

# **GUIDING FAMILY CAREGIVERS OF PEOPLE AT THE END OF LIFE**

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**A HANDBOOK**

**2016**



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## HOW TO REFERENCE THIS HANDBOOK:

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## *ABOUT THIS HANDBOOK*

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This guide was developed as part of the research project called "Caring for the caregivers: implementation of an evidence-based novel service for family caregivers of cancer patients at the end of life," although it is not specific to caregivers of people with cancer. The project was funded by the Max Bell Foundation<sup>1</sup>. It is based on the best available research evidence at the time of writing. Where there is a lack of evidence, the expertise of the authors was included. We have made this guide available in MSWord format as well as PDF so that it can be updated and descriptions of public programs that are available can be locally adapted. If you do adapt the guide, please follow the instructions in the section on authors and copyright below.

This guide provides information for volunteers who will be focusing on Guiding family caregivers of people at the end of life to both care for themselves, while providing care and into bereavement, and to provide care. We call these highly trained volunteers Caregiver Guides to indicate that while they provide emotional support, they do much more than that. This manual was developed to be used together with the Canadian Hospice Palliative Care Association's "Hospice Palliative Care Volunteers: A Training Program<sup>2</sup>" and "A Caregiver's Guide. A Handbook about End-of-life Care."<sup>3</sup> Topics that are essential to being a Caregiver Guide but which are found in those documents are not included here. A few examples of these topics are boundaries for volunteers, communication skills, caregiving skills such as changing the sheets with a person still in the bed, managing pain, and what symptoms to expect in the last few days and hours of life. Please note that these booklets cover a much broader range of topics than we have listed here.

We suggest that volunteers read the whole guide before beginning to Guide and support caregivers. Until the volunteer is experienced, we suggest that this guide is revisited after visits with caregivers to see whether there is any information that may be useful. Our research suggests that even experienced volunteers benefit from revisiting this guidebook from time to time.

THE QUOTES WITHIN THE GUIDE ARE FROM OUR RESEARCH PROJECT. NAMES AND OTHER IDENTIFYING INFORMATION HAVE BEEN CHANGED TO MAINTAIN CONFIDENTIALITY. IN SOME CASES THE QUOTES HAVE BEEN TRANSLATED FROM FRENCH.

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# *THE FAMILY CAREGIVER EXPERIENCE*

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Families play an important role in supporting individuals who are dying at home and often fill the role of a caregiver. Being a family caregiver is often rewarding and rich with personal meaning. However, family caregivers also face many physical, emotional, social, and financial challenges in their caregiving role. The family caregiver's issues may be further compounded when there is a history of familial conflict, resulting in negative feelings towards the ill family member.

Many family caregivers experience:

- a roller coaster of emotions, with many becoming anxious or depressed
- difficulty sleeping
- fatigue, often to the point of feeling exhausted
- isolation or too many visitors and no time to themselves
- feeling that the care they have provided is not good enough, feeling guilty
- financial hardship
- feeling overwhelmed
- loss of a sense of self.

## **Emotions**

Facing the loss of a family member and dealing with the many demands and stressors associated with the caregiving role results in many family caregivers experiencing extreme emotional difficulties.<sup>1,2,3</sup> Anxiety and depression, in particular, have been reported in up to 44% of family caregivers, affecting their ability to sleep and cope with their caregiving role<sup>3,4,5,6,7</sup> In addition, family caregivers have reported feelings of powerlessness and helplessness<sup>8</sup>, anger and disillusionment<sup>9</sup>, hopelessness<sup>10</sup>, fear and dread<sup>10</sup>, guilt and regret<sup>10,11</sup>, and grief<sup>7</sup>. As the patient's disease progresses and caregiving demands change, emotional distress in family caregivers increases<sup>12</sup>.

The emotional responses to caregiving are extremely important to recognize as they bring suffering on their own and may be associated with other health issues. For example, negative emotional responses such as anxiety and depression may increase a caregiver's risk for other illnesses and even death.<sup>13, 14, 15</sup>

## WHAT DOES BEING A FAMILY CAREGIVER INVOLVE?

Providing most of the physical and emotional care for the individual who is dying.<sup>16, 17, 18</sup>

This includes:

- Managing medications, symptoms, and other aspects of patient care.<sup>16, 19, 20, 21</sup>
- Providing their relative with practical support for activities of daily living, such as bathing and eating, as well as other household tasks. This often involves taking on new roles, including roles that were previously those of the patient.
- Providing emotional and social support for the patient.
- Acting as the spokesperson, advocate, and proxy decision maker for their relative, and assuming responsibility as the coordinator of care.<sup>19,22,23,24,25,26</sup>

## WHAT ARE SOME OF THE CHALLENGES OF BEING A FAMILY CAREGIVER?

- The physical demands of providing care can be extremely difficult for family caregivers.<sup>9, 27</sup> Many family caregivers are older and have health concerns of their own which can make caregiving particularly challenging.<sup>20</sup>
- Developing assessment and caregiving skills may be challenging for family caregivers. They often report that they do not feel prepared for their caregiving role.<sup>28</sup> Caregiving responsibilities and lack of feeling prepared result in a considerable amount of anxiety and fatigue in family caregivers.<sup>29,30,31</sup>
- Family caregivers who look for information to help them prepare for caregiving often feel overwhelmed by the complexity and amount of information needed to fulfill their caregiving role, adding to their anxiety.<sup>30</sup>
- Caregiving responsibilities, carrying out multiple roles, and often being unable to leave the patient alone result in significant disruptions in family caregivers' regular routines and restrictions on their time and ability to participate in social and health-related activities that they value.<sup>32,33,34</sup> Younger caregivers, women, and those who are a child of the patient often find disruptions to their own schedules especially difficult<sup>35</sup>, likely due to the stress of competing demands from work and family life<sup>33</sup>.
- Family caregivers may also experience financial stressors associated with caring for a patient at home.<sup>36</sup> Many family caregivers quit their job, lose work hours, or use special leave or holiday time in order to fulfill caregiving responsibilities.<sup>6</sup> Loss of income and out-of-pocket costs incurred for items such as prescription and over-the-counter medications, home care, as well as equipment and home modifications result in many family caregivers having some type of financial difficulty due to home-based caregiving.<sup>37,38,39</sup>

## WHAT IS IMPORTANT TO THE QUALITY OF LIFE OF THE FAMILY CAREGIVERS?

The goal of care for people at the end of life is to optimize their quality of life in this difficult situation, *and that of their families*. What is important to quality of life at an individual level will vary greatly from person to person and even for the same person over time. However, there are some general areas of life that are important for many family caregivers. Knowing what these are is a starting point for knowing how to help them.

### WHAT FAMILY CAREGIVERS SAY IS IMPORTANT TO THEIR QUALITY OF LIFE <sup>40, 41</sup>

#### *THEIR OWN STATE*

- Physical well-being
- Mental health
- Cognitive state (thinking clearly, being able to think of something other than the patient's illness)
- Feeling in control

#### *THEIR FAMILY MEMBER'S CONDITION*

- "If she has a good day, I have a good day."

#### *THEIR ENVIRONMENT*

- Feeling that their loved one is in the best place, be that at home, at the hospital, or hospice
- Having privacy when they want it

#### *THEIR OUTLOOK ON LIFE*

- Life has meaning and purpose
- Outlook/faith/spirituality is comforting
- Providing care is rewarding

#### *HEALTH CARE*

- Comfort with the way decisions are made for their family member
- Satisfied with the care their family member receives and how they are both treated

#### *RELATIONSHIPS*

- With their family member (not always a loved one)
- With others important to the family caregiver

#### *FINANCIAL CONCERNS*

## THE “DECISION” TO PROVIDE CARE AT HOME

How do family members and friends decide to become a family caregiver? Sometimes it is not a decision at all! While some make a conscious decision to take on the role, many just automatically take it on as the patient comes to depend on them more and more. Others become heavily involved family caregivers when they promise to keep the patient out of the hospital, often after the patient has a difficult experience on an acute care hospital unit or when the patient says they want to die at home. Some are happy to take on the role of caregiver, while others do it out of a sense of obligation and feel they have little choice.<sup>42</sup> This can especially be the case if the relationship is not a close one or has major difficulties prior to the patient’s illness.

***What is important to note is that, when the family caregiver role is taken on, many don’t know what it involves. This can result in problems when:***

- The care becomes so heavy that the family caregiver needs to make sacrifices they did not plan on. For example, taking a leave of absence from their job or quitting it, or not spending much time with their spouse or children.
- A family caregiver who has promised to keep the patient at home is no longer able to. This makes it very difficult for the family caregiver to decide that the patient needs to be admitted to a hospital or hospice, unless the patient makes the decision on his/her own or is unconscious. Many family caregivers who have given so much still feel very guilty in this situation.

## WHAT ARE THE FAMILY CAREGIVERS’ NEEDS?

Family caregivers have many needs, related to both their own well-being and that of the patient. It is important that they focus on meeting both types of need.

Some common needs found in studies of family caregivers are listed in the table below. The list is long but many needs will be filled by the support and care they already receive and not all apply to each family caregiver.

If they focus only on meeting their needs related to caring for the patient and neglect to take care of themselves, then they are likely to become unable to continue providing care, either because they become ill themselves or become overwhelmed.<sup>43,44</sup> *Their own health and well-being is just as important as that of the patient.*

# MAINTAINING A BALANCE

## CAREGIVER'S OWN NEEDS

## NEEDS TO BE ABLE TO PROVIDE CARE

### *PHYSICAL*

- Maintain physical health
- Strength to provide care
- Sleep
- Rest

### *PSYCHOLOGICAL*

- Cope with strong and difficult emotions
- Maintain mental health
- Manage anxiety
- Avoid depression
- Be supported emotionally
- Maintain self-esteem
- Recognition of their anticipatory grief
- Relieve guilt

### *COGNITIVE*

- Maintain cognitive functioning
- Get a mental break from caregiving and the illness
- Have privacy

### *EXISTENTIAL/SPIRITUAL*

- Retain hope
- Feel in control
- Find meaning in their new situation
- Strength from spirituality/faith
- Feel reward from caregiving
- Prevent isolation

### *SOCIAL*

- Financial security
- Learn new roles
- Be helped with other roles
- Cultural needs/differences to be respected

### *INFORMATION*

- Obtain and understand information about the patient's condition
- Feel prepared to provide care

### *HEALTH CARE*

- Healthcare team to be competent
- Healthcare team to be available
- Access to assistive devices
- Be comfortable with the way they are involved in decisions for the patient's care

### *RELATIONSHIPS*

- Patient appreciation of their caregiving
- Have a good and trusting relationship with the patient
- Have a good and trusting relationship with the healthcare team

### *ENVIRONMENT*

- Have a safe environment
- Have modifications made to the home

### *PSYCHOLOGICAL*

- Feel confidence in their caregiving ability/role

### *TAUGHT HOW TO AND/OR HELP WITH:*

- Administer medications through numerous routes (i.e. injections, suppositories, oxygen masks, etc.)
- Move and position the patient
- Be able to safely toilet, feed, bathe, and transfer the patient from one position to another
- Monitoring/assessing symptoms
- Emotionally support patient
- Household tasks (they are increased)
- Coordinate and navigate care
- Organize (e.g. medications, appointments, time for everything)
- Ask others for help
- Access available financial benefits
- Transport the patient and themselves if patient is not living at home
- Plan for death

## CAREGIVERS ARE PART OF A FAMILY

To help the caregiver to cope, it is important to understand the family or families that they are part of and their role in them. Families vary widely in their ways of functioning. Learning from the caregiver about how the family usually functions as well as how it is functioning now will help you to guide the caregiver.

Many families have longstanding difficulties functioning. While it is possible for the patient's impending death to act as a catalyst to improve functioning, it is likely that those issues will not be resolved at this time, when the family is experiencing added stressors related to the illness; the stress may even exacerbate the difficulties. It is easy to become focused on the family's shortcomings, but it is important to focus on family strengths. This can help counter a sense of helplessness, failure, and despair<sup>45</sup>.

## FAMILY CULTURE

Each family has its own culture. For example, it may have:

- its own way of sharing everyday life;
- its own beliefs shaped by dynamics of the family of origin, dynamics in their current family, religion, country of origin;
- shared attitudes, values, goals.

Individuals in the same family can differ in the degree to which they share or accept these ways, beliefs, attitudes, values, and goals. This is not problem in families that are accepting of such differences, but can be a problem in families that are rigid in their ways.

Having a shared family culture can help the family to function. However, in some cases, a family culture that served the family well in the past may not be adaptive when there is a family member who is dying. Families that have a more flexible culture are more likely to cope well in this case than those whose culture is not adaptable.

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# *INTRODUCTION TO A CAREGIVER GUIDE SERVICE*

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## THE IDEAS AND VALUES BEHIND OUR CAREGIVER GUIDE SERVICE FOR FAMILY CAREGIVERS

*In palliative care* we believe that the patient and their family are the unit of care; the well-being of both is equally valued.

*The goal of care* is to optimize, given the situation, the patient's and family's quality of life.

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*The goal of this service is to improve the coping of family caregivers of people near the very end of life, in order to reduce their stress in order to help them maintain their health and make their quality of life as good as it can be in this difficult and challenging situation.*

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If we can help the family caregiver to maintain their own wellbeing, the patient's wellbeing may improve and the family caregiver may be able to provide care for longer, if that is their wish. It is important NOT to try to convince caregivers to continue to provide care at home when they feel that they can no longer manage.

#### *VALUES OF THE CAREGIVER GUIDE SERVICE*

- Respect and compassion for everyone involved (family caregivers, patients, Caregiver Guides, health care providers )
- Recognition and cherishing of individual differences
- Doing no harm
- Helping each other
- Learning from our mistakes (they happen to everyone)
- Commitment to the project
- Transparency in planning, implementing and evaluating the service
- Appreciating what everyone brings to patient and family care, recognizing individuals' rights to self-determination through their own choices and actions
- Integrity and trust
- Confidentiality
- Cultural sensitivity
- Responsibility and accountability

## THE MODEL OF COPING AND STRESS USED IN THIS GUIDEBOOK

Folkman and Lazarus<sup>1-4</sup> developed the model of stress and coping that we are using to guide the Caregiver Guide Service. This model is briefly explained in this section.

**Coping** is what people think and do to manage undesirable situations that matter to them. It can focus on solving problems or, especially when problems can't be resolved (e.g., the patient is dying), on managing emotions and the meaning of the situation to them. More than one of these ways of coping can be used in a single situation. Some ways of coping are likely to be helpful while others are not. The most effective way of coping will differ from situation to situation and from person to person.

**Stress** occurs when a person feels that they are not able to manage (or cope with) a situation that is undesirable and important to them. What makes a situation stressful to an individual is determined by their beliefs, values, and goals, and their coping resources (material, physical, psychological, or spiritual). In this way, what is stressful to one person may not be stressful for another. The greater the gap between the coping resources and the demands of the situation, the greater the stress will be.

## WHAT CAREGIVER GUIDES DO

Some people have all the coping resources they need and will use them - they will do fine without help in this situation. However, for most people, being a family

caregiver of a person who is dying will require more coping resources than they have on their own, or different ones than they have used in the past. Alternatively, they may be so overwhelmed that they cannot articulate their own needs in this unique circumstance. While they may have the resources available they may not think of using them or have time to find them. Some caregivers do not realize that they are not coping well.

As a Caregiver Guide you will guide them to find within themselves and within their family, friends, healthcare professionals and community the resources they need to cope. You will also act as a resource in some cases, but much of the time your goal will be to empower them to manage on their own, since you will not always be available. They will be able to use some of the skills that you teach them throughout their life.

## WHERE CAREGIVER GUIDES FIT IN THE CARE TEAM

It is important for Guides to know how end-of-life care and bereavement services are organized in their region. This can be given to Guides by the Guide Coordinator if there is one or a member of the palliative care team.

## ROLE OF THE CAREGIVER GUIDE COORDINATOR

The Caregiver Guide Coordinator can:

- provide support to the Guides, both practical and emotional;
- provide information regarding resources;
- organize and lead the team support meetings of the Caregiver Guides (explained below);
- interview family caregivers in order to screen out any that are not appropriate for the Caregiver Guide Service if the service has exclusion criteria (e.g. home is not safe, there is no Guide who speaks their language);
- explain to the family caregivers what the service offers;
- match family caregivers with a Caregiver Guide;
- troubleshoot any issues that arise (e.g., a visit to the family caregiver needs to be rescheduled; the family has unreasonable expectations of the Caregiver Guide);
- liaise with the palliative care team (if one is available) to ensure a smooth interface between the services.

If there is no funding for a Guide Coordinator, highly motivated and available Guides might choose to share the role, although we have not yet tried this model.

## LEARNING AND SUPPORT MEETINGS FOR CAREGIVERS GUIDES

Guides have a team meeting approximately every 3 weeks, along with the Caregiver Guide Coordinator, so that they can learn from and support each other.

This is the most important way for guides to improve their ability to guide caregivers in a wide variety of situations and to gain confidence in their guiding.

Each Guide's experience with their caregiver is discussed (omitting details that could easily identify the caregiver or patient), with a focus on the more challenging situations. In this way each family caregiver benefits from the wisdom and creativity of all of the Guides and the Coordinator. Once the service is established, new Guides can benefit by attending these meetings before they are assigned to a caregiver. What is discussed at the team meeting remains strictly confidential.

### WHAT THE GUIDES SAID

*"I would say [the team meetings] were essential, because it allowed me to throw stuff on the table that was of huge concern to me, and then to get very-very non-judgemental and completely open and intimate comments on it. That is... otherwise you're alone, so without those team meetings, wow! How would you... because you did need somebody who was up to their eyeballs in the same sort of thing, different, to say 'What about trying this? What about trying this? What about that? Did you think of this?', you know, 'Geez, no, I didn't!' ... So it really did energize you."*

*"What I found a bit challenging is... I always question myself, for instance, when I... Let's say, very early on when I had difficulty [getting the caregiver to let me visit in person], I thought, OK, then, should I go back to the team and say, OK, what should I do? Then I realized, no, it's not about that, you cannot... No matter how much you think of it, it is situational, so that's where I had to find, within my own self, resources and figure out what I would do, is come back... rather than ask, what should I do, then I would take it back to them, and that's where the Guide Coordinator became very useful, and the other members of the group in our meetings, and I would just talk through what was the difficulty, and then this is what I did, ... So, in a way, that's what I did, I kind of looked at, for the things where I think I had some gaps, I brought it back to the team, and then with their input, I was able to say, OK, for the next time. So it either reinforced [what I was doing], or I had new suggestions, I had new ideas as to how to go about things."*

## BOUNDARIES FOR CAREGIVER GUIDES

Successful guiding begins with establishing a trusting relationship between Guides and family caregivers. This allows the caregivers to discuss concerns and feelings with the Guides that they may not feel free to discuss with the patient, other family and friends, or health care providers. While they do not become friends, the relationship is closer than that of acquaintances.

Boundaries are not clear cut in this situation. While the service needs to take measures to protect caregivers, patients, and Guides from major harm (such as the Guide doing something with the patient that they are not trained to do), the desire to protect from any potential minor harm needs to be balanced with respect for the fact that the caregivers and Guides are adults capable of making their own decisions. What each Guide and each caregiver are comfortable with is individual, and therefore needs to be negotiated in each relationship.

It is still important to make the Guide's personal boundaries clear to the caregiver.

