Chapter 8: Promoting Self-Efficacy of Family Caregivers

STEP I - CONDUCT AN AUDIT

Key item - the questions the TOOLKIT After-death Bereaved Family Member Interview asks about supporting the self-efficacy of the family

1. How confident were you that you knew what to expect while [PATIENT] was dying - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

2. How confident were you that you knew what to do at the time of death - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

3. How confident were you that you understood about the medicines that would be used to manage (his/her) pain, shortness of breath, or other symptoms - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

4. How confident did you feel about taking care of [PATIENT] at home - very confident, fairly confidently, or not confident?
   [ ] VERY CONFIDENT
   [ ] FAIRLY CONFIDENT
   [ ] NOT CONFIDENT

STEP II - ENGAGE STAKEHOLDERS & DEFINE A GOAL

8.1 Key item - the importance of focusing on promoting self-efficacy

Providing information and educating caregivers will contribute to improved care.
~Ferrell 1998
Along with informing and educating patients and families, promoting self-efficacy among family caregivers is a key process for achieving patient-focused, family-centered medical care. In fact, promoting the self-efficacy of family caregivers has a direct impact on patient care outcomes. As a result, promoting self-efficacy is an effective strategy for working with family members of patients who are dying.

Family members often feel stressed and overwhelmed by the experience of caregiving, and they often express feelings of powerlessness. They may never have cared for someone who was sick or dying. They may never even have been in the presence of one who was dying. Increasing their confidence in their ability to know what to do and how to provide care can go a long way in reducing their stress.

Self-efficacy refers to a person's confidence in how well s/he can accomplish a task or group of tasks. In the context of end-of-life care, self-efficacy is the confidence that a caregiver has in her/his ability to meet the needs of the one that is dying. Family caregivers take responsibility for or help with a variety of tasks, for many of which they have little or no experience and training. Over time, family members can gain a sense of control over the events of the dying process by mastering certain tasks in the face of difficult situations.

Health care providers play a key role in enhancing caregiver confidence in that they know what to do at crucial times of caring for a person dying at home and can share that information with the caregiver. Whatever obstacles a family caregiver may face, the health care provider can influence how the caregiver utilizes information about providing care, therefore increasing the caregiver's confidence in his/her ability to successfully undertake the task.

I want to know how to provide the care when it is needed and to be sure that I am doing the right thing.

~Family member

Self-efficacy is a process. Family caregivers often provide the hands-on care that supports a seriously ill person's ability to remain at home. Caregivers assume responsibility for pain relief and need to understand the basic pain management principles. They may need to learn new skills in assisting someone with ambulation, comfort care, and end-of-life care. The performance of each of these skills changes with the phase of the illness.

Family caregiving has an emotional impact that can be profound. When the caregiver's needs are identified, validated and supported, to the extent possible, and when the caregiver feels confident and prepared for the eventualities of the dying process, the experience can be quite meaningful and valuable for all involved. Conversely, when the caregiver feels alone and uncertain, exhausted and anxious, the caregiving experience can leave everyone involved with a sense of abandonment, inadequacy, resentment and anger.
Mary, Gloria’s Caregiver

As Gloria’s condition begins to worsen, Mary wonders if she will know what to do for her mother as she gets closer to death. Gloria has gotten weaker and needs more help to get around. Her doctor said that she would become so weak that she will not be able to get out of bed and eventually would become unresponsive. Mary has never cared for someone so sick. She is not at all confident that she will be able to give adequate care for someone that is on bed rest and who needs help with all aspects of care. The prospect of feeding her mother or changing the bed sheets, although seemingly simple, causes her to doubt her ability to provide the care her mother may need. She feels even less confident that she will know what to do as death gets very close.

While talking with an old friend, Mary worries aloud: “I want to give the right medications and keep her comfortable, but it all is so foreign to me. I just don’t know that I can do it, but I’ve promised Mom that I'll take care of her at home.” Her friend asks if Mary has considered hospice services. Mary responds, “Oh, I don’t think we’re at that point yet, do you?” After some discussion, Mary decides to call the Hospice House palliative care nurse whom she had met earlier through the hospital discharge planner.

When Mary calls Hospice House, the nurse offers to come to her home and talk with Mary and Gloria. During the visit, the nurse talks about the options and how hospice can be of help, even at this stage in the disease. They all discuss the care that can be provided at home and the support that hospice can provide so that Mary can effectively and adequately provide for her mother’s needs. After this meeting, Mary feels more motivated to continue as her mother’s caregiver since she knows that there is some backup to guide her through each step.

