

Chapter 9: **Attending to Family Members' Emotional & Spiritual Needs**

STEP I – CONDUCT AN AUDIT



Key Item -- the questions the TOOLKIT After-death Bereaved Family Member Interview asks about family members' emotional & spiritual needs



STEP I

1. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did someone talk with you about your religious or spiritual beliefs?

YES NO

a. [If yes] Was this done in a sensitive manner?

YES NO

b. Did you have as much contact of that kind as you wanted (in [PATIENT'S] last week/ while [PATIENT] was under care of hospital/hospice/nursing home)?

YES NO

2. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), how much support in dealing with your feelings about [PATIENT'S] death did the doctors, nurses, and other professional staff taking care of (him/her) provide you - less support than was needed or about the right amount?

LESS THAN WAS NEEDED RIGHT AMOUNT

3. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] talk about how you might feel after [PATIENT'S] death?

<input type="checkbox"/> YES	→	Was it done in a sensitive manner?
		<input type="checkbox"/> YES
		<input type="checkbox"/> NO
<input type="checkbox"/> NO	→	Would you have wanted them to?
		<input type="checkbox"/> YES
		<input type="checkbox"/> NO

4. (In [PATIENT'S] last week/ While [PATIENT] was under care of the hospital/hospice/nursing home), did a doctor, nurse, or other professional staff taking care of [PATIENT] suggest someone you could turn to for help if you were feeling stressed?

YES NO

Spirituality

Emotional needs

Bereavement

5. (In the last week of [PATIENT'S] life/ While [PATIENT] was under care of the hospital/hospice/nursing home), how well did those taking care of [PATIENT] do at providing emotional support for you and [PATIENT'S] family and friends?

[0 1 2 3 4 5 6 7 8 9 10]

STEP II – ENGAGE STAKEHOLDERS & DEFINE A GOAL



9.1 Key item – the importance of focusing on family members' emotional and spiritual needs

The World Health Organization defines goals of palliative care as providing the best possible quality of life for the patient and family. Inherent in the WHO definition is that dying impacts both the patient *and* those who live on. We must strive to focus on the patient, but we must also remember the important needs of the family through emotional support both prior to and after the patient's death and through attending to their spiritual needs in a sensitive manner.

One group of loved ones who often have particularly pressing needs are family caregivers. The importance of supporting family caregivers is underscored by these findings:

- Heavy-duty caregivers, especially spousal caregivers, do not get consistent help from other family members. One study has shown that as many as three fourths of these caregivers are “going it alone” (National Family Caregivers Association).
- Elderly caregivers with a history of chronic illness themselves who are experiencing caregiver related stress have a 63% higher mortality rate than their non-caregiving peers (Schulz & Beach 1999).
- Sixty-one percent of “intense” family caregivers (those providing at least 21 hours of care a week) have suffered from depression (National Family Caregivers Association).

More research is needed to fully explore the impact of caring for a loved one through the course of a serious, life-limiting illness. An important question is how systems can respond to assure quality interventions that address family caregivers' emotional and spiritual needs before and after their loved one's death.

A 1997 national Gallup Poll found that most Americans long for spiritual support at the end of life, yet few would choose their clergy members to provide it. In fact, the poll suggests that most people would look to their family and friends when it comes to good care at the end of life. Physicians and nurses scored even lower as sources of support. Only 30% of respondents said they would look to their doctors for comfort, while 21% said they would rely on a nurse.



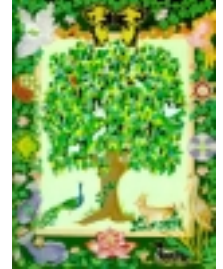
STEP II

Family caregivers may have even more need for support.

See Chapter 7 of this Guide for more on promoting the self-efficacy of family caregivers.

Who should provide spiritual support?

- ? What can we learn from this information?
- ? What improvements can we consider that will increase patients' confidence that their health care providers are interested in and concerned about their spiritual and emotional needs?
- ? What changes need to be made in our systems to respond to the stated desire for more family involvement? Do we have systems in place that can support an increased role?
- ? What do health care providers need to do to increase their own level of comfort and confidence with emotional and spiritual issues?
- ? How can Quality Improvement efforts impact patient and caregiver satisfaction with the emotional and spiritual support provided by their health care team, including clergy?



If we are to improve the quality of supportive care provided to family members, we must come to identify, validate, and appreciate their needs both prior to and after the death of their loved one. A family members' bereavement experience can be complicated by many factors, some of which may be related to events or unresolved emotional and spiritual concerns that were present before the patient died. Even the sudden absence of care giving responsibilities can deepen the void already felt by the patient's death.



9.2 **Key Item – expert advice about attending to emotional and spiritual needs**

A society needs more than anything else to care.
 ~Whitney M. Young, Jr. 1921-1971, Social worker, educator
 and Director of the National Urban league

With whom should we consult to gain insight into methods of improving how our health care system attends to the emotional and spiritual needs of the family? The logical answer would seem to be that family members themselves are the experts. While this is true, it is important to bear in mind that family members may feel uneasy about revealing their emotional and spiritual concerns, even to the most caring of professionals.