This means that:

- while not providing advice in the form of "This is what you should do", as part of their role Caregiver Guides will need to make suggestions and explore with the family caregiver what might work for them ("This is what some family caregivers find helpful"). Caregiver Guides and family caregivers will work collaboratively.
- clear limits as to what the Caregiver Guide does and doesn't do, as well as to the time availability of the Caregiver Guide need to be established at the outset with the family caregiver.
- it is natural in the home setting for the family caregiver to want to provide simple hospitality to the Caregiver Guide. For example, while we don't want the family caregiver to be going out of their way to entertain the Caregiver Guide, they may offer food and drink, and it is normal courtesy to accept; this promotes building of the relationship with the Caregiver Guide. Similarly, if the caregiver chooses to meet the Guide in a coffee shop and wants to buy the Guide a coffee, this would be ok some of the time, as long as the Guide can buy the coffee other times. However, it would not be alright for the caregiver to pay for a full meal.
- there is always the possibility of "awkward" moments arising while part of someone's life, in someone else's home. These moments that prompt discomfort, whether they be inappropriate or unusual, should be recognized as such and limits should be re-iterated by the Caregiver Guide. These moments can be personal, financial, etc.
- it is up to each Guide to decide whether or not to give their phone number to the caregiver so that the caregiver can reach the Guide directly, rather than

through the Guide Coordinator. While caregivers prefer to reach the Guide directly, if you give a caregiver your phone number there is a small risk that the caregiver may call at inappropriate times or too frequently. If you are considering giving out your number, we suggest that you only do so after you know the caregiver well enough to form a judgement about whether they will use it as you want. An alternate way of direct contact for caregivers who use email is for the Guide to set up an email address specifically for their guiding and to give that address to the caregivers.

- if the Guide and caregiver have developed a relationship that they both enjoy, it can be hard to say goodbye at the end of the service.

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# GUIDING FAMILY CAREGIVERS TO CARE FOR THEMSELVES

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## WHY DO FAMILY CAREGIVERS NEED TO BE GUIDED TO TAKE CARE OF THEMSELVES?

Family caregivers put the patient first and often do not see themselves as needing care. They also don't want to take away time and services from the patient.

They often neglect their own physical and mental health needs, pushing themselves beyond their limits. Sometimes they don't notice their own symptoms of distress, other times they notice but ignore them. For example, many will not sleep, forget to eat and even put off seeing their own doctor when needed.

If caregivers don't take care of themselves many end up suffering more than they need to and, in some cases, develop or worsen physical or mental illnesses. The primary goal of a Caregiver Guide service is to prevent this whenever possible. In addition, caregivers who learn to take care of themselves and to reach out for help in caring for the patient may be able to keep the patient at home longer, if that is their wish. The advantage of having a volunteer Guide service separate from services for the patient is that the family caregivers know that accepting this help will not take away services from the patient, the caregiver's needs do not get neglected by attending to the patient, and caregivers can see that their own needs are legitimate.

### FROM A FAMILY CAREGIVER

*"...just [the Guide] reminding me to take time for myself, and... a lot of us are very bad at policing ourselves, or having self-discipline, because we're looking at, 'OK, I'm caring for my wife, I'm worried about her, I'm worried about the kids, I'm worried about the business', so you're kind of like you don't have the instinct to allow yourself to have a rest. But having someone above you, to say, 'Hey, you'd better rest! What did you do to rest?', so you're kind of... If you have to answer to someone, then you can like think about it more, like, OK, I'd better do something to rest."*

*Of all the people on the care team, including the family caregiver, only the Caregiver Guide focuses primarily on the family caregiver's wellbeing.*

## WHAT CAN A CAREGIVER GUIDE DO?

- Listen actively.
- Provide information.
- Provide emotional support.
- Normalize what the caregiver is feeling.
- Help the caregiver to see the value in their caregiving. They may take what they do for granted (“It’s just what I do”), underestimating all that they are doing for the patient and for others.
- Explain to the family caregiver that in order to be able to continue to care for the patient, they need to maintain their own health and well-being. Guide caregivers to take care of themselves, in ways that are compatible with caregiving (this often requires creativity).
- Assess the family caregiver’s needs since they may not spontaneously tell you or health care providers what they need (a list of common needs is in the Maintaining a balance table). Needs should be assessed on an ongoing basis. Encourage caregivers to ask family, friends, health care providers, and community resources to help them meet each of these needs. Let the caregiver know that almost everyone needs help in this situation. Help the caregiver develop a list of family and friends who can help them with needs related to both caregiving and care of themselves. These two types of needs are related because caregiving needs that are met by others tend to free up time and energy for the family caregivers to take care of themselves.
- Suggest and demonstrate simple activities that they can do at home to help them maintain their well-being.
- Let caregivers know what other caregivers have found helpful.
- Teach problem-, emotion-, and meaning-focused coping (described later).

### WHAT THE FAMILY CAREGIVERS SAID: A UNIQUE RELATIONSHIP

*“[Guide] was also very empathetic and listened, but it is really [that it is] someone who is there for me (...) and not for the two of us. And that’s something that I really appreciated, someone who is there exclusively to listen to me.”*

*“... I think the most important thing that I found is having someone to speak to. You know, just openly, someone who’s not my family or not friends, because they all have a history with me and my wife, you know, and so sometimes it’s difficult to... just be upfront.”*

*“... one could say that I no longer had much place in all this, as though my life was really suspended, waiting for it to begin again, I think that [the Guide] helped me maintain the flame of my own life to keep it from being extinguished, so that I could continue to get through this without losing myself completely.”*

- Guide family caregivers to develop and use their own tools to cope and manage difficult situations.
- Provide caregiving tips, and accept that it is up to the family caregiver to use them or not.
- Encourage the family caregiver to seek professional help when needed.
- If the Guide is working with a clinical service, be the eyes and ears in the home of the health care professionals: let them know when you think the family caregiver or patient is heading for a crisis or already in one.

*CAREGIVER GUIDES SHOULD NOT:*

- tell the family caregivers what they should do, only what they might consider doing;
- take it personally if the family caregivers are not interested in their suggestions or do not follow through with them;
- say anything that might make family caregivers feel guilty if they choose not to take care of themselves and later become unable to provide care.

## ESTABLISHING A RELATIONSHIP

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*"... it's [the Guide's] humanity, but at the same time, it is really his experience..." [Family caregiver]*

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The first thing a Guide needs to do is to get to know the family caregiver, the caregiver's perception of the patient and the rest of their family, and establish a trusting relationship. Guiding can only be helpful if a trusting relationship is established. Building this trust takes some time.

To trust you, family caregivers need to come to feel the following.

- You are interested in who they are.
- You accept who they are and don't judge them.
- You respect them.

- You will respect their boundaries.
- You will get to know and respect what they want and don't want.
- You are open to learning their ways, what makes them comfortable, and what they need (rather than assuming that you know).
- You will be honest with them.
- They can trust you to do what you say you will.

Some practices that can help establish this type of relationship

- 1) Compassionate neutrality
  - Give the caregiver the space to feel the way they do
  - Give caregiver time to express themselves (if that is what they want to do)
  - Provide support rather directing them
- 2) Respectful curiosity
  - Be open to understanding and learning about the caregiver's world
- 3) Know what it is that you don't know
  - Acknowledge it clearly. Then offer to find out and bring the information back to the caregiver.
- 4) Reliability
  - Be on time for visits (in person and by phone)
  - Follow up when you say you will

#### ADVICE FROM A GUIDE

*"When I met [my first caregiver]... There was definitely that sense of, OK what am I going to do here. What's this going to look like, that sort of anticipation, What can it really bring? And I kind of felt that she had the same feeling as well. Like, what is this, what's going on with this, what kind of expectations can we have of each other, what kind of help can I really bring her? So there was that getting-to-know-you period. [...] I definitely think, with two consecutive caregivers, if I had something to do differently [...] it would be to back off on needing to create this bond right away. Like I felt this incredible pressure to... Bond! I must bond! There must be bonding! And if I had a third family caregiver, I would let that bonding develop in a more natural kind of way. And accept it could take one, or two, or three communications to get a sense of each other."*

## FIND OUT WHAT THEY UNDERSTAND ABOUT THE PATIENT'S ILLNESS

In order to Guide the caregiver, it is important to find out what they and the patient understand about the illness. With that clarification you can put what they say into context and be respectful of their understanding.

Communication with people in denial can be challenging and for that reason it may be best left to a health care professional. In our study we did not recruit people in denial. We include the box below on denial in case, as a Guide, you nevertheless encounter a caregiver or patient in denial<sup>1</sup>.

### Denial

Denial is a coping mechanism. People who use denial may need this to be able to continue functioning, as they may find the illness too threatening to acknowledge or tolerate. Therefore confronting denial is not advised.

Denial is often misunderstood as referring solely to denial of the disease. This form of denial is in fact rare. However, minimization of the implications of the disease or its symptoms is a more common expression of denial.

**Denial can occur with awareness, as it is a fluid process which may fluctuate throughout the illness... This awareness can be expressed nonverbally (e.g. a patient giving away their precious possessions).**

Denial is easily confused with hope. Someone can be realistic about the situation but still hope for a better outcome. They may even make some plans for the better outcome, just in case it happens, knowing all the while that it is unlikely.

### TO ASSESS DENIAL, WHAT CAN CAREGIVER GUIDES ASK?

- Help me understand. What has been explained to you about your family member's illness?
- What do you expect will happen in the future?
- What does your family member understand about the illness?

## FIND OUT ABOUT THEIR FAMILY

Family members are experts about the culture in their own family. With an attitude of respectful curiosity, you may be able to learn much from the caregiver about their family situation. This understanding may help you to understand some of the difficulties the caregiver faces but also some of the help that they can count on.

It is important to be compassionate but to maintain a neutral position. Each family member has a different role in the family. No two family members share an identical relationship with the patient. Each will likely have their own understanding of the family and the situation. These differences are at the heart of many family tensions and conflicts. Generally there is no clear right or wrong.

## WHAT CAN CAREGIVER GUIDES SAY?

- Tell me about your family.
- What is the patient's usual role in the family? Can you describe what he or she was like before this illness? How did the patient function in the family before they became ill?
- What is your usual role in the family? What is it now?
- How is it going within the family?
- If discussing the family seems to be upsetting rather than helping the caregiver, acknowledge their frustrations and aggravations.
- Is there anything at this time that can change this for you?

## WHEN SHOULD CAREGIVER GUIDES INTRODUCE TO THE FAMILY CAREGIVERS THE IDEA OF TAKING CARE OF THEMSELVES?

Since we are trying to *prevent* problems, it is essential to introduce the idea that it is important for family caregivers to take care of themselves as soon as possible. If they mention something in conversation as being a problem (e.g., they feel very stressed), that is a good time to see what they are doing about it and to work together with them to come up with some suggestions for addressing it. Have them describe the problem and the situation in which it occurs in some detail to help the discussion.

## WHAT CAN CAREGIVER GUIDES SAY?

You might want to begin by asking them what they are doing to address these needs or problems and if they would like some (other) suggestions. For example:

- You are doing so much, it is not surprising you feel stressed. Is there anything you do during your day that helps bring down your stress level when it gets high?
- You're having trouble sleeping. It's normal to lose sleep when caregiving. Is there anything that helps you get a better sleep?
- If yes: What makes it hard for you to do that more often? Then, if modifiable, you can use problem-solving techniques (in a later chapter) to address the barriers.
- If no: There are some things that have been found to be helpful by others in your situation, would you like to hear about them?

Some of the caregivers' self-care needs will be best addressed through problem-solving coping, some through emotion-focused coping, others through meaning-focused coping (explained later), and some through a combination of these. For example, stress can be relieved by taking better care of yourself physically, talking with a friend who provides positive emotional support, and/or looking at the situation in a new way. Since you can't know in advance which of your suggestions they would like to try, it is best to suggest a few and see which one interests them the most before going into detail. There are many suggestions in this guide.

## WHAT IS THE PURPOSE OF RECOGNIZING THE NEEDS OF FAMILY CAREGIVERS?

*It is important to focus support where family caregivers most want it.* This will differ for different family caregivers. The only way to know what type of support they need is to open up a conversation with them about what their most important unmet needs are and how they themselves, their family and friends, you (within your boundaries and limits), or the healthcare team can provide the needed support. Identifying significant or urgent needs will help prevent them from becoming a crisis. This might help maintain the family caregiver's health as well as their ability to care for their loved one. The "*Maintaining a balance*" table above lists some common needs to consider exploring.

Many caregivers will not realize what a Guide can offer besides emotional support and providing information about available services. They may not tell you about needs that they don't think you can help them with. It is important to let them know about the many things you can help them with and for you to specifically ask about some of them. For example, you may need to ask them how their sleep is, or if they are having trouble preparing meals. If they have a need that you alone are unable to meet, tell them that you'll speak to the Caregiver Guide team to see if someone else has suggestions.

### EXAMPLES OF SIGNS OF SIGNIFICANT OR URGENT NEEDS

Many of the issues below can arise appropriately under the circumstances of caring for a dying loved one. However, it is important to recognize when these progress to the point of being a barrier to the everyday functioning of the family caregiver.

Statements indicating a lack of understanding: about the illness, general management of their loved one's situation, legal/financial issues, practical questions etc.	<b><i>I don't understand his/her illness. I get the medications mixed up. I don't know what to do if he/she dies at home. I get mail from the bank in difficult jargon I can't get my head around. The laundry is piling up, I'm not sure how to use the machine.</i></b>
Tiredness caused by the intense caring process	<b><i>I feel too exhausted to go on, but I have to keep on going.</i></b>
"Life" questions	<b><i>Why is this happening? Does God exist?</i></b>
Health problems that begin to take a mental or physical toll	<b><i>My back hurts from the lifting.</i></b>
Social isolation	<b><i>I don't have time to return phone calls from family and friends or visit them</i></b>
Patient's demands are a risk to the caregiver's health	<b><i>He is afraid he'll die alone, so he wants me to stay awake next to him all night.</i></b>

### ***Opening the conversation: things you could ask the family caregiver to begin to assess their needs***

- Tell me what the average day is like for you.
- How are you feeling? How's (the patient) doing?
- Is there anything you need? Anything I can help you with?
- Do you have any specific questions?
- Are you having any physical problems?
- How is your sleep? Is it good enough for you?
- What do you do to relax? To take your mind off the illness?
- Have you been quick to anger or overly irritable? Are you feeling resentful?

- Have you considered asking someone to help with this? (This person could be another family member, friend, health care professional etc.)
- *Ask the family caregiver to elaborate on their answers.*

***Things you could ask the family caregiver to open a conversation to explore how they can be better supported to meet specific needs:***

- Can you tell me more about what sort of help you need with \_\_\_\_\_?
- What have you done in the past to get help/to help yourself with this type of thing?
- What would be most helpful?
- Do you have any family or friends who can help with \_\_\_\_\_?
- If it is an issue that likely should be addressed by the healthcare team: Did you discuss this with your doctor /the patient’s healthcare team?
  - If yes: What did they say?
  - If no: Maybe you should let them know.

***COMMON REASONS FOR CAREGIVERS NOT ASKING FOR HELP<sup>2</sup>***

- Embarrassment
- Afraid of disturbing or imposing
- Fear of being refused
- Fear of appearing demanding
- Fear that people will feel obliged to say yes
- Fear that asking for help will be seen as a sign of weakness
- Thinking that people should know what is needed
- Used to taking care of things on their own and keeping problems to themselves
- Feeling that everybody is too busy with their own life
- Thinking they can do it on their own
- Feeling that the patient will react badly to someone else helping (this may be the case but it needs to be addressed)
- Feeling that in the end it's not so bad
- Convinced that it's too complicated to ask
- Put off until later
- They may feel unworthy or undeserving of help

## ENLISTING HELP TO ADDRESS CAREGIVER NEEDS: DEVELOPING A CARE CIRCLE

Sometimes family caregivers think they need to do all the caregiving, as well as their own and the patient’s household tasks, by themselves. It may be helpful if you let them know that almost everyone needs quite a bit of help when their family member is this sick.

Often family caregivers don't know who to ask for help. Sometimes they know who to ask but don't feel comfortable asking for help. On the other hand, family and friends often want to help but don't know what might be helpful. They might say: "Let me know if there's anything I can do" and really mean it, but often the family caregiver does not take them up on their offer. As a Caregiver Guide, you can assist them to make the best use of family and friends who might help, as well as of community resources, by developing a Care Circle together with them. A Care Circle is a list of the caregiver’s needs that are matched with a list of the people or community resources that can

provide this assistance. *It is important to remind family caregivers that family and friends who offer to help feel good when they are taken up on their offer.*

Usually each family member, friend, or community resource is good at doing some things but not others. Some may be very good at giving emotional support but not good at doing practical things such as grocery shopping or cooking a meal and *vice versa*. Some may be good at caring for the patient and able to stay overnight so that the family caregiver can get some sleep, while others might be more comfortable visiting with the patient in the daytime so that the family caregiver can have a chance to do something to give themselves a mental break from caregiving and to restore their energy. Others may be good at searching the Internet or elsewhere for *reliable* information.

Family caregivers can also become so overwhelmed that they don't recognize the extent to which they are struggling, and don't even think of asking for help.

Once you are aware of some of the family caregiver's needs, you can discuss with them who among their family and friends might be best at helping with each need. If there is no one in their circle of family and friends who can help them meet a need, there may be a community resource that can help. Family caregivers will rarely have time to find available community resources themselves, although sometimes this is something another family member or friend can do. The Guide Coordinator can help you find resources in the community.

Sometimes it is helpful to create a written list of their needs, people or services who might help with each, and their phone number or other contact information. Leave several blank spaces at the end for new needs that will arise.

Sometimes the needs are so great that they can't be filled without being burdensome or they can't be met while the patient remains at home. In this case it is important to encourage the caregiver to contact the health care providers to let them know this. If the caregiver the Caregiver Guide service is closely linked with a health care service, you can let the Coordinator know so that the health care team can be informed.

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# COACHING FAMILY CAREGIVERS TO COPE

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All parts of this guide about guiding family caregivers to care for the patient or themselves are about guiding them to cope. This section differs in that it covers the three kinds of coping (problem-, emotion-, and meaning-focused) in a more general way that can be applied to any problem the family caregiver is having trouble coping with.

## OVERVIEW OF THE STRESS AND COPING PROCESS

Stress creeps into our lives without our inviting it in. However, the ways of boosting our coping in order to reduce stress often require some learning or changes in what we usually do, towards which the Caregiver Guides guide the family caregivers.

- 1) The first thing to do when trying to cope better with a stressful problem is to try to understand it better.
  - What exactly is the problem?
  - What is the nature of the problem?
    - Practical? Examples: pain control; need to get out of the house.
    - Emotional? Examples: anxious; irritable.
    - Related to the meaning of the situation? Example: having to build a new life.
  - What are the family caregiver's beliefs, values, and goals related to the problem?
  - What would the family caregiver like to happen?
  - Why does the problem exist?
  - What are the contextual factors (e.g., within the patient, family caregiver, family, social situation, etc.)?
  
- 2) Select a coping strategy that matches the type of problem.
  - If the cause of the problem *can* be modified, coping strategies to try to reduce or eliminate the problem can be used. These types of causes are often of a practical nature.
  - If it likely *cannot* be resolved, then coping strategies aimed at modifying emotions and the meaning given to the stressful problem can improve coping.
  - For many problems, a combination of strategies works best. Two examples of problems and some different kinds of coping follow.

**EXAMPLE 1.**

The patient is in pain and the family caregiver feels terrible about this.

Type of coping	Way of coping	Likely to be helpful
<b>Solving problems</b>	Give pain medication	Yes
	Call the healthcare team	Yes
	Repeat a solution that didn't work the first time	No
<b>Managing emotions</b>	Talk to a supportive friend	Yes
	Tell yourself to keep calm until the pain medication begins to work	Yes
	Drink alcohol to not feel the emotions	No
<b>Adjusting the meaning</b>	If you are worried that the pain may never get under control, remember that you have been able to bring the pain under control in the past, and that the doctor said there are other things that can be tried, so this is likely a temporary situation.	Yes
	You are only human, you did not cause the pain, but you might bring relief.	

**EXAMPLE 2.**

The family caregiver is afraid of being on their own in their bereavement.

Type of coping	Way of coping	Likely to be helpful
<b>Solving problems</b>	Join new groups	Yes
	If the feeling is severe, call a health professional	Yes
	Stay home and wait to be invited out	No
<b>Managing emotions</b>	Talk to a supportive friend	Yes
	Do relaxation exercises	Yes
	Cry <i>all</i> the time	No
<b>Adjusting the meaning</b>	This is an opportunity to do new activities important to me	Yes
	I did fine on my own when I was younger and will learn to do so again	Yes

## HOW DID THE FAMILY CAREGIVER COPE IN THE PAST?

Often the most effective coping strategies will be those that the family caregiver has *successfully* used in the past. Because they are so busy providing care, the family caregiver may have forgotten to try them or is not thinking about taking care of themselves.