Self-efficacy: Beyond Informing & Educating

Informing and educating are important parts of promoting self-efficacy. Caregivers have reported that communication with health care providers is helpful, and a lack of knowledge can result in decreased caregiver confidence. Clear, honest information regarding medications, symptoms, disease progression, comfort, and what to do in the event of a change in condition or at the time of death is essential for supporting self-efficacy.

> The provision of information prepares caregivers to support the patient, reinforces the treatment goals, and assists in managing side effects of medication and disease.
> ~Tringali (1986)

Although very important, informing and educating family caregivers cannot fully promote self-efficacy. Beyond informing and educating, health care providers need to:

- model tasks for caregivers,
- encourage caregivers as they carry out care tasks, and
- support caregiver needs.
8.2 Key item - expert advice about promoting self efficacy

8.2a The theory behind promoting self-efficacy

According to Albert Bandura (1997), self-efficacy involves three important components:

- a person's estimate of her/his own level of capability to perform in the particular environment,
- a person's feelings of increased confidence in accomplishing a particular task, and
- a person's belief system that allows an individual to have control over her/his thoughts, feelings and actions.

Defined in this way, enhancing self-efficacy can:

- explain many health and self-care behaviors;
- affect the amount of effort a person will expend in developing or learning new behaviors;
- reflect a person's belief in her/his ability to persevere as well as influence the choices that are made;
- influence preventive efforts to reduce illness risks and mortality; and
- predict change in many types of learning and behaviors, including health-related behaviors.

A person's confidence in her/his own ability to accomplish a task is primary. Knowledge and skills are not the only things that determine if a task can be performed. Rather, how much confidence a person has in performing a task will strongly influence how the person will behave. In other words, if a person feels comfortable with a given activity, the person is more likely to take part in it. People tend to stay away from activities that make them feel uncomfortable.

Furthermore, motivation has been directly linked to how capable a person feels. A very confident person will be more motivated and have a better outcome than a less confident person. The less confident person will be more easily frustrated when he/she encounters difficult changes. A challenge may be perceived as a personal threat.

8.2b Self-efficacy in practice

Pain. Patients in pain are often fearful because others have the power to control the pain medication. This can increase their fear and result in depression. If the caregiver is able to recognize a change in the person's level of pain and has information on how this can be treated, then both patient and caregiver have a sense of control and increased confidence that there is always something that can be done. The patient's and the caregiver's belief that they are able to effectively manage pain will ultimately result in more successful pain relief. They can begin to realize that a certain pain rating implies an intervention that will result in pain relief.
End-of-life care. A health care provider wants a confident caregiver for the dying patient. Although a caregiver may be intelligent, she/he often is anxious about her/his ability to provide the basics of personal care. By promoting the caregiver’s self-efficacy, the health care provider knows that the caregiver will become more competent in providing care for the patient and will feel satisfied that she/he was able to perform all the care necessary despite the grief and difficulty that accompanies the situation.

8.2c How to promote self-efficacy

Bandura identifies four ways to develop self-efficacy:

♦ Skills mastery
♦ Modeling
♦ Verbal persuasion
♦ Reducing aversive physiological signs and symptoms

♦ Skills mastery
Skills mastery is learning and practicing appropriate behaviors. The caregiver needs to have a sense of what the tasks will be. Even though the trajectory is not clear, some idea about the course of the illness can be outlined. If the caregiver knows what needs to be done for a person who is dying, she/he will feel more confident. Give the caregiver the information that is needed to perform each task.

www.Caregiver.com - This web site offers information on a variety of diseases, Fact Sheets, and resource links.

www.stoppain.org - This is a resource guide intended to help caregivers feel less alone and overwhelmed. It offers resources, facts, and advice about caring for a loved one at end of life.

♦ Modeling
Modeling means observing others who have mastered a behavior and copying that behavior. Since, it can be difficult to visualize how a task will be accomplished in a particular situation, observing how the task is performed can be quite useful. For example, a caregiver may know how to make a bed but not have any idea of how to do this when someone is in the bed. A health care provider can demonstrate and request that the caregiver assist in changing the bed next time. If the caregiver is not able to be present when the health care provider is present, a video or web site that shows someone performing the task that might be helpful.

www.webofcare.com - This site posts helpful videos showing how to perform certain tasks, such as caring for a bed-bound patient and feeding a patient. A caregiver can choose animation (with or without sound) or the printed version. This site will allow the caregiver to model behaviors.

