay with the ill person until the episode is over, put a pillow under his/her head, help to keep him/her on his/her side, remove objects that can cause physical harm, reassure the ill person and help him/her relax, alert the nurse if possible.
7. Hemorrhaging: ask for help and provide towels to absorb the blood, try to alleviate a sense of panic.
8. Living environment: make certain the room temperature is comfortable and add a humidifier or air conditioner if needed. Make certain the bed sheets and covers are clean and neat and the room well aired and free of odors if possible.

POSTURE RELATED COMFORTING

1. Make sure that the bedding is clean and dry. Advise family caregiver if not.
2. Make sure that the bedding is well placed.
3. Put some pillows or cushions to ease the posture of the ill person.
4. Give a light massage to the hands, the front, the neck, the back or the feet with an appropriate oil or cream.

PHYSICAL ASSISTANCE FOR THE NON-AUTONOMOUS ILL PERSON.

Getting out of bed

1. Put a chair or sofa near the bed so that the person can easily sit down and get up.
2. Raising the head of the bed to its maximum, place his/her legs on the side of the bed so that they hang down on the side of the bed. Assist him/her to reach a sitting position by putting your arm under his/her shoulder and around his/her neck. do physically to raise his upper body, place his legs on the side of the bed, allow time for the ill person to adjust to the position and not feel faint. Allow time for the ill person to adjust to the position and not feel faint.
3. If the bed is high, place a stool beside the bed to ease the way down.
4. Put on his/her slippers and help him/her to move on the chair.

Walking

1. Ensure the slippers or shoes are nonskid.
2. Offer help to the weakest side of the person so that he/she can make use of his/her strong side. If the person uses a cane make sure he/she uses it on his/her strong side.
3. Stand next to the ill person, slightly behind him/her, and place an arm around his/her back or shoulder. Use your other hand to hold his/her elbow or hand.
4. Ensure that the person that the person does not cling to you because it would make it difficult for you to support him/her if his/her knees were weakening.
5. If the person gets weak and you cannot maintain him/her standing up anymore, put your forearms under his/her armpits, bend your knees and bring him/her down slowly to the floor holding him/her close to your body. Have his/her legs moving forward until he/she is in a sitting position or moving backward so that he/she can kneel.
6. Ask for help.

Wheel chairs

1. Make certain the break is on before placing in or taking him/her out of the chair.
2. Make certain the person is comfortable and secure with elbows in the chair and feet on the footrests.
3. If needed ask for help when moving the person from the wheel chair to the bed.
4. Move backward when going into and out of elevators.

Touching

Touching can be very comforting and reassuring for the ill person.

- Most people want to be touched when dying. At birth we need to be held and touched in a loving way. The same is true at the end of life. The feeling of isolation brought by dying can be immense. Touching the ill person can help fill a great need for contact.
- Always ask for permission before touching.
- Approach your hand gently from the ill person's hand. If she/he does not want to be touched, he/she will withdraw his/her hand.
- Touch his/her hand or lower arm without moving or by massaging lightly.

When the ill person is sitting in a chair or sofa, approach a chair and sit directly in front of him/her. Look at him/her in his/her eyes. It may then be possible to establish a contact with his/her knees and

OBJECTIVE 4

Identify practices that volunteers should not undertake

1. Do not offer any help which come within the responsibility of nurses such as offering information on or administer medications, adjusting medical equipment, etc.
2. Do not adjust the oxygen intake.

3. Do not use matches or any form of fire where oxygen is provided.
4. Do not provide massage or physiotherapy treatments.
5. Do not move the ill person from one place to another if he can't move himself, because he/she is too weak, confuse or drowsy.. Check with the nurse or the family caregiver first.

Exercize 1: Before leaving for Mrs Boily's home, the nurse informs Françoise, a volunteer, that Mrs Boily is confused and agitated. What should be Françoise's attitude with Mrs Boily ?

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Exercize 2: Mr. Viger has bouts of nausea this morning. How can Sophie, a volunteer, can help him?