Caregiver Guides can ask the family caregiver how they coped in the past with a similar situation or other stressors and explore with the family caregiver whether any of these coping strategies might be helpful at this time. Sometimes a little creativity may be required to adapt the previous strategies to the current situation.

***For example, if they previously went to the gym or a yoga class to de-stress, they might now need to find a way to be physically active at home or arrange for a family member or friend to stay with the patient while they go out to the gym, for a walk or a jog.***

If the family caregiver has already tried their previous strategies and they are still having trouble coping, if the strategies seem to be inappropriate for this situation, or if they feel they never had particularly successful strategies, it may be helpful for you as a Caregiver Guide to suggest and explain some new strategies from the chapters that follow, what other caregivers have found helpful, what you have found works for you, or what other Guides suggest at a team meeting.

## WHAT IF THE FAMILY CAREGIVER IS COPING POORLY?

Because watching a family member deteriorate and caring for them at the same time is an extremely demanding situation, often, at some point, the demands of the situation will exceed the family caregiver's ability to cope well, even with your guiding. The point when this may be reached differs from person to person.

***If you think that a family caregiver is coping so poorly that it is affecting or will affect their well-being or that of the patient, you should make the Caregiver Guide Coordinator aware of it before it becomes a crisis, so that the Coordinator can alert the health care team.***

This might help maintain the family caregiver's and/or patient's health, their quality of life, and possibly the family caregiver's ability to care for their loved one. The family caregiver's well-being is just as important as that of the patient.

***Patients can be admitted to a palliative care unit or hospice to maintain the well-being of the family caregiver as well as that of the patient.***

## **PROBLEM-FOCUSED COPING**

Here is a 7-step process to guide you and the family caregiver through solving a difficult problem *that can likely be modified*. It is probably best to first work through a problem with the family caregiver before they use this process on their own.

### *SEVEN-STEP PROCESS TO SOLVE A DIFFICULT PROBLEM*

#### ***Step 1: Identify the problem***

One of the most complex tasks of problem solving is identifying the problem to be solved. The stressful situations of family caregivers can often seem overwhelming and too complex to handle. The first step is to give perspective and take stock of the situation. Focus on one main issue or problem that needs attention.

In the home of a dying patient, the family caregiver can be overwhelmed with money issues, time management problems, food availability, and finding time for respite, in addition to visits to doctors, and the daily (and often numerous) needs of the patient.

*In an overwhelming situation, it may be helpful to take the most stressful and difficult problem, isolate it, and make it the focus of your attention. Bringing the family caregiver to focus on one problem at a time is difficult.*

*Try asking leading questions, such as: "If there was one issue in the day that stresses you the most, what would that be?" The answer could be as simple as "How do we make the time to buy groceries?" or as challenging as "I can't cope with his moaning when he is in pain."*

### ***Step 2: Set an objective***

The next step is deciding what change to work towards. Help the family caregiver come to an understanding about realistic and focused goals. Having one principal goal is the most productive and realistic approach to solving the problem. Together you can come up with practical and achievable goals that relate to their problem. If you carefully examine the seemingly simple problem of finding time to buy groceries, you may find that the objective is to get adequate food into the house. However, it is possible that the family caregiver also wants to go grocery shopping in order to have a chance to get out of the house. Being very specific about the goal will help focus in on potential solutions.

### ***Step 3: Brainstorm Possible Solutions***

Now that you have defined the problem and one or more objectives, allow the family caregiver to take some time to brainstorm some possible solutions. At this step it is important not to limit ideas based on how feasible or desirable they might be. That will be considered later. In the brainstorming step you and the family caregiver create a broad and inclusive list of potential solutions to their problem. You can help them explore their options.

Here is an example:

*"I can't find time to buy groceries"*

Possible solutions:

- Ask a friend, neighbor or family member to do the groceries.
- Ask someone you trust to stay with the family member while you go out.
- Have the groceries delivered.
- Have a community health care agency provide care for the patient to allow the family caregiver to buy groceries.
- Hire private help to stay with the patient.

### ***Step 4: List the pros and cons of each solution***

Now that you and the family caregiver have a broad list of solutions, go over the list of potential solutions with the caregiver. Have the caregiver generate some of the advantages and disadvantages of each solution. Eliminate ones that could potentially lead to harm. This is the stage at which to try to help them focus on solutions that are the most realistic. Allow them to ask themselves which solution would possibly reduce their stress the most.

### ***Step 5: Decide on a plan of action***

You and the family caregiver have identified the problem to tackle, you have set one or more reasonable objectives, and have listed a wide variety of possible solutions and their relative advantages and disadvantages. The next step is to determine which of the solutions is most appropriate, realistic, and has the best chance of success. But don't throw out the list from the brainstorming! If the solution chosen doesn't work, another from the list can be tried later on.

*Ideally, you and the family caregiver review your list and pick the solution with the clearest advantages and the least disadvantages. It may be difficult for the stressed family caregiver to decide on a plan of action. You can always guide them to the list of pros and cons to help them come to an "objective" decision and commit to a course of action.*

### **Step 6: Implement the plan of action**

As you and the family caregiver proceed through the process of problem solving, this step can be both the easiest and the most difficult. It should be easy because you and the family caregiver have compartmentalized and isolated the problem into a manageable issue with a defined plan of action. It is likewise the most difficult because it involves taking the carefully devised plans and putting them into action!

*When you and the family caregiver decide to take action, make sure that despite your role in helping them in the process, it is in fact the family caregivers themselves who put the plan into action. It is easy for lines to become blurred as you enter other people's lives, but the most rewarding and useful part of this exercise is facilitating the confidence-building that people need to engage in as they move through a stressful situation from problem to solution. This way they can use the process to solve future problems on their own. Be encouraging, straightforward, and most importantly, supportive.*

### **Step 7: Assess the outcome and re-evaluate**

This step will probably happen on your next visit. The problem has been defined, possible solutions outlined and weighed, and a course of action set and completed. Now is the moment to look back on the events and decide if the course of action was successful. If the problem is solved, then the activity was a success. However, if the outcome was not the expected and/or desired outcome, it is time to help them go back and re-evaluate. The most straightforward method of proceeding is to look at the other possible solutions generated, along with their pros and cons, and try another option with a realistic chance of success. This process can be repeated again until a successful solution is achieved.

*It is important in this process for you to keep on encouraging the family caregiver in their pursuit of a solution to their problems. It is often difficult for the family caregiver to be objective in evaluating the outcome. Be patient, kind, and try to lend some outside perspective without judging.*

#### *SOME KEY TIPS*

##### *Tip #1: Guide the caregiver*

Guide the family caregiver to develop a problem list on their own and come up with their own solutions.

##### *Tip #2: Define the problems*

Define the problems in as clear terms as possible. The more vague the problems are, the more difficult a plan of action is to define.

##### *Tip #3: Be realistic*

There are certainly going to be problems with no easy solutions. The process is still the same. Come up with a defined problem and work through the steps.

##### *Tip #4: Don't be afraid of failure*

The issues are difficult, and not every problem has a comfortable solution. Sometimes the plan of action will work, but other times it may not. Be supportive, present, and willing to help them try again.

##### *Tip #5: Keep it simple*

Simplicity is harder to achieve than most people think. Keeping the ideas and the plans as simple as possible is the surest way to succeed.

#### *WHAT IF THE PROBLEM CANNOT BE SOLVED?*

Even though a problem seems like it is potentially solvable, sometimes none of the solutions available to that family caregiver will work. This is especially common when the patient is near the end of life, because the situation can change so rapidly that what were likely solutions one week are no longer possible the next.

It may be time to involve formal health or social services if they are not already aware of this particular problem. In addition, it is definitely time to look at

*Caregiver: "I accepted that I couldn't be there all the time, and one of my sisters came to help me, and then I found someone to come in the mornings, that way I could work in the morning, and I also found someone to come on mornings on the weekend, that way I could do my shopping and things like that."*

*Interviewer: "Did you do this yourself, or did the Guide encourage you?"*

*Caregiver: "She encouraged me, otherwise I would have tried to do it all myself. (...) And I wouldn't have been able to do it, it was crazy, it was impossible."*

managing emotions and meaning, as described in the following sections.

## COPING WITH DIFFICULT EMOTIONS

Some emotions, such as anger and guilt, although common, are rarely desirable when a loved one is dying or once the caregiver is in bereavement. Others can be so intense as to be paralyzing, such as fear of what might happen next, or of doing things on your own rather than as a couple. As a Caregiver Guide you can teach the family caregivers some strategies for managing undesirable emotions if the strategies they are using are not working well enough.

### TALKING

For many people, *but not all*, talking to a friend or family member who is a good listener will be helpful. (While talking with you may be helpful to the caregiver, you will not be available whenever they need to talk, so they will need others to talk to as well.) However, many well-intentioned people are not good listeners. They may instead seek to give advice that is not welcomed or to change the subject when the caregiver talks about difficult emotions. If you develop a Care Circle with the family caregiver, it is a good idea to indicate one or more friends or family members who the family caregiver finds helpful to talk to when they are feeling upset, down, stressed, or lonely.

*"[The Guide] gave me an ear to hear, no matter what, she lets me talk and talk and talk. It's better to say it, the more you talk the easier it is for you to breathe. [...] you feel less tense. Because when you're all bottled up and you're totally like ready to explode, that kind of feeling... So when you talk, she lets you talk, you breathe easier, you say things easier. It's an easy way of letting things go." [Family caregiver]*

*"And somehow [the Guide] manages to just take the air out of the balloon a little bit. [...]. So I spent hours venting about [the patient]. But then this morning I had to go, make sure he ate his breakfast, have a sensitive conversation about how we're going approach this situation, and all the things that we can do... I need to be in a certain mindset before I can approach him like that. [The Guide] helps with that. Because otherwise I would be... still so angry. I'm still so angry, and I'm angry that he's dying and that he doesn't have a chance to make any of it right... [...] [The Guide] helps with all of that, because if it wasn't for my ability to defuse all of those feelings, I would be very angry with my dad... [...]"*

### TAKING A BREAK FROM THE STRESSFUL SITUATION

Taking a break from a stressful situation can allow negative emotions to become less intense or completely disappear. While a long break outside of the caregiving setting might be ideal, this is often impractical for family caregivers, especially at the

time they need it. Short breaks of 5, 10, or 15 minutes in a quiet room where they can be uninterrupted can be helpful.

If the family caregiver needs some suggestions for activities that others find calming, see the [Tension-busting Tips section of this guide](#).

#### *FOCUSING ON POSITIVE EMOTIONS*

While creating positive emotion does not eliminate negative emotion (a person can experience both in the same time period), positive emotions do help people to cope by counteracting some of the effects of negative emotions. Family caregivers can be guided to engage in activities that generate positive emotion for them, such as some of their self-care strategies. At the same time, this often can give them a mental break from the situation. However, some feel guilty for having a light or good moment in the midst of their difficult time. It can be helpful to let them know feeling positive emotions can go hand in hand with negative ones, so they need not feel guilty.

*One day, a patient said that her quality of life was much better than two weeks before.*

*When asked why that was, she said: "Actually, physically I am worse. What's changed is how I am taking it".*

Some suggestions are:

- finding humor in the difficult situation or on television, etc.
- being physically active
- listening to music or watching a movie that makes them feel good
- spending time in nature (including a park or the back yard)
- thinking of pleasant memories
- using scented candles
- preparing and eating fresh food
- whatever usually works to lift their mood!

#### *MEANING: THE LINK BETWEEN SITUATIONS AND EMOTIONS*

Certain situations seem to automatically trigger certain emotions in us. But in many cases, other people don't react the same way we do. That means that while the link between the situation and the emotions may be automatic, the link can often be broken or changed if the automatic emotion is distressing. This is covered in more detail in the section on meaning-focused coping.

*An example*

*A family caregiver and patient enjoy the visits of family and friends. However, the caregiver believes that visitors will think badly of her because the house is messy. Therefore she feels panicky and anxious when people are coming to visit. If she can change the meaning of the situation so that she realizes they are coming to see her and the patient, not the house, her emotions might change to feelings of calm and joy.*

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## **MEANING-FOCUSED COPING**

One of the things that distinguish humans from other animals is that we strive to make sense of our world, or, in other words, to have a life that is meaningful. Without that, we feel distress (although we don't always recognize it to be related to a lack of meaning). Being able to fit even difficult events into the way we view the world and having a sense of purpose in life can counteract some of the distress we feel in a difficult situation and help us to cope. This is called meaning-focused coping. Together with emotion-focused coping, it allows people to carry on and have the best quality of life possible in situations where the problems they face cannot be resolved through problem-solving, as happens when a person they care about is dying. Meaning-focused coping can be used on its own or in combination with emotion-focused and/or problem-focused coping.

### *WHAT DO WE MEAN BY MEANING?*

Park and Folkman (1997) suggested that we look at meaning in two ways: global and situational.

**Global meaning** refers to the core beliefs and understandings we have about the world and ourselves, such as:

- people are generally good (or bad)
- I am a mainly a good (or bad) person
- bad things happen to people who have done bad things
- fate determines everything
- we are masters of our own destiny.

**Situational meaning** refers to our understanding of particular situations. For example, having a family member diagnosed with a terminal illness can be interpreted as:

- a punishment from God
- caused by the person not taking care of themselves
- a wake-up call to spend more time with loved ones
- a random event that occurs to everybody at some point in their life.

When we try to understand the meaning of a situation and it fits fairly easily with our global meaning it tends to strengthen our global beliefs. Even if we don't like the situation, a good fit will help keep us feeling grounded and we won't suffer specifically from meaning-related distress. For example, if our global belief is that most times the development of cancer is just nature taking its course, we will be

upset that our family member with cancer is dying but will not question whether life has any meaning.

When our understanding of the situation does not fit with any of our core beliefs of how the world works (global meaning), we experience distress (referred to as existential distress). This often leads to a search for a different interpretation of the situation so that it fits with our beliefs about the world and, if that doesn't work, we will often adjust our core beliefs. This might have other effects, such as leading to a new interpretation of many other situations that we are experiencing, and/or a re-evaluation of our priorities in life. Sometimes people's core beliefs are flexible and adjustment is easily made. In other cases, the beliefs are inflexible and the person might be struggling to make sense of the situation.

Even when the situational meaning fits with our global meaning, our understanding of the situation can be more or less helpful to our coping, as in the examples below.

*HOPE*

Hope can be considered a coping strategy. It is used by most family caregivers even in the last days or weeks of the patient's life. Hope can be thought of as a feeling that there is a possibility of a positive outcome. It can be a general feeling or linked to specific outcomes. For example, a person can *expect* that the patient will die soon, but *hope* for a better outcome, such as the patient being completely comfortable until death, living longer, or they may say: "I am hoping for a miracle, that he will get better." According to Folkman (2010, p. 905), "Hope has a very special quality that is especially important in managing uncertainty over time: it allows us to hold conflicting expectations simultaneously".

*EXAMPLES OF MEANING-FOCUSED COPING*

- 1) A family caregiver might ask themselves: "Why is this happening to my husband? He is such a good man and he is so young." Here are some answers that **they may find for themselves** which are more or less likely to be helpful.

Way of making sense of the situation	Likely to be helpful
<b>I've lost my faith in God</b>	No, but normal
<b>God must have another purpose for him that I don't understand</b>	Yes
<b>He didn't take care of himself.</b>	No (but it might be helpful in the long run if it encourages the caregiver to take better care of her/himself)
<b>Sometimes there is no reason; an illness like this is a random event.</b>	Yes

- 2) The family caregiver feels the loss of meaning because they've had to leave the care of their young children to the children's other parent.

<b>Way of making sense of the situation</b>	<b>Likely to be helpful</b>
<b>My children will develop a closer relationship with their father and he will become more comfortable caring for them when he has to do it alone.</b>	Yes
<b>This is only temporary and I will come back to my caring for the children with renewed energy and a new perspective.</b>	Yes
<b>My kids are doing so well without me, they don't need me.</b>	No
<b>I've done a good job bringing up healthy well-adjusted kids who can cope well without me.</b>	Yes

- 3) The family caregiver is on leave from a job that gives them a sense of purpose in life.

<b>Way of making sense of the situation</b>	<b>Likely to be helpful</b>
<b>My co-workers are now doing my job, so I am not needed and might be fired.</b>	No
<b>I'm glad to be part of a team that pitches in to help each other when any of us is in a tough situation.</b>	Yes
<b>After all those years of training, all I'm doing is housework and holding her hand.</b>	No
<b>This gives me a chance to do a different kind of work which is incredibly important and can only be done by me.</b>	Yes

### *WHAT CAN THE CAREGIVER GUIDE DO?*

Listening attentively and with empathy is often the best thing that you can do. People often ask questions but don't really expect someone else to provide an answer (e.g.: "What did I do to deserve this?"). *You cannot give somebody a sense of meaning in their life, but you can enable them to find their own by active and compassionate listening.*

In many situations, there can be:

- a different understanding of the situation
- a less distressing way of interpreting the situation

*while maintaining a realistic understanding of what is happening.*

### *REFRAMING: HELPFUL NEW WAYS OF THINKING ABOUT A SITUATION*

As a Caregiver Guide you can suggest that the family caregiver pay attention to their thoughts and consider other ways of thinking about the situation that might result in fewer undesirable emotions and more neutral or positive ones.

#### *An example*

*The family caregiver is very angry that her brothers and sisters visit their mother only once a week and never help out. This is the sort of situation that might be able to be changed, and problem-solving can be tried to see whether they can be convinced to help more, if friends might be able to lend a hand if they know what is needed, or if formal services can be arranged. However, while these different strategies are tried (or if they have been tried and did not resolve the problem) the caregiver's anger might be reduced by:*

- *remembering that she is choosing to provide care (if she is), a choice she can feel proud of*
- *focusing instead on the benefits the family caregiver feels from providing care, such as spending more time with her mother before she dies*
- *realizing that she is role modeling for her own children how they should care for family*
- *remembering that caregiving is a temporary situation*
- *reminding herself of some good qualities in her brothers and sisters in other situations.*

### *SETTING REALISTIC GOALS AND RE-PRIORITIZING*

At times family caregivers set goals for themselves that are almost impossible for anyone to reach. For example, keeping the house as clean as usual or keeping the patient 100% comfortable. In some cases it is the patient who sets unrealistic goals. In either case the family caregiver, unable to meet these goals, feels a sense of failure. This will likely create negative emotions such as feeling worthless or guilty, and also a loss of a sense of purpose or confidence in caregiving since they can never do enough to achieve the unreachable goals.

It can help to have a discussion with the family caregiver about the need to look at their priorities in this new situation, in order to let go of or reduce expectations for goals that have become a low priority. However, even high-priority goals are not always achievable and may need to be adjusted to something that can be achieved. For example, making meals that the patient will eat may be achievable early on, but at some point most patients become unable to eat no matter how tasty the food or how small the portion.

The actual goals and priorities must come from the family caregivers themselves. The role of the Caregiver Guide is to help them to realize that not reaching all goals is acceptable when caring for someone at the end of life, and that by adjusting their thinking they may be able to reduce their stress.

### *THINGS YOU COULD ASK THE FAMILY CAREGIVER WHO IS STRUGGLING WITH MEANING*

- Is there another way to understand this that makes sense to you?
- When you've had a problem with no solution, how did you manage to come to terms with it?
- What values are important to you? How does being in this difficult situation allow you or not allow you to live by those values?
- What usually helps you feel grounded? Who usually helps you feel grounded?
- What was meaningful to you in the past?
- What is meaningful to you now?
- What would you say to a friend in the same situation? (Often people are harder on themselves than they would be on their friends).