For more on anticipatory guidance, see Chapter 7 of this Guide.
♦ **Verbal persuasion**

The goal here is to persuade the caregiver that an action will work and that they are able to perform the task. This will influence the caregiver’s confidence in their capabilities. If you as the expert think and tell the caregiver that she/he is doing a good job, then it must be so. Give the caregiver positive feedback and good reasons as to why their actions will be effective.

[www.Extendedcare.com](http://www.Extendedcare.com): This site allows users to talk free of charge with a geriatrician.

♦ **Reducing aversive physiological signs and symptoms**

People often gauge their confidence by the emotional state experienced as they contemplate an action. Excessive physical and psychological fatigue or stress can negatively impact a caregiver’s willingness to perform a task. Sometimes a caregiver needs permission to care for him/herself. The health care provider can inform a caregiver of the difficulties that arise when the caregiver is depressed and not healthy. They want to be in this for the duration and need to be able to maintain their energy. This can be done by offering a companion or volunteer for a few hours so that the caregiver can go out for a walk. It could be as simple as reducing the amount of time that visitors stay. In short, encourage good health habits among caregivers.

[www.Caregiverzone.com](http://www.Caregiverzone.com) - Offers a variety of caregiver sites, helpful hints. It offers information on caregiving and how to stay healthy.

### 8.2 **Key item - the basics about promoting self efficacy**

*It is important to know what to expect, how you can help, and what help you can expect.*

~Bereaved family member

Promoting self-efficacy can break down barriers to effective caregiving by increasing confidence and decreasing fear of making serious mistakes. Health care workers play a key role in this process. They can provide the informational tools and practice opportunities to educate caregivers, rather than allowing the caregiver to learn by trial and error.

Following Bandura’s model, let’s review the basic steps for effectively promoting self-efficacy:
1. **Skills mastery** ➔ Ask caregivers what they know about the topic; provide information and education about the skill.

2. **Modeling** ➔ Demonstrate skills and watch caregivers perform the skills.

3. **Verbal persuasion** ➔ Give constructive feedback and complement caregivers on their successes.

4. **Reduce aversive physiological signs and symptoms** ➔ Promote caregiver’s health, and encourage him/her to call for help when needed.

To apply these steps, health care providers need to determine **WHAT** a caregiver needs to know (i.e., content) and **WHEN** he/she needs to know it (i.e., timing).

**Content needs**

To meet the needs of individual caregivers, information and education are needed in a variety of areas. Caregivers need to know what to expect, what to do in specific situations, and when to call for help.

**INFORMATION AND CORRESPONDING EDUCATIONAL NEEDS OF FAMILY CAREGIVERS**

<table>
<thead>
<tr>
<th>INFORMATION</th>
<th>EDUCATIONAL NEED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient’s diagnosis</td>
<td>What is it, how it will progress</td>
</tr>
<tr>
<td>Symptoms (particularly pain)</td>
<td>What to expect. What to do. When to call, provide a resource guide</td>
</tr>
<tr>
<td>Likely prognosis</td>
<td>What to look for- improvement or how the patient may be approaching death</td>
</tr>
<tr>
<td>Change in functional abilities</td>
<td>How to provide care. Provide tools that make simple steps for a complicated task.</td>
</tr>
<tr>
<td>Sudden changes in patient’s condition</td>
<td>How to access emergency services. Provide written resources</td>
</tr>
<tr>
<td>Patient’s and caregiver’s emotions</td>
<td>How to offer psychosocial &amp; spiritual support, Provide options</td>
</tr>
<tr>
<td>Community support agencies</td>
<td>How to access these services</td>
</tr>
</tbody>
</table>

~Adapted from Joishy (1999)
Timing: different needs at different stages

For caregivers of someone with a life threatening-illness, different needs arise at different stages of a patient's illness. Caregivers need information about the illness and its management at three basic stages:

- diagnosis and prognosis
- each new crisis
- when death is imminent

**Diagnosis and prognosis**
- Some people might seek a non-intrusive strategy as opposed to a one on one session or multiple support sessions.
- An educational program can give a caregiver the opening to seek out sources of support as she/he comes to know what is available.