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Chapter 9 - CONFIDENTIALITY AND SHARING OF PROFESSIONAL INFORMATION

OBJECTIVES

1. Explain the importance of respecting confidentiality.
2. Outline the type information that volunteers provide to PALLIACCO and how it should be shared.
3. Demonstrate application of communications strategies through situational exercises.

OBJECTIVE 1

The importance of respecting confidentiality.

Confidentiality is integral to the management and practice of palliative care. It is based on respect for privacy for the ill person and his family. Volunteers must therefore never provide the following information to others.

- Name of the ill person and family,
- health condition of the ill person,
- information learned in the presence of the ill person,
- circumstances related to the illness and death of the ill person,
- reactions of the family to the illness and death.

Volunteers are bound by the same code of secrecy as any other professional working in the Quebec Health System. All information on the client or his family is to be kept within the confines of Palliacco and **shared with professional staff and other volunteers as required to best serve clients**. Under no circumstances is this commitment to confidentiality to be broken. Discussion with other members of the interdisciplinary team must always be conducted in a secluded place and never in elevators, corridors or other public places.

OBJECTIVE 2

Information to be shared with PALLIACCO personnel.

1. A Log Book is placed in every home where PALLIACCO volunteers are sent. At the end of her visit the volunteer writes in her observations about the ill person's condition and about any incident which may have taken place. Family caregivers are also encouraged to write in their own notes and comments about the ill person's condition.
2. Reading the notes in the log book is one of the first thing a volunteer must do on his/her arrival in the home.
3. Some information must be communicated directly to the Nurse: change in medical condition, pain level, physical state, major conflicts between family members, etc.
4. A book including the list of all ill persons accompanied by PALLIACCO and updated weekly by the Nurse or Nurse is available in the Volunteers' room. It contains the ill persons addresses, some specifics concerning their condition such as capability to eat, drink, walk, etc. and any information on the ill person and immediate family judged to be relevant. Volunteers must read the information related to their client before making their first visit.

INFORMATION TO BE GIVEN TO THE NURSE.

1. Any information judged to be relevant for the nurse to know about the ill person and family caregivers: state of mind, confusion, anger, etc., that cannot be written in the log book.
2. Any indication that the ill person is in pain, even if the ill person denies to be in pain.
3. Volunteers must not share any information ill persons and their families reveal in confidence with other members of the team. Volunteers may encourage the ill person to share this information with the nurse or other professionals. Volunteers must however give this information to the Nurse if it could possibly affect the security of the ill person and family even if they are sworn to secrecy.

Note: Write in the Log Book date and duration of visit and any other relevant information about the ill person.

OBJECTIVE 3

Demonstrate application of communications strategies through situational exercises.

Exercise 1.

Mrs Smith's husband has been suffering from a terminal disease and in the past three weeks has developed a friendly relationship with a volunteer named Victorine. This morning Mrs Smith learns that Mr Sullivan, a friend of her husband died in a Palliative Care Unit about a month ago. Mrs Smith would like to contact the wife of the deceased whom she knows slightly for some mutual support. Unfortunately she does not have Mrs Sullivan's coordinates and she would like Victorine to find out the first name of Mr Sullivan and the name of the city where he lived. Victorine happens to know this information and has seen Mrs Smith offer support to her husband and recognizes her to be a sympathetic and empathetic person.
How should Victorine reply to this request for information?

Exercise 2.

Valérie is shaving a coffee with her friend Marcelle. Both of them are accompaniment volunteers at Palliacco. They are alone. The two of them have worked many years as nurses, Valérie in surgery and Marcelle in oncology. Marcelle says to Valérie: «I have learned that you are accompanying Don Smith. I have not seen him since he was told by his physician that he was suffering from a lung cancer. I have heard recently that cancer has now spread to his brain and that he and his wife had reacted quite strongly to this new development. Is it true? How is he reacting? » Noticing that Valerie is hesitating, Marcelle says : « Come on Val, I have spent my whole working life in oncology. There is nothing that you can tell me about cancer that will impress me. »
How should Valérie react?

Exercise 3.