***If the caregivers seem stuck with their distressing interpretation, Guides can tentatively suggest others.***

- *Do you think it could mean X instead?*
- *What if that's not what he meant?*
- *When I (or When my friend, or When a caregiver I knew) went through something similar, I found it helpful to think of it this way...*

- *Do you think he might be taking it out on you because he is angry he is dying rather than because of something you are doing?*

*From feeling like a failure to a competent caregiver*

*"...through all this I had the impression that I was failing, was not able to do it... It was really new, I needed to learn how to give injections, to control the morphine, all the other medications and everything, so it is something that suddenly requires knowledge that I had to learn as things went along. And so I felt that I was doing everything poorly... I was afraid that...that my husband was suffering... And then, [the Guide], throughout this, reassured me that I had strengths, that I was doing it well, helped me see the positive and not just what wasn't working. And also... helped me realize that I had the strength and that I was getting through each stage, and that it wasn't destroying me, and...reassured me that I had the strength to get through the last stage and that I'd be able to come out of it, that I would be capable of surviving it."*

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## LOSSES AND ANTICIPATORY GRIEF

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Caregivers experience and may grieve many losses prior to their family member's death. In addition, many caregivers try to mentally prepare for the death of their loved one and grieve the loss of their family member before the actual death occurs. This is called anticipatory grief. This type of grief may or may not have an impact on their grieving after the death, during bereavement.

Below we outline some general guidelines that may be useful as a framework to guide conversations with family caregivers. However, because each caregiver and each family situation is different, they may or may not apply to the caregiver you are supporting. You will need to use your best judgement as to how, or if, and when, they will be useful for the caregiver you are supporting.

*Because I'm not a psychologist, sometimes I don't know what [my kids] are going through. And just having [my Guide] touch upon it, saying... What did she call that? She says... anticipatory grief. And I said, "What is THAT?" So when she told me, she explained it, ah, then I got it, it was exactly what I was feeling, it was exactly what the kids were feeling. So I was able to come home, and then understand what they are going through. And that helped a lot. [Family caregiver]*

### **Examples of losses experienced while the loved one approaches death and in bereavement**

- a partner to socialize with or be active with outside the home
- the person they used to know when there is a personality change
- someone to share household tasks with
- feeling of security
- sense of loss of control
- income
- future celebrations together
- companionship

### *LISTEN, LISTEN, LISTEN*

It is a profound privilege when someone risks sharing a difficult part of their life story. Psychologist Dr. Robert Neimeyer encourages listening for what he calls the *narrative fractures*, those moments in a person's story when things take a dramatic turn away from the hoped for outcome (personal communication). Examples of narrative fractures include "He wasn't supposed to get sick," "She wanted to stay at

home and I couldn't keep that promise," or "We were so happy and then suddenly we were devastated."

Bearing witness to the fractured narratives can have a powerful healing impact. Approaching someone with a respectful curiosity about their experience can be a welcome source of support. Ask open questions that encourage gentle elaboration (e.g., "Can you tell me a little bit more about that?"). Learn to be comfortable with silence, especially during moments when someone is emotional, giving them the space to express what they need. On the other hand, in some situations saying nothing can evoke anxiety in the caregiver, fuelling uncertainty as the caregiver tries to figure out what is going on. Too much effort on your part to keep a conversation going can be difficult, and sometimes is a sign to stop: "Would you like to conclude our conversation (or talk about something else) for now?"

#### *DIFFERENT STYLES OF MOURNING*

People have different styles of grieving, and these should be respected. Those with a more affective style cope through processing their feelings, often through expressing themselves. Those with a more instrumental style cope through doing (e.g. exercise; being busy; doing things for themselves and others, both practical, symbolic. Both styles can be helpful.

#### *RESPECT AMBIVALENCE*

Conflicting and competing emotions are a normal part of being a caregiver. Caregivers may feel torn between wanting one thing and wanting another. "I want the suffering to end, but I don't want him to die;" "I know I need to get my feelings out, but I hate to cry with a stranger." This pull and push is very normal; simply letting the caregiver know you understand and that having conflicting feelings is normal in their situation can be useful. For example, "Are you telling me that you both want and don't want to talk about this?"

#### *FIGURING OUT WHERE THE FAMILY IS AT*

Try to figure out where a family caregiver is at regarding their hopes and expectations for the patient. Are they hoping for more treatments that will prolong their family member's life? Are they trying to avoid certain topics? Are they using the words death, dying, or dead yet? Are they talking about a future without the loved one? You can ask them what they understand about their family member's illness. Some family caregivers believe that if they start to confront the possibility that death will occur, they will in some way be responsible for the actual death (e.g., "If I give up hope, he will give up too and then die.") Respect a family caregiver's need to assert control over the direction a conversation is taking.

Keep an eye out for denial and/or magical thinking (the belief that one thing causes another even though it cannot be justified by reason or observation). It could be denial that the patient is at the end of life or that he or she very sick. For example: "He says he's too tired to get up, but he's just not trying." "He will beat this." Denial is not always all or nothing, and it can change from day to day. An example of magical

thinking is: “He died sooner because I was wishing that his suffering would end.” Denial and magical thinking are not necessarily a problem, but if they are negatively affecting the caregiver’s or the patient’s current or future wellbeing then they may need to be addressed, although not necessarily by the Guide. This is a difficult situation for a volunteer to handle; speak to your Caregiver Guide Coordinator (or a clinician caring for the patient) for guidance.

### *DECISION MAKING*

There are many important decisions to be made when caring for a family member at the end of life. “Should I be present at the moment of death?” “I am not sure if I should move or not.”

***The “looking back” question can sometimes be helpful. “Imagine yourself five years from now looking back to today; what decision do you think will have been the best to make today?”***

Resist the urge to fix things or make the decision for the caregiver. You can, however, help them explore all the options, including the benefits versus the limitations (the section in this guide on problem-solving may be helpful).

### *BE AWARE OF YOUR ANXIETY*

Conversations about life limiting illness and death can be extremely stressful. Sometimes our efforts seem clumsy, superficial, or insufficient compared to the immense suffering before us. Our expectations of ourselves can sometimes be unrealistic (e.g., Today I am going to make a difference). Acting on our anxiety can sometimes lead us to assume undue control of a conversation, influence decisions that are not ours to make, or make us freeze with indecision. Making sense of and managing our anxiety is a learning process. Consult with your Caregiver Guide Coordinator and with the other Guides. Find ways to reflect on the role anxiety is playing in your role as a Caregiver Guide. Consider answering these questions from psychologist Dr. James Hollis (2013): *What is fear making me do? What is fear keeping me from doing?* The more attention and effort we make at understanding the roots of our anxiety, the more likely it won’t take too much space in our conversations with caregivers.

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## SELF-CARE FOR FAMILY CAREGIVERS

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***This section of the guide and several that follow provide some self-care strategies that may be useful for family caregivers to try.***

*The importance of family caregivers taking care of themselves*

*"... especially when there is little time left with someone, you certainly don't want to waste the little time that's left. And... I wanted to be there to take care of his needs. [...] Then, at one point, [my Guide] insisted that it was important for me to take time, time to rest, time just to get out, to take a walk, to clear my mind, and all of that. At the beginning, when faced with that I was somewhat resentful, I didn't feel like taking a walk when I could be with my husband. But then I realized I had no idea of what was to come, and [Guide], she knew it. She knew what it would be, and that the longer it went on, the more demanding it would get, and that I would need physical and mental strength, and to keep my spirits up, and everything. She knew that I'd need all my strength if I was to keep him at home until the end. And I was ambivalent, but I followed her advice anyway because I had great confidence in her, but always in the back of my mind I felt guilty: maybe I should have spent more time with him, talk to him and everything... But in the end I realized that if I hadn't taken her advice I would never have been able to keep him at home until the end. [...] And that's why I greatly appreciate... that she helped me with this, because in the end the thing that I wanted most is that he be able to die at home. And that, I was able to do it specifically because I was not down, I was not depressed, I was not physically exhausted, because I had managed to keep some moments where I could catch up on my sleep, recover from fatigue and all that." [Family caregiver]*

Many of the signs and symptoms below can arise appropriately under the circumstances of caring for a dying loved one. However, it is important to recognize when these signs and symptoms progress to the point where they are a barrier to the everyday functioning of the family caregiver. If the caregiver's functioning is impaired, this is a sign that they need more help to avoid becoming ill themselves, and to be able to continue providing care, if that is their wish. In some cases, as a Caregiver Guide you will be able to help the caregiver cope better and these signs and symptoms will be relieved. In other cases, professional help may be required. In addition to reading the section below, please see the Signs of Impending Caregiver Crisis section about the signs that professional help may be required. There is some overlap between that section and this one because it is not always clear when professional help is required; sometimes it will only be clear if you try some of the suggestions below and the caregiver's distress is not relieved.

## SIGNS AND SYMPTOMS OF A FAMILY CAREGIVER'S POOR SELF-CARE TO LOOK FOR

Social withdrawal from friends and activities that once brought pleasure	<i>I don't even want to talk to my friends on the phone. I didn't go to my grandson's birthday party.</i>
Exhaustion that makes it nearly impossible to complete necessary daily tasks	<i>My arms and legs feel so heavy that it makes me move around slowly.</i>
Poor sleep (see Sleep hygiene section)	<i>I have so much on my mind at night that I can't fall asleep.</i>
Irritability that leads to moodiness and triggers negative responses and actions	<i>Go away!</i>
Lack of concentration that makes it difficult to perform familiar tasks	<i>I couldn't focus on what the doctor was telling us. I find myself forgetting my friends' phone numbers.</i>
Health problems that begin to take a mental or physical toll or that aren't looked after	<i>I hurt my back helping him out of bed. I cancelled my doctor's appointment.</i>
Previously physically active and now almost inactive	<i>I like to walk every day but now I get no exercise</i>
Too busy to sit down for a few restful moments during the day	<i>I made a cup of coffee in the morning and didn't get to drink it all day. I didn't even have time to sit with (the patient).</i>
Lack of organization	<i>I didn't get around to paying my bills on time, my to-do list keeps on getting longer and longer.</i>

### **Things to ask:**

- Have you been experiencing (one of the symptoms mentioned above)?
- How are you holding up?
- How is your mood?
- Have you noticed any changes in your health recently?
- What do you do for a break during the day?

### **TENSION-BUSTING TIPS**

Help the family caregiver make a list of things that usually relax them. Ideally, some could be done in a few minutes, while others might take half an hour or an hour. Suggest that they try *at least* one each day. Here are a few suggestions you can give to the caregiver.

- There is a natural reaction to deep, slow breathing: relaxation!
  - Deep breathing involves the abdomen, NOT the chest.
- Slowly take a deep breath in through the nose, past your chest, into your abdomen. Breathe out slowly through your mouth. Do this 10 or more times. If you find you are getting light-headed, you are breathing too fast.
- Repeat a word or sound over and over and focus on it. When an external thought enters your mind, acknowledge it and gently push it out of your mind and focus on the word or sound again. Don't get discouraged if external thoughts keep coming, just keep pushing them out of your mind. You can repeat this exercise as many times as you want.
  - Take a warm bath.
  - Write down your feelings/emotions/worries in a diary.
  - Try to take a *break* every day: take a short nap (e.g. 15-30 minutes) or do something you enjoy, such as reading or listening to music.
  - Pay attention to which sense(s) are calming for you, and then find activities using that sense.<sup>4</sup> For example:

- *Sight.* Look at some images that are calming to you. For example flip through a picture book or pictures from a museum collection on the Internet, or visualize a calming image.
- *Sound.* Listen to some calming music or sounds.
- *Taste.* Savor slowly, focusing on the taste, a drink or healthy food whose taste you really enjoy.
- *Smell.* Consider energizing and comforting smells from aromatherapy, scented candles, potpourri, flowers, baking or cooking.
- *Touch.* Cover yourself with a soft blanket, or wear soft clothing, stroke your pet if you have one, brush your hair, massage your own skin or muscles (or have someone else give you a massage). If you like to work with your hands, see if you can find some time to do an activity that uses your hands, such as painting or gardening.
- *Movement/physical activity.* Dancing, stretching, yoga, running on the spot, or walking.

- Make a list of things you *must do* and the things you *would like to get done* each day. For some, separating what is essential and what is less essential helps to make sure the essentials get done first. Don't worry if you don't get everything (or anything!) done other than the essentials. Note that while this may be helpful for many, for some a list may make them feel more pressure to get things done rather than less.
- Look after your *relationships* with those who matter most to you. Stay in touch with others (over the phone, in person, on the internet), but limit the number of visitors if they are tiring you or your family member.
- If there is more than one family caregiver, set up a *system to share the load*. Who will do what? Who is available at different times of the day and week? Make sure that everybody gets a break.
- If the family caregiver is employed, he/she can take 8 weeks off of work and be partially paid for 6 through the Compassionate Care Benefit. (See Websites section at the end of this guidebook).
- Although the situation is difficult, *look for any positive aspects* as well (e.g., spending more time together; finding that an acquaintance has become a good friend).

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## **BACK CARE**

Caregivers often do a lot of lifting and bending in order to provide care and take care of the household that they may not have done before.

Here are guidelines for maintaining a healthy back:

- Get some exercise (e.g., walking, abdominal exercises).
- Lifting or moving someone: keep a straight back with bended knees. Get help if possible.
- Sitting: use a chair with a good lower back support. If the chair does not support the small of your back (the lower indented part of your back) use a little pillow in the small of your back to maintain its shape. Try to keep your thighs parallel to the floor.
- Standing for long periods of time: place one foot on a low footstool to take some of the pressure off your back.
- Major repositioning of the patient without the patient's help: try to seek help from a second person. If this is not possible, try to maintain a straight back with bended knees as much as possible.
- If the patient falls to the floor, get help from a second person. Put a pillow under his/her head and put him/her in a comfortable position when seeking and waiting for help.

## **SLEEP HYGIENE FOR FAMILY CAREGIVERS**

Even though everybody has different sleep habits and patterns, *good sleep is essential to good physical and mental health.*

### **What is poor sleep?**

Poor sleep arises when the normal sleep gets disturbed for any kind of reason. Poor sleep is sleep that is too short or not deep enough for the mind and body to be able to rest and be repaired.

The sleep of family caregivers is usually disturbed by:

- needing to get up frequently throughout the night to provide care (e.g., to give medication or check on their relative).
- the family caregiver's own stress, anxiety, and worry which makes it difficult for them to fall asleep or stay asleep.

While it is normal for family caregivers to have poor sleep, it is important to recognize when it causes problems for them as they cope with everyday life and caring for their family member at the same time.

### **What is fatigue?**

Fatigue may result from poor sleep, from doing too much, or both. It's a feeling of lack of energy or motivation that can be physical, mental (e.g., not thinking clearly), or both.

### *WHAT IS THE PURPOSE OF RECOGNIZING POOR SLEEP?*

Family caregivers who have trouble sleeping may be at an increased risk of depression<sup>8</sup>. In addition, their ability to effectively continue caregiving is affected when their sleep is disturbed.<sup>1,5</sup> Many family caregivers also report feeling fatigued.<sup>2</sup> Fatigue in turn contributes to family caregivers having decreased motivation, feeling that they are unable to fulfill their caregiving responsibilities, and neglecting their own interests.

It is important to recognize the early signs of poor sleep so that you can see whether the family caregiver wants to try some of the suggestions below. The health care team may also need to be made aware of it before it becomes a crisis. This might help maintain the family caregiver's health and their ability to continue providing care if they wish to.

### SIGNS AND SYMPTOMS OF A POOR SLEEP

<b>Exhaustion</b> that makes it nearly impossible to complete necessary daily tasks.	<i>I'm too tired for this.</i>
<b>Sleeplessness</b> caused by a never-ending list of concerns.	<i>What if he needs me and I don't hear him call?</i>
<b>Irritability</b> that leads to moodiness and triggers negative responses and actions.	<i>Don't ask me for anything else!</i>
<b>Lack of concentration</b> that makes it difficult to perform familiar tasks	<i>I can't even read my book.</i>
<b>Health problems</b> that begin to take a mental or physical toll.	<i>I am having new pains, and my old ones are worse.</i>

#### **Things to ask the family caregiver:**

- Have you been able to stay awake during the day?
- Have you been feeling sleepy during the day?
- Are you having trouble falling and/or staying asleep, not including when you get up to help?
- Are (the patient's) symptoms keeping you awake at night?
- Are you getting much less sleep than you did before?
- Are you finding it difficult to wake up in the morning or do you wake up much earlier?
- Do you find that you are very fidgety or restless? Or are you feeling very slow and sluggish?
- Have you been quick to anger or very irritable? Are you feeling resentful?
- Do you take anything to help you sleep?

#### **THINGS YOU CAN GUIDE THE FAMILY CAREGIVERS TO DO**

The next list contains tips, but these should be tailored to each individual family caregiver. Always explore with the family caregiver to determine if appropriate or not, rather than giving advice as to what they should do.

*If the patient's symptoms are keeping the family caregiver awake at night, the patient situation is not well controlled which is affecting both the patient and the caregiver. In this case, encourage the family caregiver to call the patient's healthcare team to see if the symptoms can be better controlled.*

**During the day:**

- Try to take a short nap (e.g., 30 minutes) when needed, but preferably before 3-4 P.M.
- Try to avoid heavy meals during the day, as they may make you sleepy afterwards. Try to maintain a healthy food intake with smaller, more frequent meals.
- Try to limit the intake of alcohol, caffeine, chocolate, non-herbal teas, diet aids, smoking, and anything that tends to keep you awake, as evening approaches, and preferably after noon. These will make it difficult to sleep.

**Before going to bed:**

- Try to avoid stimulation before going to bed, e.g., watching the news or an action movie, or having a difficult phone conversation. Avoid looking at a computer screen as your body interprets the light as daylight.
- Try to create a bedtime routine, one that lets you unwind a bit before turning off the light.
- Create a comfortable environment as much as possible. For example, reduce noise and light, and have a comfortable room temperature in the sleeping area.
- Try to sleep in a comfortable bed (even if it is a different one from your loved one's bed).
- Place the clock out of sight, unless you have to set an alarm at night.
- If you can't fall asleep, try to read a book (not one that is too exciting!) or listen to some music. Often it is best to get up and do this in another room.
- Try to avoid heavy meals right before bedtime. If hungry, have a light snack (e.g., a few crackers and ½ glass of low-fat milk).
- Try to go to bed when you feel drowsy, rather than staying up until a set time. This will allow you to follow your body's natural rhythm.
- Try to find ways to address worries and concerns before bedtime. If you are worried about all that you have to do tomorrow, making a list before bedtime so that you don't have to remember it all night can help to clear the mind.

*Short periods of relaxation during the day or evening are important for sleep, health, and the ability to provide care the next day.*

### ***An important message to pass on to family caregivers***

Don't be afraid to ask for help with caregiving so that you can rest or sleep. You do not have to do everything on your own. Even a small bit of help can make a big difference. For example, you can ask someone to cover for you while you take a nap or to sleep overnight 2-3 times a week.

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## **NUTRITION**

Family caregivers may neglect their own nutrition in order to focus on the tasks, responsibilities, and emotions related to caregiving.

Nutrition is often associated with food, eating, pleasure, and health. The food, or nourishment, that we eat plays an important part in providing the energy our bodies use in order to perform its daily functions.

### *WHAT IS GOOD NUTRITION / EATING HEALTHY?*

Eating healthy involves having a balance of foods that contain protein, carbohydrates, fats, vitamins, minerals, and water.

For more information, please refer to the Canadian Food Guide at:

<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>

A healthy diet will help a person to:

- have energy that the body needs.
- regulate body processes, emotions, and concentration.
- maintain, build, and repair body tissues.

Mealtime and eating together are a source of pleasure and socialization for most people. Mealtime and meal preparation are often linked with rituals, culture, and traditions in many families. These rituals and routines may be affected by caregiving.

### *WHAT IS POOR NUTRITION?*

A diet that does not meet the daily requirements of an individual can affect a person's life and body in several ways.

Poor nutrition can affect:

- how the mind functions
- how we cope with our emotions
- our energy levels (they are often lower when we are not eating well)
- our ability to perform our daily tasks
- our ability to concentrate
- our ability to make decisions and prioritize activities
- our body's ability to fight infections and to remain healthy (our immune system).