**At one oncology clinic, an educational program is part of their protocol. A palliative care nurse practitioner meets with the patient and family after the diagnosis to present all the available support options, including the educational classes that are offered on symptom management, the disease process, pain management, and care for a person who is dying. The community agencies that can be of support are discussed, including the option of hospice.**

**Each new crisis**
When a crisis occurs, the focus is still on the patient, but caregiver involvement also increases. The caregiver might now need to drive the patient to medical appointments, watch for side effects of a new treatment, or listen to the patient talk about how she/he thinks that life is coming to an end because the pain is getting worse. At this point, caregivers may need:
- an ongoing educational program on pain management and symptom management;
- review of the disease process and a person's social supports;
- literature about the disease process; and
- information about the availability of a palliative care consultant.

**When death is imminent**
When death is imminent, the information and educational needs focus primarily on the caregiver. Caregivers can benefit from:
- literature about what it is like to be with someone who is dying;
- websites that provide instruction for different aspects of care step by step;
- a 24-hour hospice service; and
- literature on non-invasive comfort measures.
More about Gloria and Mary…

About a week later, Gloria is no longer able to feed herself. The hospice nurse and nurse's aide review with Mary some techniques for safely and comfortably feeding her mother. They ask Mary to observe them feeding Gloria and then to give it a try herself. They are very supportive and never criticize Mary when she doesn’t get it right the first time.

At about the same time, Gloria loses the ability to get out of bed. She clearly is getting weaker. The nurse and nurse's aide again review the process of changing the bed and applying a brief for incontinence, having Mary assist and then eventually try it alone. In addition to in-person instruction, Mary likes to search for information and review effective techniques for providing care on her computer. The hospice nurse suggests a web site that is interactive and can offer extra helpful tips. During each subsequent visit, the nurse reviews the care skills and is always sure to point out the positive aspects of the care Mary provides.

Mary is beginning to feel confident that she is capable of providing her mother's care. She is both surprised and grateful that, while offering help for her mother, the hospice staff members are concerned about her health as well. Hospice House sends volunteers who stay with Gloria so that Mary can go to the gym two times a week to swim. For Mary, swimming is the best way to relieve stress. In addition, the social worker and chaplain who visit Gloria also listen to Mary’s concerns. Mary begins to realize that maintaining her own physical and emotional health is essential for being able to care for her mother.

In addition to areas related to the patient's illness, caregivers often need to be reminded that they must also take care of themselves.

10 Messages that Caregivers Need to Hear
~Adapted from Schmall and Stiehl (1987)

1. Take care of yourself.
2. Maintain contact with friends and involvement in outside activities.
3. Caregiving to adults is more stressful than childrearing.
4. It is okay not to love (or like) the older person who needs care.
5. Asking for help is not a sign of weakness, inadequacy, or failure.
6. You have a right to set limits and to say "no".
7. Begin taking regular breaks early in caregiving - it is not selfish.
8. Make caregiving decisions based on the needs of everyone involved.
9. Moving a family member to a care facility can be the most loving step.
10. Focus on what you have done well - and forgive yourself.
**Tips for Promoting Self-efficacy**

- Focus on the needs of each particular situation. For example, it may appear to a health care provider that the focus should be on the symptoms of pain and the decrease in bodily functions, but the caregiver may not be able to move beyond the stress and anticipatory grief.

- Provide easy to read literature; write out key points on a small card.

- Determine if community support groups and resources have been helpful to others who have used them. If so, inform caregivers of these resources.

- Build on caregiver strengths by encouraging her/him to seek resources.

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**Returning to Gloria and Mary...**

Despite trying to maintain her health, Mary is exhausted. She has not gotten much sleep the past few nights because Gloria's confusion is increasing and she often is awake during the night. Mary's brothers come by frequently, but they are uncomfortable with providing hands-on care for their mother.

Talking with an old friend, Mary worries aloud: "There are times when I wish this would be over for Mom...then I feel so guilty for even thinking that way." Her friend asks if Mary has considered placing Gloria in a nursing home. "Oh, I promised Mom I would try to take care of her at home. I want to try, but I suppose I should think about other options in case I can't continue to do it." Again, Mary calls the nurse at Hospice House.