Mr Roy has told his volunteer caregiver Gisèle that he has pain in his legs but he does not want to bother the physician. When Gisèle replies that she can speak to the physician for him, Monsieur Roy asks the volunteer to promise not to tell the physician. When the volunteer returns home she has misgivings about the conversation.
Should she tell the nurse and ask her to inform the physician? How will this affect her relationship with Mr Roy in the future?

Exercise 4.
Janine is a volunteer in the home of the Thomas. Mr Thomas has to go out and asks Janine to remind his wife to take her pills at 4 o'clock. He explains that the pills are on the bedside table. Janine knows that Mrs Thomas is too weak to take the pills on her own and that she will have to give her the pills. According to PALLIACCO rules, volunteers are not to give pills to ill persons.
How should the volunteer reply to Mr Thomas?

Exercise 5.
Françoise, a volunteer, has been sent to look after Mrs Cooke who is confused and agitated.
How should Françoise act when he enters Mrs Cooke's room?

Exercise 6.
Me Hunt is very nauseous this morning.
How could the volunteer Sophie help him?

Chapter 10 - DEATH

OBJECTIVES

1. Identify attributes of a “healthy” death
2. Explore attitudes, feelings and beliefs concerning death and
3. Describe the symptoms and physical changes as death approaches.
4. Identify the responsibilities of the volunteer following the death of the ill person.

OBJECTIVE 1

Identify attributes of a “healthy” death

1. Effective pain and symptom management
2. Clear decisions
3. Responsibility for decision making is clear
4. Preparation for death is ongoing
5. Finishing unfinished business
6. Ill person contributes to others
7. Ill person affirms her/ himself in her/his totality

OBJECTIVE 2

Explore attitudes, feelings and beliefs concerning death.

EXERCISE.- Visualization and drawing: “How would you draw or describe death if it was a person”

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OBJECTIVE 3

Symptoms and physical changes as death approaches.

Describe the symptoms and the physical changes most often seen as death approaches.

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Ill persons may display the following physical/physiological changes progressively or simultaneously several days or hours before death.

1. Consciousness: The ill person will sleep more often and longer and eventually fall into a state of unconsciousness. Several hours before death, the ill person will fall into a coma and will not awake.

The eyes may be open or semi-open but the ill person does not see. The look is glassy and tearful. Certain parts of the body stiffen, often the neck. There is a belief that the sense of hearing and of touch remains until the end.

2. Breathing: The ill person's breathing will be become slower and irregular and at times stop for 10 to 15 seconds and then begin again with effort and remain irregular. It is a normal reaction and not painful. It can last for several days or hours.
3. Death rattle: The noise from breathing is caused by the fact the ill person can not cough or release saliva or other secretions that accumulate in the mouth, throat and lungs. This phenomenon can be disconcerting for the immediate family but it is not painful.

4. Circulation: The gradual stopping of vital functions is accompanied by a slowing of circulation. The skin becomes cool and moist to the touch starting with the hands and feet. The nails as well as the lips take on a bluish hue and the skin can look marbled. The face becomes pale and waxen as the heart has difficulty pumping blood. As well, the body toxins no longer eliminated by slower functioning kidneys, liver and lungs give a gray complexion.
5. Pulse and blood pressure: The pulse can be quick or slow but will slowly become feeble and almost imperceptible; the blood pressure will fall slowly and become impossible to measure.
6. Fever.

OBJECTIVE 4

Identify the responsibilities of the volunteer following the death of the ill person.

The volunteer may be present when death occurs. The moment of death is sacred. Words said and gestures made stay with the family during their mourning period and sometimes long after.

- Offer sympathies.
- Let it be known you can be of assistance.
- Ask if help is needed with food or drink.

Before leaving

- Let it be known you can be of assistance in the days to come.
- Record the date and time of death and any other pertinent information in the log book.
- Write a last note in the log book expressing your sympathy.
- Leave the log book in the client’s home.

Chapter 11 - GRIEF

OBJECTIVES

1. Define the meaning of Grief.
2. Identify the reactions people can have during this experience.
3. Identify ways that can help the volunteer deal with loss.
4. Learn to respect cultural and spiritual differences in dealing with death and grief.