*HOW CAN CAREGIVER GUIDES SUPPORT FAMILY CAREGIVERS TO MAINTAIN THEIR OWN NUTRITION?*

- Listen actively.
- Help the family caregiver develop strategies for meal preparation, accepting help from others (for meals or to free up time for meals), and for making time for mealtimes and rituals that may bring the family caregiver comfort.
- Provide emotional support.
- Use coping strategies and tips to address issues/barriers that may be keeping the family caregiver from regularly eating a healthy and balanced diet.
- Assess the needs of the family caregiver on an ongoing basis.

If the family caregiver is hardly eating or eating so poorly that it might affect their ability to think clearly, their emotions, or put their health at risk, discuss this with the Caregiver Guide Coordinator.

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## PHYSICAL ACTIVITY

Physical activity has many physical and psychological health benefits. As long as a doctor has not otherwise instructed them, a thoughtful approach to physical activity may be one way to help family caregivers cope with the demands of caregiving.

It is difficult for many people to keep physically active, even under normal circumstances when they are not family caregivers. With the additional work of caregiving and emotional stress of accompanying a family member who is dying, or in early bereavement, many family caregivers engage in little physical activity, whether or not they were active before.

A misconception about physical activity is that a person has to engage in long bouts of moderate-high intensity activity to gain health benefits. However, there are many approaches to physical activity, depending on the reason a person chooses to engage in it. When the patient is near death or the caregiver is in the first few months of bereavement, the goal is not to achieve high levels of fitness, but rather to engage in physical activity as a way to relieve tension and potentially increase the caregiver's energy and help them sleep.

### *HOW CAN CAREGIVER GUIDES SUPPORT FAMILY CAREGIVERS TO ENGAGE IN PHYSICAL ACTIVITY?*

Explain to the caregiver that the main reason for being physically active when they are a caregiver (or in early bereavement) is for them to try to improve how they feel, physically and emotionally, and to try to maintain their own health and wellbeing. You can begin by explaining to the caregiver that enjoyable physical activity, even in short bouts that fit into their weekly routine, can help release both mental and physical tension and improve their mood (e.g. less irritable). This might even result in them feeling less tired during the day and better able to sleep at night.

*It is important to let caregivers know that even short bouts of physical activity that can be integrated into their daily routine (e.g. 10 minutes) may be helpful in these ways. The more physical activity a person is able to do, the more benefits they will have, but an important message, especially in the context of caregiving, is that **'something is better than nothing'**.*

### *WHAT CAN A CAREGIVER GUIDE ASK?*

- How did you feel about physical activity before you were caregiving?
- What types of physical activity do you enjoy, or make you feel better?
- When you are able to do physical activity that you enjoy, in what ways does it help you?

- What makes it difficult to do physical activity?
- How can these challenges be overcome?
- How can those enjoyable activities be integrated into your week?
  - If needed: How can they be adapted for your current situation?
  - If the activity the caregiver enjoys is not feasible: Is there a similar activity or another one you enjoy that might be feasible?
  - If there is no time for long bout of activity: Can it be broken down into several shorter bouts?

Based on what you have learned from each of the points above, work together with the family caregiver to help them develop strategies to integrate physical activity into their everyday routine. This should be individualized to suit the caregiver's needs, interests, and abilities.

Help the family caregiver to set weekly physical activity goals. Encourage them to set realistic goals.

Remind the family caregiver that physical activity can be broken up into several small bouts throughout the day/week. Encourage them to take short "time outs" for themselves.

#### *GUIDING THE CAREGIVER TO STICK WITH THE PHYSICAL ACTIVITY PLAN*

- Encourage the family caregiver to keep track of their physical activity.
- Encourage the family caregiver to find a friend or family member who will encourage them to keep to their activity plan. It is helpful if the caregiver reports to this person what physical activity they have done each week. This also serves as a reminder to take care of themselves.
- Whenever you visit them you can ask how it is going and use problem-solving skills to overcome any barriers they are facing to engaging in the activity they would like to do. Of course, there will be times when it is just not possible. In that case you can encourage the caregiver not to be too hard on themselves and not to give up. Remind them that just because they were unable to be active one week does not mean that they can't be active in a week or two, and that some physical activity is better than none.

*SOME EXAMPLES OF PHYSICAL ACTIVITY ARE:*

- take a short walk around the block
- yoga/stretching exercises
- gardening
- walk or cycle for short errands
- walking up and down the stairs at home or the office

## REFERENCES

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## *LEGACY ACTIVITIES*

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Leaving a legacy is important for the patient but also for the remaining family members. Everybody leaves a legacy of one sort or another. Some consciously work towards that throughout their life while others never do but yet their impact on people and their creations may remain for quite some time after they have died. If the patient is still able to communicate, a legacy activity can be something meaningful that the patient and family caregiver (and perhaps other family members) can do together. If the patient is not able to participate it is still possible for the family caregiver to do a legacy activity on behalf of the patient on their own. Keep in mind that for some patients, legacy work is emotionally too difficult, as it means saying good-bye. It is important to be sensitive to what patients themselves are able to cope with. For some patients this can be highly satisfying. Many family caregivers will not have time for this, but since it can be done in bits and pieces it may be manageable for some. It can also be done during the bereavement period.

### WHAT IS A LEGACY ACTIVITY?

In the case of someone nearing the end of life, we are referring to a smaller project to allow the patient and/or the family caregiver to express some of the patient's most meaningful thoughts, beliefs, values, and feelings. When the patient is so ill, legacy activities usually involve capturing their words of wisdom, lessons learned, advice, and/or a description about the important parts of their life. If they are artistically inclined and still have the ability to create things, then they might choose to create something to leave to specific people.

### FORMAT FOR THE LEGACY

Creativity is welcome here! The legacy can be left as an audio- or video-recording, as a written document, a webpage, a scrapbook, or in any other format that is likely to remain intact for decades. Because it is important for the main messages to be clear, it is a good idea to work on them carefully first, editing them as needed, before putting them into the final format. Of course if the patient is very ill it is important not to wait so long that they cannot complete the work.

### GETTING GOING

You can guide the family caregiver to come up with the type of project and topics to address with the patient, or on their own, and/or resources to use. Often it is easiest to capture the important thoughts in a question-and-answer conversation that can then be edited by the patient and/or the caregiver. The questions should focus on

what was important to the patient and what the patient wants to tell their loved ones and family members who will be born in the future.

Here are some examples of general questions. Of course there are many more, and some more specific ones might be more relevant.

- What do you most want your family to know about you?
- What do you most want to be remembered for?
- What important lessons have you learned through your life?
- What advice would you give to your children/grandchildren when they
  - are in high school?
  - looking for love?
  - about to get married?
  - have children of their own?
- Do you have advice for getting through the tough times? (This could be made specific by addressing the tough times with relationships, job, serious illness, or other aspects of life.)

If the patient dies or becomes too ill to continue while the work is in progress, the family caregiver might want to carry it on at a later date based on what they know about the patient. For example, the family caregiver might be able to document what were the patient's most common sayings, his/her perspective on life, or how he/she lived their life, and loved.

## *FINANCIAL HELP*

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The brief description of Canada's Compassionate Care Benefit that follows is a general description and cannot be used as the basis for a claim. The details of benefit can change over time. Definitive information can be found at the website [http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml).

The Compassionate Care Benefit allows eligible family members of someone who has a life expectancy of 26 weeks or less to leave work for up to 26 weeks to care for family members at the end of life and receive a paid benefit for up to 24 weeks through the Employment Insurance program (the first 2 weeks of leave are not paid for). However, many family caregivers are not aware of this resource. The total period of the benefit per person who is at the end of life is 26 weeks, but those 26 weeks can be shared by more than one family member.

Family members who wish to claim the benefit must apply no later than 4 weeks after their last day of work or they risk losing part of the benefit. When the ill person dies, the benefit stops, even if not all 26 weeks are used.

Medical proof that the family member is expected to die within 26 weeks and needs care or support must be provided on a special form, along with another signed by the patient or their legal representative giving permission to release the medical information. An application can be made online or at a Service Canada Centre.

# *SIGNS OF IMPENDING FAMILY CAREGIVER CRISIS*

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The following section provides information to help Caregiver Guides recognize when a family caregiver is heading for or is in a crisis or unsafe situation. Sometimes new coping strategies and non-professional support will help the situation, but usually professional intervention is required.

*It is important to note that we are mainly looking for issues arising because of caregiving, not long-standing ones that existed prior to caregiving. If the issues are long-standing ones, then the family caregiver should be encouraged to seek help through their usual medical and social services. If you are not sure if the issue is new or longstanding, discuss it with the Caregiver Guide Coordinator.*

## **RECOGNIZING FAMILY CAREGIVER PSYCHOLOGICAL DISTRESS**

Many of the signs and symptoms below can arise appropriately under the circumstances of caring for a dying loved one. *However, it is important to recognize when these signs and symptoms progress to the point that they are a barrier to the everyday functioning of the caregiver.*

### *WHAT IS PSYCHOLOGICAL DISTRESS?*

Psychological distress is psychological suffering that can come from any situation or thought that makes you feel frustrated, angry, nervous, or anxious. Distress can cause problems for the family caregiver as they cope with everyday life and caring for their loved one.

### *WHAT IS DEPRESSION?*

Depression is a common mental disorder where the person has depressed mood, loss of interest or pleasure, excessive feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, poor concentration, and inability to make decisions.

### *WHAT IS ANXIETY?*

Anxiety is a psychological and physical state accompanied by excessive feelings of fear and concern to the point of disturbing the ability to function normally.

### *WHAT IS THE PURPOSE OF YOUR RECOGNIZING PSYCHOLOGICAL DISTRESS IN THE FAMILY CAREGIVER?*

Your special relationship with the family caregiver may allow you to recognize the early signs of potentially disabling distress while you are in their home. This information can be given to the Caregiver Guide Coordinator, who will alert the health care team before it becomes a crisis. This might help maintain the caregiver's

health. If it is urgent, for example the family caregiver may have a plan to commit suicide and is prepared to carry it out, call 911.

*SIGNS AND SYMPTOMS OF FAMILY CAREGIVER PSYCHOLOGICAL DISTRESS TO LOOK FOR*

<b>Denial</b> about the disease and its effect on the person who's been diagnosed	<i>I know Mom is going to be cured.</i>
<b>Anger</b> at the ill person or others, anger that no cure exists or that people don't understand what's happening	<i>If he asks me one more time I'll scream!</i>
<b>Social withdrawal</b> from friends and activities that once brought pleasure.	<i>I don't care about seeing friends anymore</i>
<b>Anxiety</b> about facing tasks at hand, getting through another day, or about the future.	<i>I get very anxious when I think about all I have to do.</i>
<b>Despair</b> that begins to break one's spirit and affects one's ability to cope.	<i>I don't care anymore.</i>
<b>Exhaustion</b> that makes it nearly impossible to complete necessary daily tasks.	<i>I'm too tired for this.</i>
<b>Sleeplessness</b> caused by a never-ending list of concerns.	<i>What if she needs me and I don't hear her call?</i>
<b>Irritability</b> that leads to moodiness and triggers negative responses and actions	<i>Leave me alone!</i>
<b>Lack of concentration</b> that makes it difficult to perform familiar tasks.	<i>I was so busy, I forgot we had an appointment.</i>
<b>Health problems</b> that begin to take a mental or physical toll.	<i>My back is hurting from all the work I'm doing.</i>

### ***THINGS TO ASK***

- Are you able to keep up with the household chores such as cleaning and preparing food?
- Have you been able to bathe regularly?
- Are you finding it difficult to wake up in the morning?
- Are you having trouble falling and/or staying asleep (not including when you get up to help)?
- Have you lost or gained any weight recently?
- Do you find that you are very fidgety or restless? Or are you feeling overly slow and sluggish?
- Are you putting off your own healthcare visits?
- Has your mood been mainly depressed?
- Have you lost interest in things that previously brought you pleasure?
- Have you been feeling excessively guilty lately?
- Are you feeling unusually hopeless or demoralized?
- Have you been quick to anger or very irritable? Are you feeling resentful?
- Have you been having difficulty concentrating on simple things like watching TV or reading the newspaper? Are you finding yourself more forgetful lately? Are you having difficulty making decisions?
- Have you been feeling badly about yourself, or thinking that you have let yourself or your family down?
- Have you ever thought of hurting yourself or others? Has suicide been on your mind?

*If the answer to any of the above questions is “yes”, then ask them to elaborate.*

*If they have a plan to commit suicide or to hurt someone else and seem prepared to carry it out, call 911.*

## **RECOGNIZING FAMILY CAREGIVER PHYSICAL DISTRESS**

### *WHAT IS MEANT BY PHYSICAL DISTRESS?*

Illness and injury are, of course, signs of physical distress. But since we also hope to prevent illness and injury in the caregivers, we also consider physical distress to be physical symptoms that may, if not attended to, lead to the family caregiver injuring themselves or getting sick.

### *WHY IS THIS A CONCERN?*

Family caregivers are possibly aged and/or have chronic health issues themselves. They can also be uniquely at risk of major health issues while they devote their time, energy, physical strength and attention to the patient, leaving little left to take care of themselves. Family caregivers sometimes miss their own medical appointments, forget to take their own medication or ignore signs of their own failing health. The physical demands of caregiving and the vulnerabilities of older or previously ill family caregivers may compromise their functioning and increase their risk for physical health problems.

### *WHAT ARE SOME OF THE WORRISOME SIGNS OF A FAMILY CAREGIVER AT RISK OF PHYSICAL DISTRESS?*

On questioning:

- They complain of constant fatigue and lack of sleep.
- They complain of back pain or is there undue physical strain of any sort from caring for the patient.
- They are not eating regular and/or full meals.
- They are losing weight (their clothes are too loose and belts are too big).
- They have missed recent medical appointments.
- They complain of poor memory, misplacing objects, and/or forgetting appointments.
- They complain of worsening signs and symptoms of pre-existing medical conditions (e.g., angina, arthritis, high blood pressure).

On observation of the home:

- They display poor personal hygiene.
- The living space is unclean and/or dangerous (see chapter on Safety Issues in the Home).
- Mail is left to pile up.
- Dishes are unclean or misplaced.

- Food is found in unusual places or spoiled.
- Their bed appears unused or they have been sleeping in chairs.
- Medication bottles are dispersed, open.

On observation of the caregiver:

- Their clothes are ill fitting and/or unclean.
- Their skin is dirty, broken, or has ulcerations.
- Their feet are swollen and/or their shoes are unable to fit on their feet.
- They are short of breath or unable to catch their breath while speaking.
- They are walking with a new limp.

# IMPORTANT SAFETY ISSUES IN THE HOME

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Some of the issues that are described below are particular to the homes of family caregivers living with seriously ill patients. There are also general safety issues that should be taken into account in any home. Please consider the issues below, but exercise your own judgment with regards to safety.

The sections below first present lists of things you may notice that indicate a physical or emotional safety issue, followed by some suggestions for what you can do in general. There are separate chapters that address the specific cases of abuse and a patient's request for a hastened death.

## RECOGNIZING SAFETY ISSUES

As a Caregiver Guide, it is not your place to do a safety inspection of the home, ask probing questions about the psychological state of the caregiver or patient, or about abuse. However, there are many things that you can observe while you are in the home in the course of your regular visit. These may be things that you see, smell, or hear from the family caregiver or the patient.

*Many people choose to live in ways that others, such as yourself, may not. It is important to respect these choices. Since homecare professionals will already have visited the home, it is more important that you look out for a recent deterioration in the situation, as the professionals may not yet know about this.*

## PHYSICAL SAFETY ISSUES

### Adaptable Furniture and Fixtures

- Does the family caregiver have the ability to safely move and manipulate the patient without putting undue physical stress on themselves?

*For example:*

- Is there a proper seat for the toilet?
- Are there rails on the bathtub? Do they have a shower chair/bath bench?
- Are there railings in place on the stairs?
- Are there rails next to the bed to assist the patient to stand or turn?

- Is there a nonslip surface in the bathtub?
- Do they have an electric bed (in some areas these can be obtained through local social and health care services if the patient spends much time in bed and there is space in the home).
- Can the patient safely navigate the house (if they are semi-ambulatory) without the physical assistance of the family caregiver?
- Do they have a walker in the house?
- Are there railings on the stairs and walls as appropriate?

### *Tripping and Falling*

- Are there things on the floor that a person might trip on? (e.g., throw rugs, clothing dropped on the floor in a walking path.)
- Are heavy things that are in use stored up high where they might fall on someone's head when they are taken down?
- Are the inside and outside stairways clear?

### *Smells*

- Is there a smell of rotted food in the fridge?
- Is there smelly garbage piled up inside the home?
- Is there an overpowering smell of human or animal urine or feces?

### *Electrical Issues*

- Do the medical devices used (beds, lifts, etc.) have the proper outlets?
- Are there too many plugs in a socket?
- Are there wires running across the floors?

### *Fire Prevention*

- Is the house equipped with smoke detectors, fire extinguishers?
- Are they functional?
- Is there an exit strategy for the family caregiver and the patient in the event of fire?

### *Medication*

- Is the patient's medication properly organized and set aside in a safe location?
- Is the medication out of the reach of children and pets?
- Is the caregiver's medication kept separate from the patient's medication?
- Are the pills expired?
- Are the pill bottles labeled correctly (i.e. patient's name, medication was not switched into a different bottle for convenience?)
- Are they using a medication cassette or blister packs?
- Does the family caregiver mention having trouble keeping track of which medications were given when?
- Does the patient take the medication as prescribed?
- If alternative or over-the-counter medications are used by a patient, who has prescribed these medications, and has the patient's doctor been told?
- Are there drug addicts in the household or who visit? There is a risk that they might use the patient's narcotic medications so the healthcare professionals should know so that they can make suitable arrangements (e.g. prescribing less medication at time).

### *Oxygen*

- If oxygen is being used in the home, is there any smoking anywhere in the home (there should not be)?

### *Heating and Air Quality*

- Is the house heated appropriately for the winter months? In the summer, is it so hot that it causes people not to feel well, including having trouble breathing?
- Is the air is so dry that you experience static sparks? If it is it may put the patient at risk of skin breakdown.
- Is the ventilation appropriate?
- If a space heater is being used, does it have a thermostat and is the heating element protected so that people cannot touch it accidentally?
- Is a camp stove being used inside?

## EMOTIONAL SAFETY ISSUES

- Is there a great feeling of tension in the home?
- Do you hear any verbal abuse?
- Is the family caregiver afraid to talk freely, even when the patient is not in the room?
- Does the family caregiver have the right amount of social support for him/her? Isolation is a risk factor for emotional distress, but so much social interaction that it is exhausting can also place the family caregiver at risk of distress.

## WHAT YOU CAN DO IN GENERAL

If the problem is new, you may want to gently draw attention to it along with some helpful tips for managing the situation. For example, you may want to say: "Are you finding it hard to keep the medications organized? If you are, the pharmacist can put them in a special box where they are organized for each time of the day and day of the week." "Are you finding visitors are tiring you out? You may want to set a specific hour or two of the day for visitors." If the family caregiver does not want to accept the tip, respect their choice.

If this situation seems dangerous, you can report this to the Caregiver Guide Coordinator or healthcare team member.

# ABUSE

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While relationships can improve or remain good at the end of life, because of the stresses involved and the changes in roles, sometimes abuse of the caregiver or of the patient can occur. The abuse may be new, longstanding, or longstanding and worsened. Here are some things to think about if you suspect or see abuse.

Risk factors for the family caregiver to be abused may increase when the patient becomes more dependent, that is, needs more help with activities of daily living (e.g., dressing, bathing, preparing food or eating). Conversely, if the family caregiver is abusive, the patient is now at higher risk.

*Abuse may be physical, emotional/verbal, or financial.*

*Abuse of the family caregiver by the patient can take many forms, for example:*

- hitting or pushing the caregiver
- constantly criticizing the caregiver (e.g., telling them that they are not doing things right or not doing enough)
- the patient uses emotional blackmail to get what he or she wants (e.g., “You don’t care about me”; “I know you’ll be happier when I’m gone”)
- not allowing the caregiver some control over finances, or insisting the caregiver use his or her own money to pay for objects and services that the patient needs.