When the hospice nurse arrives for her visit, Mary talks with her about the options for more help at home as well as about residential nursing facilities. Mary is feeling very conflicted—on one hand wanting to honor her promise to her mother and yet on the other hand feeling the burden as Gloria's care becomes increasingly demanding. They decide to have the hospice social worker plan a family meeting to discuss caregiving options with Gloria and her children.

During the family meeting, Mary's brothers agree to pool their resources to hire private help to give Mary a break three nights per week so she can go out with friends, do errands, and attend church services. Mary appreciates the opportunity to raise her brother's awareness about her needs. As a family, they make a contingency plan for Hospice House inpatient services just in case the combination of hospice home services, private help, and volunteer assistance is not sufficient.
8.2.1 **Defining an overall goal for promoting self-efficacy**

Take a look at the audit results concerning the domain of promoting self-efficacy. Remember that, when considering your results, it is useful to look at both the overall problem score for this domain and the individual question scores. The scores on the individual items can help raise awareness of specific opportunities to improve and may provide clues about processes that need improvement.

With your knowledge of the importance of the basic facts about this domain, work with the stakeholders in you institution to define an overall goal. This process should lead you to answer the fundamental guiding questions for improvement:

*What is our overall goal?*

*How will we know this goal is achieved?*

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**STEP III - DEVELOP INTERVENTIONS AND MEASURE CHANGE**

“Our goal is to improve (X) and we will know this by a change in (Y). For our first PDCA Cycle, we will improve (X) process of care by specifically addressing (Z).”

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8.5 **Key item - the kinds of interventions that are appropriate and measurable for promoting self-efficacy**

Returning to Bandura’s theory, recall the four main ways to promote self-efficacy among family caregivers for patients at the end of life.

♦ Inform and educate the caregiver about each skill.

♦ Model the particular task as appropriate for each stage.

♦ Support and persuade the caregiver of his/her effectiveness.

♦ Emphasize the importance of the caregiver’s health, and encourage him/her to call for help when needed.
Based on this theory, below are some ideas for developing interventions that will promote self-efficacy, with the end goal of decreasing caregiver stress and increasing overall satisfaction.

**Develop a packet of educational fact sheets, informational booklets, or pamphlets** that are easily available to caregivers. Potential topics include pain and symptom management, what to expect when death is imminent, and what to do at the time of death. Be sure to personalize the available resources to reflect your facility. For ideas, check out the web site [www.stoppain.org](http://www.stoppain.org).

**Give caregivers information about end of life services.** Tell them about the structure and staff of the service. Be sure to include contact and when. Brochures, leaflets and family conferences are useful methods for disseminating such information.

**Make tools accessible to caregivers and staff.** Encourage the use of step-by-step pictures on educational fact sheets, teaching videocassettes, and even web sites. Have these readily available for the staff to obtain, and offer a lending library so that they are readily accessible to family caregivers.

**Provide training sessions.** A structured education intervention will provide the opportunity for staff members to model particular tasks and for caregivers to observe that others are able to perform the tasks. The program could include skills training as well as communication strategies that will prepare caregivers to provide their best care for a patient. One-on-one sessions can be a powerful influence on the caregiver's self-efficacy and confidence.

**Focus on pain management and comfort measures.** Two areas in which caregivers often need to build confidence are administering the appropriate dose of morphine to avoid negative side effects (e.g., addiction, respiratory depression or drug tolerance) and being creative with non-pharmacological ways of providing comfort. Offer training sessions that inform caregivers about the appropriate use of morphine to manage pain and model non-pharmacological ways of providing comfort.

**Offer a round-the-clock resource.** A 24-hour phone service or home care service can offer essential information, seven days a week. This will enable a family caregiver to feel safe enough to try to give the care. A caregiver’s anxiety is always present and at times s/he is frightened. Having the support of others is important.
Many caregivers can access the internet from home.

When developing you interventions remember to...

- ...answer the fundamental guiding questions for each intervention.
  - What are we trying to accomplish with this intervention?
  - What change can we make that will result in improvement?
  - How will we know that a change is an improvement?

- ...utilize the quality improvement tools to help identify and develop your interventions.
  - Process Flow Charts
  - Ishikawa Cause and Effect Diagrams
  - Multiple PDCA Cycles

More ideas for promoting self-efficacy

Provide online information. The Wall Street Journal reports that there are 21 million Americans who are caregivers to aged and ailing family members, and many are looking online for information. Caregivers are often isolated from other caregivers and cannot go out to a support group to attend an educational session.