OBJECTIVE 1

Define the meaning of Grief

Traditionally Grief has been used to refer to the experience felt by people after the loss of a love one by death. In today's context Grief has a broader meaning. For example a person suffering from a terminal disease such as cancer experiences Grief all along his/her illness. The same is true of family caregivers who are witnessing powerlessly the decline of the sick person.

Family members experience grief at each phase of the illness

- Diminished energy and overall health.
- Loss of hair (cancer).
- Work / employment reduced / stopped.
- Loss of income.
- Restricted activities.
- Needing help from others for personal hygiene, eating.
- Imminent death.

EACH PHASE REQUIRES SURRENDERS, GRIEVES, TRANSITIONS ON THE PART THE TERMINALLY ILL PERSON AS WELL FROM THE FAMILY CARE GIVERS.

Family and friends have to go through one grieving phase more than the ill person: his/her death.

OBJECTIVE 2

Define the reactions people can have during this experience.

Grief is a multi-faceted response to loss. Although conventionally focused on the emotional response to loss, it also has physical, cognitive, behavioral, social and philosophical dimensions. Common to human experience is the death of a loved one, whether it be a friend, family, or other close companion. While the terms are often used interchangeably, **bereavement** often refers to the state of loss, and grief to the reaction to loss. Losses can range from loss of employment, pets, status, a sense of safety, order or possessions to the loss of the people nearest to us. Our response to loss is varied and researchers have moved away from conventional views of grief (that is, that people move through an orderly and predictable series of responses to loss) to one that considers the wide variety of responses that are influenced by personality, family, culture, and spiritual and religious beliefs and practices.

GRIEF IS A NON-LINEAR PROCESS.

- Denial, negation.
- Bargaining, searching for miraculous solutions.
- Depression, despair.
- Aggression, anger, rebellion.

- Acceptance.
- Hope, serenity.

POSSIBLE PSYCHOLOGICAL REACTIONS DURING THE GRIEF PROCESS.

It is important to note that these reactions do not happen to everyone or in any order.

1. Shock : phase of coming to terms with the death of a loved one.
   Reactions include shock, denial and numbness.
2. Confusion : phase of experiencing emotional suffering.
   Reactions include agitation, lack of concentration, tears and sobbing, search for meaning, anger, depression, self blame, guilt, identification with the deceased, idealization of the deceased, relief and liberation.
3. Renewal : phase of learning to live without the person
   Reactions include a modification of self image, adaptation to new responsibilities and relationships.
4. End of grief : phase of moving on
   Reactions include emotional stability and a return to one's interests.

POSSIBLE PHYSICAL REACTIONS INCLUDE

- Tight throat and chest,
- loss of appetite and weight,
- digestive problems,
- muscle aches,
- lack of energy,
- insomnia,
- irritability,
- extreme sensitivity to noise,
- breathlessness,
- palpitations,
- loss of sexual desire.

FAMILY MEMBERS VS GRIEF

- **UNRESOLVED** : The person remains in denial, depression or aggression. The person becomes isolated and loses interest and the will to live.
- **RESOLVED** : The person accepts that life has changed and moves on taking charge of his/her life. The person reaches a level of serenity and wisdom that allows for happiness and kindness with others.

OBJECTIVE 3

Identify ways that can help the volunteer deal with his/her own feeling of loss.

1. Recognize there will be pain and accept it.
2. As death approaches, treat each visit as the last one and say adieu in your mind to the person who is dying.
3. Allow time to live through the pain and talk about the loss with those who will be sympathetic to you.
4. If possible, stay with the body for a short time after death.
5. Assume your own needs for a mourning ritual (religious and non-religious) and respect those of others.
6. Take time to relive for yourself shared experiences with the deceased and the family.

7. Reflect on how the relationship had an influence on you and what you learned about the dead person and yourself. Put these thoughts down on paper.
8. Accept the fact that the emotional impact of loss will vary in intensity and at times memories will be very painful and at others will offer a sense of relief.

OBJECTIVE 4

Learn to respect cultural and spiritual differences in dealing with death and grief.

CONCLUSION

OBJECTIVES

1. Identify your motivation and expectations in relation to the role of accompaniment volunteer
2. Identify your concerns
3. Evaluate quality and relevance of training course

OBJECTIVE 1

Motivation and expectations as a volunteer.