Abuse of the patient can take many forms, for example:

- neglect of the patient’s physical needs
- verbal or emotional abuse, such as yelling at the patient, blaming or shaming for their state (e.g., incontinence; cognitive problems), insulting or putting the patient down
- financial, including not letting the patient use their own or family money to purchase objects or services they need

If the patient is abusive, is this new?

*Recent alterations in behaviors need to be assessed by healthcare team, as there may be an intervention to improve them.*

These changes can be due to changes within or around the brain itself.

Medications can also cause changes in the brain and behavior. One common example is steroids, which can be used for symptom control (e.g., to shrink tumors that are decreasing the quality of life of the patient. Unfortunately, side effects of steroids can contribute to rapid mood changes: increased irritability and tempers flaring is not uncommon.

Changes in other organs, common at the end of life, can also affect brain functioning.

## WHAT CAN A CAREGIVER GUIDE DO IF THE ABUSE IS LINKED WITH AN ORGANIC/MEDICAL CAUSE?

Help family caregiver to set gentle but firm limits. Constantly appeasing patient's anger or hostility does not positively enhance the patient's quality of life. Role playing between the Guide and family caregiver may be a helpful to provide family caregivers with strategies for gentle limit setting.

Are these behaviors instead part of a long standing pattern, but have intensified or changed in other ways?

The long term nature of the relationship between family caregiver and patient may be the primary factor in predicting instances of abuse. Do you have a gut feeling that there is a dynamic of abuse in this situation? It is likely your gut feeling is correct.

***If there is suspicion of abuse by either the patient or family caregiver, if you raise this issue it must always be raised with the family caregiver or patient separately.*** If there is a history of abuse, discussing it with the two of them together may escalate the abuse.

If this is an issue that you have identified as being problematic, it would be helpful to gently explore the situation to follow up on your gut feeling. However, if you are not comfortable with any or all of these suggestions, you do not need to explore this. In any case, report your suspicions to the Caregiver Guide Coordinator. However, if you have not obtained answers to at least the first few questions below the Coordinator will likely not be able to follow up on the situation.

- Would it be helpful to check in with the family caregiver in a neutral, nonjudgmental manner if this is a problem for the family caregiver?
- Has the family member reported this to you directly?
- Is it an issue they wish to discuss with you?
- Is it part of a longstanding history?
- Inquire how they have been managing with the patient's behaviors in the past. How have they coped with it in the past? What has helped?
- It would be important to explore whether or not the family caregiver feels he or she is in danger. If so, help the family caregiver understand that calling 911 is critical.

A key issue is that abuse in general holds a stigma and is underreported. The family caregiver may have been living in this style of relationship for a long time. In palliative care that stigma may be increased, because it is complicated by the fact that the patient, who is increasingly dependent, is in their last days. At the same time, the family caregiver's energies are generally more depleted. Are they willing to be referred to a health care professional? A referral to a social worker may be helpful.

If the family caregiver feels that they cannot accept being referred, most women's shelters have phone services, where a woman in the community can discuss their situation, and receive support and guidance. Men can call a helpline or look for a support in their community.

Repairing longstanding relationships at this phase in life may not be an option.

If either patient or family caregiver is abusive towards the other, a home death is not recommended. This leaves one or both members in a highly vulnerable position. It is in their mutual interest to be in a palliative care unit or hospice, where there are many more resources to support the family.

## WHAT IF YOU BELIEVE THAT THE FAMILY CAREGIVER IS ABUSING THE PATIENT?

Even if you are not sure, if you suspect abuse, inform the Caregiver Guide Coordinator, so that the patient's health care team can be notified and explore whether abuse is occurring and try to improve the situation.

## *CARING FOR PEOPLE WITH DELIRIUM*

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Delirium is one most frequent and serious problems experienced by people nearing the end of life. It is an altered mental state. It is not caused by psychological problems or problems within the family caregiver-patient relationship. It can be very difficult for a family caregiver to cope with.

Delirium can be due to a wide number of causes (e.g. brain metastases, infection, dehydration, medication related issues).

Delirium is characterized by:

- alterations in the state of consciousness
- difficulties in the areas of attention, cognition, and/or behavior
- disturbances in perception

These may develop over a short time span and last hours or days. The presence or absence of these problems can fluctuate rapidly.

### SYMPTOMS OF DELIRIUM

(adapted from Gagnon et al, 2002 and Simard and Hamel flyer)

Delirium symptoms usually have a rapid onset, and can last for hours, or days. A patient in a delirious state may fluctuate in and out of it. The lack of predictability or consistency may add an extra level of stress for the family caregiver.

- Disorientation
- Disturbed attention or memory
- Confused speech
- Wanting to do unreasonable things
- Personality changes (e.g., becoming aggressive)
- Mood changes
- Hallucinations
- Mistrust
- Restlessness *or* very slow reactions
- Anger
- Changes in the sleep cycle: awake at night and/or sleepy during the day

The last two symptoms above commonly occur for other reasons when someone is at the end of life, but together with some of the other symptoms, or with rapid onset and/or frequent fluctuations, they are likely part of a delirium.

## GUIDING THE FAMILY CAREGIVER TO COPE WITH THE PATIENT'S DELIRIUM

Research has shown that up to 50% of patients in delirium can show improvement, if it is assessed and treated early on. Encourage the family caregiver to bring it to the attention of the health care professional as soon as it is noticed. It is important to acknowledge the feelings of the family caregiver in this situation (which can include frustration, fear, helplessness, etc.).

### **SOME THINGS THAT YOU CAN GUIDE THE FAMILY CAREGIVER TO DO**

#### *The environment*

Keep the environment as calm as possible

Include objects that are familiar and comforting

Minimize, when possible, excessive stimulation (e.g., loud noises)

#### *Communicating with the patient*

Use simple, clear speech

If the patient has inappropriate thoughts try to bring them back to reality

*BUT* avoid arguing with the patient's reality, as it will not help the situation. It may in fact worsen the patient's state

Don't take it personally if the person is aggressive (e.g., says something horrible to you); it is the delirium rather than the person talking.

#### *Take breaks*

Try to have periods of rest, and if possible have others available to provide periods of respite

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## *WHEN A PATIENT REQUESTS A HASTENED DEATH: A CRY FOR HELP*

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Sometimes patients say that they want a hastened death, and may even ask the family caregiver or a physician to help with this. Needless to say, this can be very distressing for the family caregiver.

Often people at the end of life mention wanting to die, or to have death come sooner. This doesn't always mean that they plan to commit suicide or have someone else kill them. Sometimes they feel that they want to die soon, but the feeling passes. Some have a plan "just in case things get too bad" but don't intend to carry it out now – and often things never get bad enough for them to act on the plan. ***However, the seriousness and immanency of their desire for a hastened death should always be assessed.***

Here are some suggestions you can give to the family caregiver.

### **ASSESSING AND ADDRESSING THE SITUATION**

The reasons for the desire for hastened death may be multifaceted, and may fluctuate over time. Several of these elements may reflect the patient's feeling of being overburdened in one or more domains:

- unrelieved physical symptoms, especially pain
- unrelieved psychological symptoms: depression, hopelessness, loss of dignity
- fears regarding death
- loss of autonomy often accompanied by a greater sense of being a burden to loved ones
- feeling that their life no longer has meaning or purpose.

These symptoms should be assessed by a health care professional, as they may benefit from intervention.

In a minority of situations, pain or symptoms cannot be controlled. If this is the case, a patient's needs may be best served within a medical setting, as this situation is highly distressing for both patient and their family member.

If this desire for hastened death reflects a suicidal wish, the family caregiver should ask the patient right away:

- Does the patient have a plan to commit suicide?
- If so, are they feeling ready to carry out this plan?
- If they have a plan but are not ready yet, will they tell the caregiver if in the future they feel ready?

**If the patient has a plan and feels ready to carry it out, an urgent psychiatric evaluation is indicated**, especially because these thoughts are commonly associated with a reversible mental illness.

If they have a plan but are not ready yet and it is not clear that they will let the caregiver know in advance, this is also of great concern. The patient's health care team should be notified promptly.

## WHAT CAN A CAREGIVER GUIDE DO?

As a Caregiver Guide, you can first encourage the caregiver to assess and address the situation as described above. It happens quite frequently that once symptoms are diminished a patient may say, "I really did not want to die, I just did not want to suffer." In cases where desire for a hastened death persists, it is helpful for the patient to be able to identify and articulate the unique sources of their distress, often referred to as 'soul pain'.

You can support the caregiver through active listening. You can also guide them in how to have a conversation with the patient that might relieve some of the patient's psychological or spiritual distress.

- *Please tell me more about your relationship with [patient]?*
- *What has been important that the two of you have shared?*
- *What has this time together been like for you?*
- *How has it impacted your relationship with [patient]?*
- *Is there anything you or [patient] feel could make any aspect of this situation a bit easier?*

Let the caregiver know that allowing the patient to express their distress may provide some sense of relief. It may also be helpful for the caregiver to focus their conversation with the patient on what gives the patient meaning at this time in their life.

## SOME TIPS FOR THE FAMILY CAREGIVER TO HAVE A DISCUSSION WITH THE PATIENT

If the caregiver does not already know the answers to the following, they can ask:

- Help me to understand what aspects of your situation are most difficult for you?
- What is it that helps you get up in the morning? (i.e. what are those things that you find worth living for?)

Explore the unique, *irreplaceable* importance of that patient to their family caregiver, rekindling their sense of self-worth. The patient may be feeling a sense of hopelessness, helplessness, or hold perceptions of being a burden on their loved ones, etc. They will often lose sight of their unique value to those who love them.

One of the main reasons patients whose physical symptoms are under control request a hastened death is the patient's sense of being a burden. While it is difficult to be a caregiver, they do not usually describe caregiving as a burden. You can find out if the caregiver considers it to be a burden to provide care. If not, if the family caregiver is amenable, and comfortable enough in their role, it can be helpful to have a dialogue between the patient and family caregiver regarding this issue. It may be helpful for patient to directly hear how the family caregiver feels about the caregiving role. The caregiver (or anyone else) can ask the patient:

- If the situation were reversed, would you care for your loved one under similar circumstances? Would it be a burden for you?
- It may be reflected to the patient that they are imposing this burden (of feeling like a burden) on themselves. It can be suggested to the patient that they consider lessening this burden on themselves.

Despite being a difficult time, this time is precious. It is rare in our lives that we stop being busy, and have this opportunity to take all or most of our time to spend with one individual. It may be a helpful way to reframe this burden, if the patient and family caregiver share a close bond.

*{ If this request for a hastened death cannot be mitigated, it is essential that the healthcare team is alerted. }*

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# LEGAL ISSUES FOR FAMILY CAREGIVERS IN CANADA

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This section explains a few legal terms and issues in end-of-life situations that caregivers may bring up in conversation. We provide this information to inform Guides to enable them to better listen to the caregiver. *It is by no means a substitute for the law.* A legal representative should always be contacted for advice and the most up-to-date information.

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## **GUIDES SHOULD NEVER PROVIDE ADVICE ON LEGAL ISSUES.**

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**PROVIDING SUCH ADVICE CAN PLACE THE GUIDE AT RISK OF PROSECUTION.**

**INSTEAD, SUGGEST THAT THE CAREGIVER CONTACT THE APPROPRIATE PROFESSIONAL (LAWYER, NOTARY, OR HEALTHCARE TEAM).**

### **Some terms**

**Advance care planning** is a discussion a person has with their family, friends, and healthcare providers about their wishes for healthcare and how they want to live when they cannot make decisions for themselves. It also includes who they want to be responsible for making decisions about their health care in a way consistent with their wishes, called the *substitute decision-maker* or, in Québec, a *mandataire*. Sometimes these wishes are written down and this is called a *living will* or, in Québec, a *mandate*. Sometimes these discussions can involve financial and legal professionals as well. However, if the person's wishes involve illegal activities, the substitute decision-maker, healthcare professionals, legal professionals, and of course Caregiver Guides are not expected to carry them out.

More information, including a workbook and a wallet card indicating who the substitute decision-maker is can be found at:

[www.advancereplanning.ca/](http://www.advancereplanning.ca/) (English)

<http://www.advancereplanning.ca/fr/> (French)

**Palliative care** can reduce much suffering.

People can always **refuse treatments** that are prolonging their lives or causing them unwanted side effects (e.g., antibiotics). They can also ask for any treatment to be withdrawn.

If all other ways to reduce suffering have been tried, then palliative sedation therapy is possible.

**Palliative sedation therapy** is a treatment with the goal of relieving the suffering of a person in the terminal stage of the disease that uses a medication to reduce their level of awareness or responsiveness. The depth of sedation varies from light enough that the patient can still communicate to deep sedation for those rare occasions when nothing else works. Deep sedation until death occurs naturally is referred to as *continuous palliative sedation*. Palliative sedation should only be considered after all other available treatments that can reasonably be expected to relieve suffering have been tried. It must only be administered after discussion with and with the consent of the patient or the patient's substitute decision-maker.

**Physician-assisted suicide** is the **voluntary** termination of one's own life by administering a lethal substance with the direct or indirect help of a physician. Physician-assisted suicide is the practice of providing a competent patient with a prescription for medication for the patient to use with the primary intention of ending his or her own life.

**Euthanasia** is the act of intentionally ending the life of someone who is suffering in order to prevent more suffering.

**Suicide** is when a person initiates a behavior with the expectation that it will lead to the person's own death.

This is a legal act, although most life insurance policies are voided if the person has committed suicide.

**People who wish to commit suicide should be assessed promptly by a health care professional, since a reversible mental illness may be causing the desire to die.**

## AT THE TIME OF DEATH

A physician must examine the patient and declare the death. This can be done wherever the person has died, including in the home. The physician completes the appropriate legal documents. As this is not an emergency, a certain delay is expected between the call and the visit by a physician. If the death is expected, the body and the forms will then be picked up by the funeral home. (If the death was not

expected, or there is a suspicion of wrong doing, the physician will communicate with the coroner and the body may be sent to the morgue for further examination).

The funeral home is responsible for guiding the family in obtaining all the documents needed.

Family members can often get part of the cost of travel by plane or train to attend the funeral refunded, depending on the company's policy. In most cases they will need to produce a copy of the death certificate, so if these will be needed they should be requested from the funeral home.

## GUIDING TIPS

Not all of these tips will be right for you. You can try the ones that you think are possible.

- Encourage the family caregiver to get in touch with a legal representative (e.g., a lawyer or notary).
- Help the family caregiver make a list of questions and the appropriate persons/organizations to address these to.
- Encourage the family caregiver to access the Canadian Virtual Hospice website. There are discussion forums where a person can ask questions confidentially to a palliative care professional. Although no direct legal advice is given, the experts could give some direction.
- If someone asks you – as a Caregiver Guide – to help with any of the above mentioned acts, it is of great importance that you try to understand and listen to what makes the family caregiver request this. But always bear in mind: you cannot help with it because it is illegal for you to perform as a Caregiver Guide.

{ If someone seems *suicidal* call the healthcare team. }

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# *BEREAVEMENT*

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Loving and losing are inevitable parts of being human. Over our lifespan we tend to build relationships with others, struggling through their inevitable ups and downs. Together we laugh and cry, share milestones, create memories, and naturally make plans for the future. Facing the death of someone we share our life with is almost never part of these plans. Death can thus evoke many different reactions in surviving family and friends as they tackle the next part of their life without a significant other.

Common sense, as well as numerous research studies, suggests that psychological distress commonly occurs following the death of a significant other. In the days and weeks following loss, individuals may express some of the following statements.

- I am haunted by the memories of her suffering in the hospital.
- I have lost many people before, but nothing has prepared me for this.
- No one seems to understand what I am living through.
- When will things start to get better?
- If I really loved her, how can I ever allow myself to be happy again?
- I think I am coping well but many people think I am coping badly.
- I know they are dead, but I don't believe it.

These statements capture some of the struggles individuals face in coping with bereavement. People frequently attempt to keep the deceased in their lives (e.g., in memories, symbolically, spiritually, etc.) while simultaneously trying to rebuild a new life in which the deceased is no longer physically present.

This chapter explores these complex issues by addressing questions such as:

- What does bereavement look like?
- How does one cope with loss?
- When it is appropriate for a bereft individual to seek professional support?
- How can I help someone struggling to rebuild a life in the aftermath of death?

## WHY IS BEREAVEMENT IMPORTANT?

One might ask why bereavement is important. Part of the answer lies in the increased vulnerability of people who are bereft, including increased risk for numerous psychological difficulties (e.g., anxiety and panic, major depression, post-traumatic stress). In a minority of cases, bereavement symptoms can persist for years with little or no relief. Suicide and even homicide (though rarely) may be considered and attempted. Families and friends surrounding the bereft also suffer, preoccupied with worry about whether or not the bereft will be okay. Society in general is also affected. For example, there is an economic impact following bereavement, including time missed at work and loss of productivity.

## KEY TERMS

To help orient you through the sections that follow, here are definitions of four of the terms most commonly used in everyday conversations.<sup>1,2,3,4</sup>

*Loss* is a term that can apply to various domains of life (e.g., job, marriage, possessions) and suggests that one no longer has someone or something they used to have.

*Bereavement* is defined as the circumstance of having lost someone significant through death. It is often assumed that bereavement is limited to a specific timeframe.

The term *grief* is defined as an emotional reaction to loss with accompanying psychological, cognitive, behavioral, and physical manifestations.

Lastly, *mourning* is defined as the expressions of grief that are influenced by social and cultural factors.

## CONTEMPORARY UNDERSTANDINGS OF BEREAVEMENT

### *COMMON UNDERSTANDINGS*

Over the past century, many different theories have been put forward about the nature of bereavement and how best to cope with it. Household names like Sigmund Freud and Elizabeth Kübler-Ross are often associated with theories of bereavement. Freud<sup>5</sup> argued that grief is about abandoning the bonds one has with the deceased and reinvesting energy into other relationships. Kübler-Ross' stage model of grief<sup>6</sup> has become so popular that most people can recite it from memory: denial, anger, bargaining, depression, and acceptance. Unfortunately, there remains very little scientific support for this model despite its continued prominence.<sup>7,8</sup>

### *THE DUAL PROCESS MODEL OF GRIEF*

The Dual Process Model of Grief<sup>9</sup> suggests that, typically, a bereft person will tend to focus their energy in two directions:

**Loss-orientation activities:** processing the aspects of the death itself. For example, talking about the deceased with others, creating a memorial.

**Restoration-orientation activities:** activities to build a new life without the deceased. For example, distracting oneself, forming new relationships, learning new skills.

### *HOW IS THE DUAL PROCESS MODEL DIFFERENT FROM TRADITIONAL MODELS OF GRIEF?*

The model suggests that the bereft person alternates between loss- and restoration-oriented coping.

Each orientation is stressful, and the stress of bereavement is relieved through alternating between the two orientations. Think of it as a balancing act. It is too stressful to always avoid the pain of loss. It is also too stressful to always be dwelling on the loss and not have a break. Making space for both orientations makes coping with the stress of bereavement possible.

### *BEREAVEMENT AS A TIME FOR RECONSTRUCTING MEANING*

The theory of bereavement as a time when a process of meaning reconstruction takes place proposes that people cope with grief by learning to make sense of their own experience as well as their own unique responses to loss. Making meaning can involve the bereft:

1. Discovering creative ways to revision their future life
2. Finding a new sense of purpose
3. Re-learning what makes life still worthwhile,
4. Identifying the subtle imprints the deceased continues to symbolically make on one's life.

This process of meaning making provides a sense of continuity for individuals with *who they were*, but also integrates the loss into the story of *who they are now*<sup>10,11</sup>.

#### *PSYCHOLOGICAL CHARACTERISTICS OF BEREAVEMENT*<sup>12,13</sup>

Often competing emotional states occur at the same time and can be disorientating for the bereft.

*Sadness* is one of the most common emotions, sometimes surrounding the fact that plans made together have come to an end, or life will never be the same again.

*Anger* is often expressed towards the irreversibility of the situation. Occasionally anger is directed towards God, the health care system, or even the deceased for leaving.

*Guilt* can occur following a period of distraction. A week of relative well-being is sometimes followed by profound guilt that one should not be enjoying oneself at any time when the loss is still fresh.

*Self-reproach*, also called *self-criticalness* can be a powerful force of criticizing one's own feelings, coping, and experience.