- Refer caregivers to a chat room or message board aimed specifically to address issues of caring for a person at the end of life.
- Refer caregivers to online sites that specialize in information on how to handle medical care and related topics. These are appealing especially if the caregiver is pressed for time.
- Offer a resource list of sites that may be helpful. The National Alliance for Caregiving offers a clearinghouse of web sites that rates the best sites and resources (www.caregiving.org).

Offer to facilitate family conferences. Decisions about care affect not only the caregiver but also other family members. Sometimes the family members who are not actively involved in caregiving perceive that they are being left out of decisions regarding their loved one. A family conference gives everyone an opportunity to know the plan and even to vent their feelings, decreasing the potential for dissention to occur.

Provide support groups for caregivers. Caregiver may experience a variety of feelings, including grief, frustration, anger, inadequacy, resentment, or guilt. The support group can validate these feelings and support the caregiver. Knowing that others have the same feelings often lifts the burden.
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Chapter 8 • Appendix A

Signs and Symptoms of Approaching Death

The hospice staff realizes that this particular period of time is one of the most difficult times you and your family will have to endure. Our approach in all matters affecting you during this time is to be as honest and straightforward as possible. In this way, the hospice team members can establish a trusting and open communication relationship with your family member who is very ill and the members of your family who are concerned about the possibility of impending death. Our philosophy of care is that the “fear of the unknown” is always greater than the “fear of the known”.

Why do I need to know this information?

We offer you this information to help you prepare and anticipate symptoms, which are indicative of approaching death. We want you to know what to expect and ways to respond. Your hospice nurse, volunteer and physician are your best resources to help you clarify your concerns about this information. Not all these symptoms will appear at the same time and may never appear. It is important to remember that the signs and symptoms of approaching death vary with each individual and with the type of illness. We want to relate each possible symptom to you in order to decrease your fear if one should appear suddenly. All the symptoms described are indicative of how the body prepares itself for the final stage of life.

What will we see in the final days of life?

1. The arms and legs of the body become cool to the touch and you may notice the underside of the body becoming much darker in color. These symptoms are the result of blood circulation slowing down.

2. The Hospice patient will gradually spend more and more time sleeping during the day and at times will be difficult to arouse. This symptom is a result of a change in the body’s metabolism.

3. Your family member may become increasingly confused about time, place and identify of close and familiar people. Again, this is a result of body metabolism changes.

4. Incontinence (loss of control) of urine and bowel movements is often not a problem until death becomes imminent. Your hospice nurse can help you prepare the bed linens to provide comfort to the individual.

5. If your loved one has a catheter in place, you will notice that the amount of urine will decrease as death comes closer.

6. Oral secretions may become more profuse and collect in the back of the throat. You may have heard friends refer to a “death rattle”. This symptom is a result of a decrease in the body’s intake of fluids and inability to cough up normal saliva production.
7. Hearing and vision may decrease slightly.

8. You may notice your loved one becoming restless, pulling at bed linen and having visions of people or things which do not exist. These symptoms are a result of the decrease in oxygen circulation to the brain and a change in the body’s metabolism.

9. Your family member will have decreased need for food and drink because the body will naturally begin to conserve energy which is expended on these tasks.

10. During sleep, at first, you will notice breathing patterns in your loved one change to an irregular pace and where there may be 10-30 second periods of no breathing. Your doctor and nurse refer to this as period of “apnea”. This symptom is very common and indicative of a decrease in circulation and build up in body waste products.

What can I do about these symptoms?

1. Keep warm blankets, but not electric, on the family member’s body to prevent him/her from feeling overly cold.

2. Plan your time with your family member for those occasions when he/she seems most alert. We encourage you spend time talking, sharing and touching your loved one. It is equally as important to remember to take breaks (e.g. maybe getting outside for a brisk walk; sharing with friends; etc.)

3. Remind your family member frequently what day it is, what time it is and who is in the room talking to him/her.

4. Consult your hospice nurse for pads to place under the incontinent patient and for hygiene techniques for cleanliness.

5. Keeps light on in the room when vision decreases and never assume the patient cannot hear you. Hearing is the last of the five sense to be lost.