My motivation to become a volunteer

My expectations as a palliative care accompaniment volunteer

OBJECTIVE 2

Concerns (questions or emotions) about being a palliative care accompaniment volunteer

OBJECTIVE 3

Evaluate quality and relevance of training course.

- **Quality of teaching**
- **Quality of content**
- **Relevance of content**
- **Two aspects you have liked**
- **Two aspects to be improved**
- **Other comments**

GLOSSARY

Aphasia: loss of the ability to speak due to injury to brain areas specialized for these functions.
Apnea: technical term for suspension of external breathing. During apnea there is no movement of the muscles of respiration and the volume of the lungs initially remains unchanged
Ascites accumulation of fluid in the peritoneal cavity.
Body temperature : normal oral temperature:
37 °C or 98,6 °C. Fever: 38 °C + (or 100,4 °C+).
Normal rectal temperature 38,5 °C (or 101 °C).
Butterfly shaped needle: needle with two small wings, like a butterfly, linked to a narrow tube through which medication is injected.
Catheter: a tube that can be inserted into a body cavity, duct or vessel such as an artery, vein, bladder, urethra, ureter…. Catheters thereby allow drainage or injection of fluids or access by surgical instruments. The process of inserting a catheter is **catheterization**. In most uses a catheter is a thin, flexible tube: a "soft" catheter; in some uses, it is a larger, solid tube: a "hard" catheter.
Colostomy: connecting a part of the colon onto the anterior abdominal wall, leaving the ill person with an opening on the abdomen called a stoma. This opening is formed from the end of the large intestine drawn out through the incision and sutured to the skin. After a colostomy, feces leave the ill person's body through the stoma, and collect in a attached to the ill person's abdomen which is changed when necessary.
Confusion. Loss of orientation (ability to place oneself correctly in the world by time, location, and personal relations and identity), and often memory (ability to correctly recall previous events or learn new material).
Convulsions : abnormal non voluntary often violent contraction or series of contractions of the muscles which may cause unconsciousness.
CVA (Stroke or **cerebrovascular accident)** is the clinical designation for a rapidly developing loss of brain function due to an interruption in the blood supply to all or part of the brain due to embolism, thrombus or hemorrhage
Cyanosis is a bluish coloration of the skin due to the presence of deoxygenated hemoglobin in blood vessels near the skin surface. It occurs when the oxygen saturation of arterial blood falls below 85%.
Dyspnea: shortness of breath or **short of breath** (**SOB**) is perceived difficulty breathing or painful breathing. It is a common symptom of numerous medical disorders.
Force-feeding: where a ill person is intubated through the nose or mouth and fed because he or she is incapable of swallowing due to some medical condition
Gastrostomy: surgical opening into the stomach. Creation of an artificial external opening into the stomach for nutritional support or gastrointestinal decompression.
In between dose : analgesic taken or given to a ill person at his/her request in between prescribed medications
Levin : tube inserted in the ill person's stomach through the nose either to feed him/her or to drain stomach liquids
Metastasis: , is the spread of a disease from one organ to other parts of the body. Only malignant tumor cells i have the capacity to metastasize.
Neurological signs : indicators used to assess the nervous system (pupil, muscular tone, reflexes, consciousness)
NPR (do not reanimate in French) / **DNR.** Do not resuscitate. Prescribed by a physician to avoid therapeutically extra-ordinary measures.
Ttracheotomy or **tracheotomy**: surgical procedure to secure an airway. The procedure is performed on the neck to open a direct airway through an incision in the trachea (the windpipe).
Vital signs : indicators used to assess the cardiovascular system (blood pressure, pulse, breathing)

WEBSITES

Canadian Health Network
- www.canadian-health-network.ca

Canadian Hospice Palliative Care Association (CHPCA)
- www.acsp.net/

Council on Palliative Care / Conseil des Soins Palliatifs
- www.med.mcgill.ca/orgs/palcare/copchome

International Association for Hospice and Palliative Care
- www.hospicecare.com

Réseau de soins palliatifs du Québec
- www.aqsp.org/