*Anxiety* is also very common. Many bereft are surprised by their fear of forgetting the deceased. Some will replay the intense and anxiety-provoking memories of the last moments in the hospital.

*Fear of judgment*: Many fear that others will (or are) think(ing) badly of them because of the way they are grieving. They worry that their grief process is not in tune with their own or other's expectations.

*Loneliness/Isolation*: These are two distinct processes. First, some people have never experienced loneliness before or in a long time. Conversely, being isolated is withdrawing from others (e.g., refusing social invitations).

*Fatigue*: There is frequently a build-up of physical and psychological fatigue due to the end-of-life caregiving. In bereavement, there is finally time to stop and people sometimes experience burnout.

*Helplessness*: In partnerships where there was a strict division of labor, bereavement can mean that many new things need to be learned, which can make the bereft feel helpless until they learn to do them. For example, some individuals have never driven a car and are forced to learn to do so after the death.

*Shock*, or a sense that life is not real, can be short-lived or prolonged in bereavement.

*Yearning* involves nostalgia or the wish the person was still there. Feelings of intensely missing the person will lead some to seek out the person constantly, roaming the house, calling out their name and looking for the deceased.

*Emancipation* or freedom often takes place when the burden of caregiving was extensive or the suffering of the family member was severe. Many bereft will report feelings of freedom that often occur together with guilt (e.g., I am so glad I have my life back and I feel so guilty for feeling this way).

*Relief*: In some cases, the deceased may have been violent or abusive (verbally, physically, or sexually). In circumstances such as this, it may be a relief that the person is deceased. Some will also experience relief that a period of intense suffering prior to death is over.

*Numbness*: Facing a loss can sometimes be too powerful to comprehend. The result is a form of numbing or self-anesthesia.

*PHYSICAL CHARACTERISTICS OF BEREAVEMENT*

Physical sensations are often overlooked, but play a significant role in the grieving process.

Hollowness in the stomach	Tightness in the chest
Tightness in the throat	Oversensitivity to noise
Dry mouth	Breathlessness
Weakness in the muscles	Lack of energy

Sometimes any of the above sensations are so disturbing that individuals seek a consultation with a physician. For example, *oversensitivity to noise* is common and is sometimes associated with desire to avoid loud and busy places such as a movie theatre.

*BEHAVIORAL CHARACTERISTICS OF BEREAVEMENT*

Absentmindedness	Social withdrawal
Dreams of the deceased	Avoiding reminders of the deceased
Searching and calling out	Sighing
Restlessness	Crying
Visiting places that remind of the deceased	Treasuring objects that belonged to the deceased
Changes in sleep	Changes in appetite

*Absentmindedness:* Memory disturbances are regularly reported (e.g., forgetting keys, forgetting tasks) as well as lapses in concentration (e.g., cannot focus enough to read).

*Social withdrawal:* Frequent irritability in hearing “small talk” results in individuals reporting they have a short fuse and cannot abide engaging in conversations.

*Dreams of the deceased:* Dreams can be comforting and/or disturbing. Recurrent nightmares are sometimes reported. Some do not dream but wish they could, yearning for some form of contact (e.g., “I hope I dream about her and she tells me she is okay”).

*Avoiding reminders of the deceased:* Some will remove all photographs from the home, or avoid places they used to visit together. For some, music, once a source of shared pleasure with the deceased, can no longer be tolerated in bereavement.

*Searching and calling out:* This characteristic can overlap with yearning (see above).

*Sighing:* Taking deep breaths and slowing expiration can occur (e.g., yawning).

*Restlessness:* Agitation, trembling, and the need to move about are customary. Some have a difficult time being alone or in silence, and may, for example, keep the television on all day.

*Crying* comes up in unexpected waves, though normally reduces stress.

*Visiting places*, such as the cemetery, is important for some. This varies depending on socio-cultural tendencies or spiritual/religious practices.

*Treasuring the objects that belonged to the deceased:* Many bereft keep a picture or a keepsake of the deceased in their purse or wallet. There is often fear of being judged by others if they give objects away, but also if they hold on to objects for a long time (e.g., clothes, pictures, the ashes).

*Changes in sleep* are common, from difficulties falling asleep and insomnia, to oversleeping and difficulties getting out of bed. At night, things may seem more difficult to surmount, with more anxiety (e.g., sleeping alone). Some will report a fear of not waking up and dying in their sleep, perhaps in the same way the deceased died.

*Changes in appetite:* Under-eating and overeating can occur. For example, some will find they cannot overcome their guilt when enjoying a pleasant meal at a restaurant.

### COGNITIVE CHARACTERISTICS OF BEREAVEMENT

Disbelief	Confusion
Preoccupation	Sense of Presence
Hallucinations	“Nothing seems real”

*Disbelief.* Sometimes the recent death is the first one a bereft person has ever encountered. This lack of precedent is so powerful that it can be overwhelming and difficult to assimilate.

*Confusion:* Forgetting appointments, losing everyday objects (e.g., car keys) and difficulty completing tasks are usual. Some individuals become afraid that they will start to forget their memories of the deceased.

*Preoccupation:* Mildly obsessive thoughts tend to occur, including intrusive thoughts or images of the deceased. Some will express their deep regret about decisions made during the illness, or anger that events unfolded a certain way. For example “I should have brought him to the hospital for further tests; if I had, he might still be alive.”

*Sense of Presence:* The grieving person may think that the deceased is somehow still physically present. This can be especially true during the time shortly following the death.

*Hallucinations:* Both brief visual and auditory hallucinations are normal grief reactions in the early stages. They are usually transient illusory experiences of the bereaved and generally do not require professional intervention. Nevertheless, it is a troubling experience for someone who has never had hallucinations. Some fear that they are “losing their mind.”

*Nothing seems real:* A common sensation, sometimes a feeling that one is floating above oneself watching life pass by. This is typical in the early periods of loss, and naturally diminishes over time.

### TRAUMA DUE TO EXPERIENCES WITH THE ILLNESS

Prior experiences dealing with the illness often play out in the course of bereavement. For example, surviving spouses tend to report high levels of anxiety, depression, and sleep disturbance during bereavement in cases where the deceased partner had experienced unrelieved anxiety and pain prior to death<sup>14,15</sup>. A lack of perceived preparedness for death by the bereft, as well as exposure to potentially traumatizing illness-related events can be detrimental to bereavement adaptation<sup>16</sup>. Traumatizing events include those listed in the table below<sup>17,18</sup>.

Acute or ongoing pain crisis	Physically wasted
Major visible bleeding	Emergency hospitalizations
Shortness of breath and choking	Severe psychomotor agitation
Paralysis following compression of the spinal cord	Delirium (sometimes with w/paranoid or aggressive features)
Being cared for in an intensive care intensive care unit	Wounds that do not heal (e.g., broken skin, bed sores, dying tissue, often smelly)

### *THE DEATH OF A PARENT: CHALLENGE FOR YOUNG CHILDREN*

Research suggests that children cope better when families communicate about the death and the deceased. Children whose surviving parent is poorly adjusted tend to suffer with more depressive and anxious feelings. As such, for the wellbeing of their child parents need to seek out support if they are having difficulties.

The grieving parent often has a lot of questions about what to say, or how to involve the children. Here are some guidelines for parents.

#### ***Children need to know...***

- They will be cared for
- They did not cause the death
- Clear information about the death
- They are important and can be involved in all aspects (e.g., the time before death, the funeral)
- They will continue to have routine activity
- The family is not breaking up (e.g., they will not be abandoned)
- Someone will take the time to listen to their questions
- They can find ways to remember the deceased parent

### *CULTURE AND BEREAVEMENT*

Culture is dynamic and evolving; it includes shared elements of perceiving, believing, evaluating, communicating, and acting that are passed down through generations<sup>19</sup>. Grief is felt and experienced within cultural norms (i.e., mourning). It provides a basis for how people represent their bereavement and is the foundation for their feelings and behaviors<sup>20</sup>. Culture influences how grief is expressed (e.g., which feelings are acceptable to share). One of the greatest challenges of cross-

cultural bereavement is the risk of labeling a cultural tendency as wrong, deviant, or abnormal when compared to the dominant cultural norm.

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## **ASSESSING BEREAVEMENT RISK**

The vast majority of individuals (approximately 80-90% of the bereft population) cope relatively well with grief. Most bereft people are distressed, but are still able to function in their daily lives and do not require any professional services. We refer to this as uncomplicated grief. Although they do not require professional services, some people with uncomplicated grief will want professional support and may benefit from it. However, some bereft individuals discover that the stresses of grief are too difficult to manage alone despite their best efforts. This is referred to as complicated grief. In such cases, consulting a mental health professional is one of the best things to do to prevent things from getting worse.

### *UNCOMPLICATED GRIEF*<sup>1</sup>

Uncomplicated grief is the common emotional reaction to death. While understandably distressing, the grief does not impair everyday functioning at work, home, or in relationships. In uncomplicated bereavement, individuals are able to clearly articulate the loss experience, talk easily about the deceased, can refine life goals, and are able to find the silver lining in the clouds. This bereavement profile tends to follow a fairly predictable path. Relatively good functioning tends to occur in the first 3 months, associated with numerous tasks to attend to following death (e.g., settling the estate, being well surrounded by the social network). Significant distress usually takes place between 3 to 9 months. This 3 to 9 month window is usually the lowest an individual in uncomplicated bereavement will experience. Drops in functioning are also found when there are significant anniversaries (e.g., wedding dates, birthdays, holidays, 1 year anniversary of the death). Most individuals will experience an overall and steady increase in everyday functioning across the second year, with a return to baseline by 24 months<sup>2,3</sup>.

### *SPOTTING COMPLICATED GRIEF*<sup>4,5,6</sup>

Complicated grief is the heightening of grief reactions to such a degree that the individual becomes overwhelmed, engages in maladaptive behaviors, or the level of distress is fixed and the individual is unable to adapt to the loss. Approximately 15% to 20% of people continue to report significant impairment in functioning between 1 to 2 years post death. Individuals in complicated grief tend to become immobilized; they stop moving forward. The story of the loss is repetitive and doesn't change over time. They are plagued with a persistent sense that life has lost all meaning since the death. They become socially isolated. Some are preoccupied with the events surrounding the death. Excessive bitterness and anger are not uncommon. They are often very critical of themselves.

### *WHEN IS IT TIME TO GET A PROFESSIONAL INVOLVED?*

As a general rule we recommend that individuals schedule a regular check up with their family doctors in the weeks and months after the death. This can help prevent complications in coping down the road. We suggest an individual consult a professional when one or more of the following occurs:

- The person's daily functioning is significantly impaired
- They are not sleeping at all
- They say "I am depressed"
- They are a danger to themselves (e.g., "I am thinking about killing myself").

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## **THE ROLE OF GUIDES IN BEREAVEMENT SUPPORT**

Caregiver Guides are well placed to accompany family members in bereavement, as well as identify family members who are experiencing a complicated grief reaction or are becoming depressed.

### *INFORMAL QUESTIONS WHEN SUPPORTING A BEREFT INDIVIDUAL*

Here are some questions you may wish to blend into your contact with grieving caregivers.

- How are you coping?
- How are you sleeping?
- How are you eating?
- Are you feeling well surrounded?
- Are you finding any moments of joy during the day?
- Are you having any preoccupying thoughts or memories?
- Are you having any dark thoughts or thoughts of suicide?
- What are the most difficult aspects of this loss?

### *WHAT CAN BUILD A RELATIONSHIP WITH SOMEONE GRIEVING?*

(Adapted from Ackerman & Hilsenroth, 2001; 2003; Safran & Muran, 2000; Yalom & Leszcz, 2005)

In some cases, a Guide may not have time to establish a relationship with the caregiver before the patient dies, and will need to establish a relationship in bereavement.

- Remain flexible and discuss topics of relevance to the bereft
- Stay respectful
- Be heartfelt, friendly, and affirming
- Be predictable and trustworthy
- Allow for moments of silence when words are not enough
- Be honest
- Instill hope

#### *ADVICE FROM A GUIDE*

*Guide: "I am less anxious [now] when I meet a new person, because the very first time I wasn't sure what they would need from me. The second time as well, but it just built my confidence, so by the time I went in with the third one,[...] really [now] I want to get to know who that person is that they are talking about [the deceased], and once they begin to talk about that person, it's interesting how you can understand their grief differently. And so now I go in with that thought first, let me get to know who [the caregiver]'s talking about, and then when he talks about her, I'll be able to connect things. And you know, like the readers, let's say, they love to read, let's see what we can do about this commonality that they had [with the deceased] to help with his grief. The other girl, she loved to cook, she loved to cook different meals for him, and we talked about, so that's, you know, like again, you create a common subject between the two of you as well. So that was interesting, too."*

*Interviewer: "So that's a good point, too, that you need to focus on the patient. Although the focus of care is not the patient, but the patient is very present in your relationship."*

*Guide: "Absolutely. Because that's who it was all about. And they really want to talk about the patient, because that's where their grief starts."*

#### *WHAT CAN UNDERMINE A RELATIONSHIP WITH SOMEONE GRIEVING?*

- Rigidity
- Being critical
- Self-disclosing inappropriate personal details
- Being aloof, distant, distracted or disengaged
- Being silent too often
- Trying to have all the answers

#### *WHAT NOT TO SAY TO SOMEONE WHO IS GRIEVING*

- You're still young; you'll meet someone new.
- Just think positively.
- It's not that bad.
- You still have your health.
- Look on the bright side.

- It was meant to be.
- Everything happens for a reason.
- She's in a better place.
- Just give it time.
- Try not to think about it.
- You have to pick yourself up and keep going.
- Nothing good comes from feeling sorry for yourself.
- You're strong; you'll get over it.
- You're just in the depression stage. It will pass.
- You're making too much of this.

*WATCH FOR THESE SIGNALS OF POOR LISTENING<sup>5</sup>*

- Over-identification: "I know just how you feel."
- Disapproval of emotions: "You shouldn't feel that way."
- Over-control: "You need to listen to me."
- Giving advice: "This is what I would do..."

*COMMON FEARS OF VOLUNTEERS*

(adapted from Pipes & Davenport, 1999<sup>5</sup>)

- Becoming overwhelmed
- Making a fool of oneself
- Of the caregiver getting too close and becoming dependent
- Of not being competent
- Of making the caregiver worse
- Of not liking the bereft
- Of the caregiver not liking us
- About losing control (e.g., of emotions)
- About not making a difference

*HOW TO DEAL WITH YOUR OWN FEARS*

- Try to see it as a learning opportunity: What can I learn from the fear? What is the fear making me do, or keeping me from doing?
- Remember that you can only be who you are: don't try to be someone or something else.
- When the fear is impairing your service, it is time to consult the Guide Coordinator for guidance.

### *HELPING THE CAREGIVER BRING GOOD MEMORIES TO THE FORE*

Most of the recent memories the bereaved caregiver will have of the deceased will be of them very sick, perhaps suffering, and not looking like themselves. As a Guide you can help the caregiver to bring memories of better times to the front of their minds again.

*“She [the Guide] will ask you questions, like “How did that happen? How do you feel?” And I answer her questions, and I tell stories about me and [my husband], she asked me how we met, and stuff like that... The things that you have to remember about the person are the good things that two of you had shared, and that way you don’t feel bad. So she lets me tell the stories, where we met, places we go, places we share, and things that we do together, things that we go together that make us happy. That way, I remember him that way instead of remembering him on the other side, in pain...” [Family Caregiver]*

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## THE EXPERIENCE OF BEING A GUIDE

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Overall, the volunteers found the experience of being a Guide to be very positive. Like anything else complex that you undertake, it is hardest at the beginning, when you are most unsure of yourself and there is still much to be learned. The Guides joined the service to help caregivers and to contribute to society, and it made them feel good that they were able to do both through their service. They felt especially good about empowering the caregivers to take care of themselves and empowering them to bring family, friend and community resources to help with caregiving, where desired. The Guides also felt good being able to provide support when the caregiver really needed it. They also felt that they grew from their experience as a Guide.

### *IN THE GUIDES' OWN WORDS:*

*It's a very enriching experience, meeting different people, and their needs are different as well, so I'm really enjoying the interaction with these people (caregivers).*

*I just got so much out of it, and it's like... with the very first one, I... because I had just met her at a coffee shop and he [her husband] died within a week, and I never got a chance to meet him. Her devastation was so palpable, it was so hard to take, she was like very childlike and depended on this man, that I thought, "Oh, is she ever going to get better?" Because she just kind of fell apart. And I kept telling her, "I feel cheated that I never met him, you need to keep telling me about him, what he was like," and as she kept talking about him and explaining him and things that he did for her, I think she kind of outgrew her need of him eventually. Not because of me, but because of being able to face the challenges out there, and it was... she was like a child that blossomed, and I was so excited for her... it just was so exciting to watch ... I felt honoured. I know this sounds really strange, but I was just so happy to be with her during that time, and I'm glad that she's on the other side of it, that she's doing really well.*

*Best is knowing that, you know, you, and it's the collective you (the team), you've helped. And it's also not just from your own perception that you've helped, but when the person (caregiver) actually says, for instance, when I hear, she recounts, she literally says to her friends, what aspects of this...really helped her.*

## EMBRACING CONTINUOUS LEARNING

To be a successful Guide, it is important to embrace continually learning from yourself, from the other Guides and the Guide Coordinator, and from the caregivers. Our Guides described ongoing learning as one of the things they liked about the service.

1. Learn from yourself: through reflection on how each visit with a caregiver went.

*I go over the time we have together, I go over it as I'm going home, I'm driving and I'm thinking to myself, what could I have said better, what could I have offered that would have been easier for that person.*

2. Learn from the other Guides: discussion at team meetings about the issues their caregivers were facing allowed each Guide, and therefore each caregiver, to benefit from the wisdom of all of the Guides.

*...coming together for the team meetings was great. It's a lot of learning, and a lot of sharing, and knowledge building.*

*...then I would take it back to them (the team), and that's where the Coordinator became very useful, and the other members of the group in our meetings, and I would just talk through what was the difficulty, and then this is what I did, and then everyone... So, in a way, that's what I did, I kind of looked at, for the things where I think I had some gaps, I brought it back to the team, and then with their input, I was able to say, OK, for the next time. So it either reinforced (what I did), or I had new suggestions, I had new ideas as to how to go about things.*

3. Learn from the Guide Coordinator: through discussions with her after initial visits and at team meetings.

*It's really OK to be a learner, right. You're not going in as some kind of expert coach, you're going in as a learner of this person's experience and you've got someone you can rely on, right, and that's because the Coordinator is so key, you've got someone that you can go, who's also a learner by the way, but that you can go back and get help from, and you don't need to know everything or answer everything right there in front of them (the caregiver), and you really, I think, have to go in with that humble... Like the attitude of, "I'm a learner". Humility, high on the list of the needs of a Guide, I think, is humility.*

## THE FIRST VISIT

Many Guides felt nervous for the first visit with a new caregiver, even after some experience as a Guide. They felt some pressure to make a good connection with this person who they had never met on the first visit, so that there would be a second visit. They worried about being able to meet the caregiver's needs. It was the unknown that was scary; once they got to know the caregiver a bit they almost always made a good connection as they were able to find something in common to talk about, and the caregiver could sense that the Guide was caring. In contrast, some Guides felt that they were embarking on a new adventure when they met a new caregiver, making them look forward to it. Of course, you may feel both excited and nervous! As Guides had experience with more caregivers, they began to feel less anxious about that first visit.