6. Talk calmly and assuredly with the confused person so as not to startle or frighten him further.

7. Giving your loved one small amounts of ice chips and using swabs dipped in water, ginger ale or club soda will help relieve the feeling of dehydration. Wiping the person’s face with a cool moist wash cloth also helps to provide comfort. If your loved one’s lips are dry, applying chapstick is helpful.

8. Elevating the head of the bed often relieves the person who has irregular breathing patterns.

9. Consult with your hospice nurse as the urine output decreases, for there is a possible need to irrigate the catheter to prevent blockage.

10. If the person is not communicating, using a blink system may be helpful (e.g. one blink of the yes for “yes” and two blinks for “no”).
How will I know that death has occurred?

1. No breathing
2. No heartbeat
3. Loss of control of bowel and bladder
4. No response to shaking or shouting
5. Eyelids slightly open
6. Eyes fixed on a certain spot
7. Jaw relaxed and mouth slightly open

What do I do at the time of death?

Your hospice nurse will help you confirm that death has occurred and handle calls to the mortuary and your doctor. A call to the police or 911 is not necessary. Please know that although this information may sound frightening, the Hospice team’s first goal is to help prepare you for what to expect. Your physical and emotional well being is as important to us as the dying person is. It is important not to expect that all of these symptoms of approaching death will occur. The focus of this paper is to help you prepare for when or if they do occur. Remember that a member of the hospice nursing team is always available to help you.
Chapter 8 • Appendix B

**Hospice: Comforting the Dying Patient**

While traditional medicine seeks to cure the patient and prolong death, the intent of hospice is to treat the symptoms of disease to allow the terminally ill patient to die with as much comfort as possible. The primary goal of the hospice team is to minimize the patient's pain and maximize the patient's comfort level while death approaches. "Comfort" is more than just pain reduction; the patient will need spiritual and emotional comfort as well. The hospice team attempts to achieve "comfort" in a number of ways.

**Physical Comfort**

Minimizing the physical pain experienced by many terminally ill patients is a major goal of the hospice team. Acute pain is pain of a relatively short duration. Chronic pain, experienced by patients with degenerative joint disease, chronic obstructive pulmonary disease, emphysema, cancer and other conditions, is experienced constantly and over an indefinite period of time. Terminal patients frequently require treatment for chronic pain.

Both narcotic (usually morphine) and non-narcotic (aspirin, acetaminophen) analgesics are used to control pain symptoms. When used properly, analgesics provide tremendous, much-needed relief to the terminal patient.

Unfortunately, many health care providers are not knowledgeable about pain control. Often, patients are under medicated because "it's not time yet" for their next dosage. The patient is then forced to endure pain until the next scheduled dosage, by which time it will take even longer for the drug to take effect because of the increased severity of the pain. Other symptoms can arise out of this unnecessary pain such as increased anxiety which in turn can lead to nausea and a decrease/loss of appetite. These secondary symptoms then need to be addressed as well.

Sometimes drugs are administered only when a patient requests them. The patient may suffer needlessly if he or she is unwilling to speak up, or if he or she feels that the pain medication should only be requested if the pain is extreme.

The key to appropriate pain management lies in thoroughly assessing and monitoring the patient's pain. The hospice worker and the patient work together so that a record of the patient's pain can be maintained. This record should include pain rating, duration of pain, the drug used to alleviate the pain, side effects, and the duration of the drug's effect. The record allows the physician or nurse to evaluate the effect of the medications and to change the drug and/or dosage schedule as necessary, providing optimal pain relief for the patient.

Physical agents offer effective, non-drug methods that can be used to control pain. Physical agents are often used in conjunction with medication. Massage benefits the patient by increasing circulation, restoring homeostasis, and reducing pain via counter-irritation. One study showed that men with cancer who received ten minutes of massage experienced a significant decrease in pain. Massage also provides soothing effects that can help a patient relax both physically and mentally. Superficial heating and cooling of tissues can help decrease muscle spasm, pain, and resolve local infections. TENS can be used for pain relief associated with decreased mobility secondary to poor posturing.

Appropriate positioning and movement of inactive patients can help alleviate pain. Patients are often unable to make the little adjustments in posture and position that healthy, mobile people do without even thinking. These patients need to rely on their health professionals or caregivers for relief. Proper positioning can provide relief and decrease the complications...
associated with prolonged bed rest such as pressure sores and contractures. Static posturing, ischemia, and contractures can cause pain; AROM and PROM can decrease the pain by benefiting the muscles, joint surfaces, connective tissues, vasculature, and nerves.

Pain is not the only physical symptom that needs to be addressed. Anorexia is a symptom that accompanies many major illnesses and is also caused by various treatments. Appetite can sometimes be improved with nutritional supplements and feeding tubes. Patients should not be pressured into eating more than they can tolerate. Dehydration can actually have a palliative effect by decreasing anxiety and pain. Weakness can be treated by various means such as physical therapy or changes in medication and fluid intake. Dyspnea is a frequently experienced symptom. Because oxygen and pleural effusion and rarely effective treatments for dyspnea in the terminally ill patient, morphine is often administered to decrease anxiety and respiratory drive.³ Dry mouth can be treated via oral care and by sipping liquid. A catheter can be put in place for the incontinent patient.

When a patient has any sort of infection, the "natural" response is to treat it. However, initiating treatments such as antibiotics should be discussed with the patient's family ahead of time, for sometimes an incurred infection can lead to a more comfortable death than the underlying disease would allow. A comfortable death, after all, is the point of hospice care. Patients often suffer from sensory and motor dysfunction and accommodations should be made for these deficits. For example, if a patient has poor vision, good lighting should be provided and eye wear should be kept clean. If a patient has painful joints, he or she should be handled gently and minimally. If a patient tends to react and respond slowly, then ample time should be set aside for that patient's visit. These compensations for the patient's deficits helps to make the patient more comfortable in his or her surroundings and with other people.

Spiritual Comfort

It is important that the patient's spiritual needs be met with hospice care. Zerwekh describes four areas of Spiritual Caring: Recognizing Spiritual Issues, Dialogues about Spiritual Issues, Fostering Reconciliation, and Sharing Nearing Death Experiences.⁴ Recognizing Spiritual Issues deals not only with overt religious beliefs but with the more subtle issues of meaning, purpose, forgiveness, and transcendence. Unresolved issues can lead to agitation and further the patient's suffering. An appropriately trained hospice worker can help a patient to work through these spiritual issues.

Dialogues about Spiritual Issues involves being able to facilitate sharing between the hospice worker and the patient. Patients often want to explore questions such as "Why is this happening to me?" and about the meaning of life. The hospice worker can also help facilitate spiritual sharing between the patient and patient's family.

Fostering Reconciliation is about resolving relationships. Life review is encouraged in an attempt to integrate life experiences so that meaning and forgiveness can be found.

When Sharing Nearing Death experiences, patients often describe seeing a beautiful place or sensing the presence of benevolent beings. These experiences appear to bring great comfort to the dying patient. Sharing these experiences often brings comfort to the patient's loved ones.

Emotional Support

Counseling is a method by which emotional comfort can help be attained; hospice care would not be complete without it. The patient needs help coping with his or her impending death and the separation that death will bring. The counselor attempts to create an atmosphere in which the patient will feel comfortable enough to talk about his or her concerns. The counselor should be a skilled listener that is able to draw the patient out. The patient should not
be bombarded with questions, nor should a counselor moralize or preach to the patient, for this would contradict the concept of emotional support.

Hospice does not end with the death of the patient. The patient's family receives help during the patient's decline and after the patient's death. The hospice team can help the family by assisting with daily chores that have become cumbersome, such as grocery shopping, cooking, and cleaning. Counseling while the patient is dying involves facilitating communication between the family and the patient. The counselor also helps the family deal with anticipatory grief that accompanies the impending death of a loved one. Grief, either anticipatory or after the patient's death, can lead to divorce, separation, drug and alcohol abuse, and a decline in health. The hospice attempts to help the family avoid these unfortunate "side-effects" of death. Families are periodically visited and assessed in their time of need. Risk factors, such as family discord or an inability to express feelings, are assessed during the initial visit and are addressed in subsequent visits. The families are not quickly forgotten; follow-up visits sometimes take place up to several years after the death of the patient.

Conclusion

The hospice treats the patient as a whole person who needs comfort and support in a variety of areas in his or her life. The dying patient needs love and needs to know that someone will be there at any given moment. A properly trained hospice staff can meet the needs of the patient and family while making the transition into the unknown much more bearable for everyone involved.

References

Chapter 8 • Appendix C

_The Care Givers’ Guide: An Instructional Booklet for Home Care_

This booklet is published by Home & Hospice Care of Rhode Island and can be viewed by clicking here.