*So there's that little aspect of sort of stage fright or queasiness till the curtain rises, you know, that sort of thing... But you have to be prepared to at all times just be talking from the heart, so you need the confidence and competence to... to just be able to operate from the heart, you know, without a planned agenda, but I did have an agenda, an aid-memoire there to make sure we didn't forget something that I thought was sort of critical that we cover off and I was upset I had forgotten it last time, I put a little note there, you know... But... no, it wasn't difficult, it was not hard.*

*(...) going and not knowing exactly what to do, with someone who doesn't know what they want, and what you can offer, it's really hard, until you find a connection, and then, once the connection starts, then everything can start building from that, and you feel more comfortable, but until that moment where you feel that you have connected, it's really... (tough)*

*I think, the initial one, I was super-nervous, but I think as we progressed, like each case, I took the experience of what I felt like each time, and built on that, so I found personally it was amazing to have that depth of experience and I didn't feel nervous with the last one, so I've gotten from being super-nervous to "I'm looking forward to this experience", and I wasn't that nervous as I tap on door, so that's huge. And it takes from the Guides as well, their experiences, because they are saying the same thing as me about being nervous and you feel better because you can share that.*

In some cases it took several phone conversations to even be able to set up a home visit, so don't despair if at first the caregiver is hesitant. It is often difficult for caregivers to imagine what type of help they can use if it is not direct help for the patient. Some caregivers will want you to help them find solutions to pressing problems right away, and through that a relationship is formed. Others will want to form a relationship first before accepting guidance.

Our Guides liked to speak to their Coordinator after the first visit with a new caregiver, as well as when they encountered a particularly challenging issue on a visit. They found this contact reassuring. If your service does not have a Coordinator who is easily available, we suggest that Guides can contact one another after a first visit. It was important to the Guides to be able to bounce ideas off of someone else, and to debrief about difficult issues the caregiver or they were facing. This happened at team meetings, but unless a team meeting was scheduled for the next day or two, individual debriefing was desired.

## TEAMWORK

The importance of working as a team to guide the caregivers has been mentioned in other chapters and has already been mentioned in this one. However, working as a team was also good for the Guides: they described it as one of several best parts of the experience of being a Guide. They enjoyed being an equal member of a team that worked in a collaborative way to help others. The spirit of collaboration extended beyond caring for the caregivers to include working together to improve the service and mentor new Guides.

Since Guides work alone when they are in the home, it is important to develop good team spirit. Genuinely valuing the different contribution each team member makes and always treating each other with respect were key to everyone feeling valued and welcomed as part of the team. The team members cared about each other, and this became clear in the spontaneous chats at the beginning of each team meeting, with some continuing after the meeting. This created a context where Guides felt safe to bring up difficulties they were having with a caregiver, a caregiver's issues, or their insecurities about their ability to guide a caregiver. They knew they would not be judged and would receive support and helpful suggestions.

## BOUNDARIES

Services set their own boundaries for their volunteers. Therefore, while some boundary issues that arose in our service and our way of resolving them are described below, they may not apply to your service. Please discuss boundaries with your team. We include this section on boundaries because figuring out where to establish boundaries was something that our service and many other services struggle with.

There are some boundaries that must not be crossed in any situation. For example, counselling suicide or having an intimate relationship with a caregiver. These are obvious and do not make it difficult to determine what is the right thing to do. However, many issues fall in a 'grey zone', where what is the right thing to do in most situations may feel like the wrong thing to do in a few.

As a Guide you are likely to be faced with some situations where you feel torn between what you were told is a boundary or what you feel your own boundary should usually be, and a particular situation where doing what feels like the morally

right thing to do involves crossing a boundary. Here are some things to consider when faced with this type of situation.

- 1) If at all possible, delay any decision to cross a boundary until you have had a chance to discuss it with your Coordinator, and with the rest of the team if such decisions are usually made together.
- 2) Think of the potential benefits and harms of crossing boundaries. Why was the boundary set in the first place? Does that reason apply in this particular situation? Are the risks of not crossing it worse than maintaining the boundary?
- 3) Was the boundary established to protect the Guides, or to protect the caregiver or patient?
  - If the boundary was established to protect the caregiver or patient, there would need to be an extreme circumstance to justify it being breached. Exceptions would be:
    - where there is a greater risk to the caregiver or patient of not breaching the boundary. For example, this is why the law makes it clear that if someone is suicidal, even if confidentiality has been promised, it must be breached to inform a health care provider;
    - if there are boundaries that are set because the Guides do not have the training to do something that might do harm, but you have the training to do that. For example, while our Guides were not trained to safely help move a patient, one was a licensed nurse and so she could safely breach that boundary if a caregiver needed help.
  - If the boundary was set to protect the Guides, carefully consider what potential harm there is to you and decide whether or not you want to cross the boundary.
    - Respect for yourself and your own boundaries is as important as your respect for the caregiver and theirs. If you feel pressure from the caregiver or anyone else to cross a boundary set by the service to protect you, or that you have set for yourself (such as how much of your personal life or beliefs to divulge; or the amount of time you can spend on a visit), there is no need to give in to that pressure. Because a caregiver chooses to share certain details about their life with you does not oblige you to share in the same way.

After careful consideration of the risk to yourself of crossing a boundary established to protect you, we decided that the Guides could cross it. Remember that the risk to you of crossing a boundary may be different with different caregivers, or even with the same caregiver at a different time.

*AN EXAMPLE*

Sharing your phone number with a caregiver poses a risk that they will call you at an inconvenient or inappropriate time, or that they will call very frequently.

- Will you be able to say to the caregiver that you'll call them back later?
- If it is your home phone and you live with others, will it be a problem for them or the caregiver if they answer the phone?
- When it is time to end the service, is the caregiver likely to refrain from further contact?
- If the caregiver persists with unwelcome phone contact, in rare cases you might need to change your phone number.

Are you willing to take these risks? The answers to these questions might be different for different caregivers and for different Guides. Many of our Guides decided to share their phone number with some caregivers once they felt that they knew the caregiver well enough that the chance of problems occurring was low. They chose not to share their phone number with others.

## NEGOTIATING RELATIONSHIP BOUNDARIES

The relationship between a Guide and a caregiver does not fit in any of the usual categories. As a Guide you are not a health care provider, more than an acquaintance, but not a friend. Many caregivers will share things with you that they don't share with health care providers, family (including the patient), or friends. You will prove a safe outlet for sharing their frustrations with anyone else: they know you will keep it confidential and you won't judge them. You don't have a relationship with the patient that might be hurt if they divulge some of their less than nice thoughts about the patient. For example, they may feel anger at some of the patient's or a health care provider's behavior, express frustration about being a caregiver, or

tell you that because the patient has been suffering, they hope that death will come soon. Furthermore, the relationship is mainly one way rather than reciprocal.

This unique relationship can make it challenging to know where to set boundaries. For example, what do you do if a caregiver wants to reciprocate in some way? It is not unusual for a caregiver to want to do something for their Guide. Many people are uncomfortable taking without giving, unless it is from someone who is paid to do a job. While Guides should never accept money from a caregiver, should they accept that the caregiver pays for a coffee if they meet in a coffee shop? What about lunch or dinner? What if it is at the end of the Guide's service, as a thank you from the caregiver? What if it is a gift?

What usually happened in our service was that the Guide let the caregiver know that they were not supposed to accept anything from the caregiver. If the caregiver insisted, the Guide said that they'd discuss it with the team (unless it was similar to a situation we've discussed before and so the team's thoughts were known). This also allowed the Guide a graceful way out if they felt uncomfortable accepting. Here are some things we considered.

1) What seems to be the motivation behind the caregiver's offer?

The motivation needed to seem purely to reciprocate in some way, rather than to indebt the Guide to the caregiver in even a small way or to procure a favor (including a continued relationship). For example, if the caregiver preferred to meet the Guide at a coffee shop rather than at home, we decided it was alright to have the caregiver pay for coffees for both of them one time, and the Guide would pay for both of them the next time.

2) Does what is being offered seem appropriate?

For example, coffee or a meal may be appropriate, but the offer of something that is particularly meaningful to the family is not.

3) The cost, as well as the caregiver's capacity to pay, if there was a financial cost.

We felt the cost always needed to be small. For example we decided that a caregiver taking the Guide out for dinner to thank them at the end of their service was too big, but an inexpensive (for that caregiver) lunch was alright since it was for the Guide's help over the whole period of service. When we knew that the caregiver had financial concerns, we decided that the Guide would suggest going for a coffee instead if a meal was offered.

Clear limits as to what the Caregiver Guide does and doesn't do, as well as to the time availability of the Caregiver Guide need to be established at the outset with the family caregiver.

There is always the possibility of "awkward" moments arising while part of someone's life, in someone else's home. These moments that prompt discomfort, whether they be inappropriate or unusual, should be recognized as such and limits should be re-iterated by the Caregiver Guide. These moments can be personal, financial, etc.

## ENDING THE SERVICE

It can be hard to say goodbye at the end of the service. Giving the caregiver warning that the end of the service is coming up, and increasing the time between visits towards the end of the service can make the end feel less abrupt. In some cases, after the official end of the service, if you think that the caregiver would welcome it you might contact the caregiver occasionally by email or phone for the first few months, on anniversary dates that you know are coming up (such as the patient's or caregiver's birthday or their wedding anniversary) or important holidays, to check on how they are doing and so that they know you are thinking of them over the few months to a year after the service ends.

By empowering the caregiver rather than making them dependent on you, they will in most cases miss you but be able to cope well on their own once you have helped them through the first 3-6 months of bereavement. In the rare case that the caregiver does not seem to want to end the relationship, if it is feasible in your service, the Coordinator can phone the caregiver to make it clear that the service has ended.

If the caregiver seems to need more help, they can be encouraged to seek professional help or join support groups, depending on their need.

# HELPFUL WEBSITES

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## IN ENGLISH

### Canadian Virtual Hospice

Information about palliative care and a special section for family caregivers. Videos for family caregivers such as how to make a bed with the patient in it.

[www.virtualhospice.ca/](http://www.virtualhospice.ca/)

### Compassionate Care Benefit (Canada)

Information and forms through employment insurance to allow caregivers to take some time off from work at partial salary to provide care.

[http://www.servicecanada.gc.ca/eng/ei/types/compassionate\\_care.shtml](http://www.servicecanada.gc.ca/eng/ei/types/compassionate_care.shtml)

### Family Caregiving for People at the End of Life

Includes links to many family caregiving resources.

<http://eolcaregiver.com/>

### Advance care planning

[www.advancecareplanning.ca/](http://www.advancecareplanning.ca/)

### Palliative Care Victoria (Australia)

Special section for families and patients

[www.pallcarevic.asn.au/families-patients/](http://www.pallcarevic.asn.au/families-patients/)

### Helpguide

Guides to various aspects of health and wellbeing, including mental health, stress relief, and caregiving.

<http://helpguide.org/>

## EN FRANÇAIS

### Portail Canadien en soins palliatifs

Information sur les soins palliatifs et une section spéciale pour les proches aidants. Vidéos pour les proches aidants, par exemple, comment faire le lit avec la personne malade dedans.

[www.virtualhospice.ca/fr\\_CA/Main+Site+Navigation/Home.aspx](http://www.virtualhospice.ca/fr_CA/Main+Site+Navigation/Home.aspx)

#### Assurance-emploi et prestations de compassion

Information et formulaires à remplir pour permettre aux proches aidants de s'absenter temporairement de leur travail avec une compensation partielle de salaire, afin de prendre soin d'un membre de leur famille.

[www.servicecanada.gc.ca/fra/ae/genres/prestations\\_compassion.shtml](http://www.servicecanada.gc.ca/fra/ae/genres/prestations_compassion.shtml)

#### Soigner un être cher en fin de vie

<http://www.soignantfindevie.com/ressources/aide-%C3%A0-domicile.aspx>

#### Planification préalable des soins

<http://www.advancecareplanning.ca/fr/>

## *SCENARIOS FOR PRACTICE*

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What follows below are scenarios we created to discuss together in training with other Guides and the Guide Coordinator. If clinicians are available to attend these discussions they could also participate in the discussion to teach the Guides. What is important is that the team learns to think creatively about ways to help the caregivers and become familiar with how different strategies in this Guidebook could be useful.

### **ANNIKA**

Annika is a 40 year old woman who met her husband, William, 5 years ago in the apartment complex in which they lived. She has an adult daughter, who does not live in the same city but to whom Annika provides some financial support, and a 12 year old son, Chandra, both from a previous relationship, and an 18 month old daughter, Emma, with her husband. She has been a full time caregiver for her husband since his diagnosis six months ago and, as a result, stopped working at her job cleaning houses. She and William were married shortly after his diagnosis because, according to Annika, he wanted to make sure that both she and the children would be taken care of after his death.

William's illness has been a time of great distress for Annika as he is very afraid of his impending death, and often keeps her awake at night with the ensuing anxiety, requesting that she remain alert so that he won't be alone if he dies during the night. As a result, she is often exhausted during the day, and sometimes irritable with both him and her children. She would have liked to get outside to enjoy her bicycle or take long walks, but told the Guide that her husband's demands made it difficult for her to do so.

Chandra has recently begun to express both great sadness and anger as his step-father's disease has taken a dramatic and quick turn towards the end. After walking into their bedroom, he saw his mother in tears at the bedside, and William cringing in terrible, and seemingly intractable, pain. Upon seeing their suffering, he yelled out to them, "What am I supposed to do now?" Chandra then stormed out of the room and went directly to the family's Hindu shrine. He overturned it with both great drama and resulting destruction. "What did I do to deserve this? He's not even my real damned father.... Karma....phew.... I'm out of here." He then left the home after yelling at his mother over his shoulder, "I'm going to spend the night over at Steven's house, his mother's been more of a mom to me than you've been lately anyways! There's some Karma for you to deal with, a gift from me to you!" Annika helped calm and soothe her husband after the drama, then left their room and entered the kitchen where she spent a few quiet moments in prayer trying to settle

her nerves and regain some sense of direction. Later she called the Guide and shared with her the elements of her family's latest trials.

At the time of William's death and funeral, the Indian community, which she is part of, was very supportive, calling on her and bringing over food, etc. She also has a good relationship her husband's adult daughter who at times will help Annika out with the children. However, despite this support, Annika still keenly misses her husband and often questions why he had to leave her.

While still well enough to do so, William had prepared a portfolio of resources for her to consult to help deal with the household responsibilities that he would normally have taken care of, such as car maintenance. Notwithstanding this, she frequently feels overwhelmed by the day to day business of living and often vacillates between tears and laughter when speaking with the Guide.

In addition to the loss, Annika's other major concern is finances. William's bank accounts are frozen (normal practice) and she has had to deal with a lot of red tape and bureaucracy regarding his pensions, as the government has many questions surrounding their marriage and the motivation for it. She does not yet have her permanent residency papers, so she is not eligible for government assistance programs. Chandra is starting school soon but Annika does not have the money to buy the required supplies; it is difficult for her to pay her rent and also to buy groceries. She has also not been bringing Emma to daycare anymore as she does not have money for a monthly bus pass and getting Emma there is just too difficult.

## BRENDA

Brenda is the primary caregiver for husband, Kevin, who is dealing with end-stage cancer. He's very sick with constant pain, has difficulty walking and takes anti-depressants for depression. Both are retired and in their eighties. They have five adult children: one lives in the same city, one lives a couple of hours away, the others live across the country. The children are quite supportive but are limited in what they can offer. Kevin is very angry and resentful of Brenda's perceived good health. He is demanding and controlling of her time, and sometimes emotionally abusive towards her. The only outside help he will accept is the community nurse who comes to give him his daily injections.

Brenda has been caring for her husband alone for almost a year. She suffers with health issues of her own and is beginning to resent the demands Kevin places on her. She no longer visits with her friends and is also concerned about the financial strain her husband's illness is placing on them. Although her friends and extended family sometimes come to visit, she doesn't ask them for help.

Initially, although Brenda was quick to sign up for the service with the Guide Coordinator, it was difficult for the Guide to connect with her. It took several attempts for the Guide to speak over the telephone with her and multiple rescheduled meetings before they finally met in person. Brenda was always very busy but the Guide faithfully called each week to follow up, explain the purpose of the service and offer support over the telephone.

Kevin always controlled the finances and Brenda depended on him for help with almost everything, including the paper work. She struggles with the organizational skills needed to assume many of the tasks normally handled by him. They both need help with transportation to get to and from multiple appointments during the week. Brenda does not know nor understand the health care system and the social services networks. She is also not very resourceful in terms of problem solving, which contributes to her frustration. She does not communicate well with the medical support team and the local community health and social services personnel; this has kept her and Kevin from benefitting from many of the services that could have been provided.

Kevin's difficult character, attitude, and overall lack of cooperation make it difficult for her to be with him and cause her much distress. Brenda's own health is not optimal nor she does have the necessary resources to deal with the threats and challenges of Kevin's advancing cancer. Although they both wish for Kevin to continue to be cared for at home and, ultimately, to die there, Brenda is unsure of what to do when the death is actually imminent. She tells the Guide that her immediate needs are: help with cooking and cleaning the house, assistance with Kevin's hygienic care, and respite for her to have some alone time. However, the family's pride prevents them from accepting help from any of the community services from their religious community, with which they are familiar, and they are

unwilling to disclose their financial status in order to receive the means-tested reduced rates for services from community health and other services to which they are legitimately entitled.

## MATTHEW

Matthew is in his forties and has been the primary caregiver for his mother, Eileen, who is in the late stages of decline from breast cancer. Eileen lives with him and his 25 year-old son, Alex, but there is 24/7 private help for mom. Matthew also has a sister, Janice, who lives in another province but controls the mom's finances and, indirectly, Matthew's, as he is unable to work for health reasons. There is friction between Matthew and his sister because of the finances. Matthew feels considerable pressure to justify his every expense, and this has led to him being extremely nervous during the mother's illness about anything that surrounds expenses. He feels that his caregiving role is not given any value or validated by Janice.

Matthew admits that he has a large amount of guilt surrounding the family history. His father, who died 5 years ago, could be cold and emotionally neglectful of Eileen. Matthew often wonders if he could have done more for his mom, especially as he matured in adulthood. Matthew feels extremely close to his mother; their relationship prior to the illness included many outings together and he says his mom is "my number one fan when it comes to my music and encouraging me to continue with my passion". Matthew expresses that he may lose a huge part of his identity when his role as a caregiver and friend to mom ceases to exist. He is very unsure of his future plans and often expressed the fear that he would end up working at a fast food restaurant.

Matthew laments that he does not really have any friends that he can talk to anymore and admits that his own neediness may have pushed them away. He finds it difficult to see beyond his own situation and to even talk about anything else when he does see other people. The Guide Coordinator also noticed during her preliminary visit with Matthew that he did seem to feed off her energy and she felt exhausted when their visit was over. It took a lot of effort on her part to keep the discussion focused and restricted to the time she had allotted for the visit.

Matthew's mother died shortly after the Guide's third visit. Therefore, the Guide/caregiver relationship ran for approximately 4 months and was more bereavement focused.

When the Guide first asked Matthew what his expectations of this service were, his reply was along the lines of "well, this is therapy for me, I get you to talk to and to help me." Matthew was demanding in the respect that he had so much to talk about apart from the situation surrounding his mother, and with his conversations flowing from subject to subject it was often difficult to keep the focus. It was agreed that he could email the Guide between interview sessions. The emails were a stream of consciousness, in a similar vein to his conversation style, and he said that just writing it down helped him to get it out of his system. Often he was able to look through these emails and realize the solution to his problem or see a bigger picture that eventually led him to greater understanding. Many emails were contained questions which he then answered himself. He always expressed that this helped

him and that he was glad to have the opportunity and outlet that having a Guide provided.

## JOHN

John works in a managerial position at a nearby company. He has been able to work flexible hours in order to be more available to care for his mother, Donna, but is very frustrated with his children's lack of involvement in her daily care, feeling that too much burden is falling on his partner Marc. He mentioned to the Guide that the children don't seem to understand the seriousness of their grandmother's condition and continue with their day to day lives as though nothing is wrong.

John has always had a difficult relationship with his mother, a devout Catholic, who is very critical of John's sexual identity. Donna can be quite vocal about a lifestyle which she perceives as an abomination against God, and although Marc is supportive of John, the strain of caregiving is beginning to weigh on their relationship.

John struggles with a past punctuated by an abusive, alcoholic and fanatical mother, and a present where he feels duty bound to care for her. When he and Marc first agreed to take Donna into their home, they thought that it would be for a matter of weeks, but it has now turned into months.

Donna is very resistant to accepting help from the community health care service, and is still adamant regarding her own independence, despite medical advice to the contrary. Mobility and danger of falling are major concerns and she uses furniture to navigate throughout the home.