Who are the experts in this domain?

As a result, any intervention in this domain will need to take into account the family's willingness or ability to share intimate and personal thoughts about grief, loss, and spiritual meaning. Recognizing the need to attend to family's emotional support, many professional and consumer organizations have guidelines that should be considered as your Quality Improvement Team begins its work in this domain.

Last Acts Precepts of Palliative Care

“Palliative care: ...

- provides physical, psychological, **social and spiritual** support to help the patient and **family** adapt to the anticipated decline associated with advanced, progressive, incurable disease.
- extends support beyond the life span of the patient to assist the **family in their bereavement**.
- appreciates the substantial physical, emotional and economic demands placed on families caring for someone at home, as they attempt to fulfill care giving responsibilities and meet their own **personal needs**.
- anticipates that some family caregivers may be at **high risk** for fatigue, physical illness and **emotional distress**, and considers the special needs of these caregivers in planning and delivering services...”



National Hospice & Palliative Care Organization (NHPCO): A Pathway for Patients and Families Facing Terminal Illness

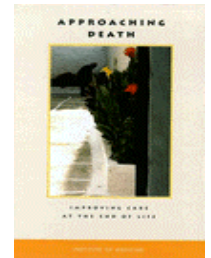
As part of the goal of self-determined life closure, safe and comfortable dying, and effective grieving, the NHPCO makes several statements about the **family**.

- “...**Treat** problems associated with coping and grieving, such as **anxiety and depression**.
- Assist **family members’** emotional adjustment to **changing role** in relation to patient and within family system.
- **Educate** caregivers in preparation for eventual loss.
- Assess family members for risk factors that may contribute to **complicated grieving**; refer to bereavement service prior to death if necessary.
- **Promote opportunities** for growth, reconciliation, sense of completion, expression of self in relation to dying person, sense of involvement and accomplishment in dying person’s life, sense of preparedness for death, higher sense of connectedness, integrated concept of life and memories. ...”



Institute of Medicine's Approaching Death: Improving Care at the End of Life

- "...The psychological dimension of end-of-life care, which encompasses both cognitive function and emotional health, **calls for openness and sensitivity** to the feelings and emotional needs of both the patient and the **family**.
- **Psychological caring** involves recognizing and managing emotional barriers to accepting incurable illness and preparing for death.
- **Emotional care** extends beyond a patient's death to concern for **grieving families** and friends.
- **Spiritual**—like emotional—caring embraces **those close to the patient** and extends beyond the patient's death. ..."



National Family Caregivers Association 10 Tips for Family Caregivers:

- Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
- Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- **Watch out** for signs of **depression**, and don't delay in getting professional help when you need it.
- When people offer to **help, accept the offer** and suggest specific things that they can do.
- **Educate yourself** about your loved one's condition. Information is empowering.
- There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
- **Trust your instincts**. Most of the time they'll lead you in the right direction.
- Grieve for your losses, and then allow yourself to **dream new dreams**.
- **Stand up for your rights** as a caregiver and a citizen.
- **Seek support** from other caregivers. There is great strength in knowing you are not alone.



Canadian Palliative Care Association

The Canadian Palliative Care Association's Model Guideline for Palliative Care Standards of Practice includes goals and objectives for care that relate specifically to family members.

- "... **Goal: Psychological, social and spiritual support** meets the expectations and needs of patients and families.
Objective 1: The patient and family are satisfied with the individualized psychological, social & spiritual support.
- **Goal: Loss, grief, death planning and bereavement support** meets the expectations and needs of patients, families, caregivers and service providers.
Objective 2: The family is satisfied with the loss, grief, death planning and bereavement support. ..."



9.3 Key Item - the basics of attending to emotional & spiritual needs

*To keep a lamp burning,
we have to keep putting oil into it.*
~Mother Teresa

Family issues are often neglected as part of the patient assessment process. Health care systems generally are designed to identify and treat physical problems. Often, a patient's psychological, emotional and spiritual concerns are given a low priority in these designs.

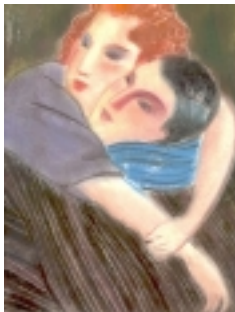
With that in mind, it is not too surprising that a loved one's emotional and spiritual needs may go unattended. Yet, in order to develop strategies and interventions that promote coping and problem solving, relieve anxiety, and support an understanding of the changing nature of hope in the face of serious and life-limiting illnesses, the psychological vulnerabilities and spiritual frameworks of families must be identified (Anderson 1989).

*Dying
presents
emotional and
existential
issues for
both patients
and their
loved ones.*

9.3a Emotional assessment- including family and loved ones in the plan of care

*"I was not prepared for how it actually went.
I was not prepared for my emotions."*

~Focus group participant talking about the death of a loved one



It is important to appreciate the balance between patient autonomy and inclusion of family/loved ones into the *patient's* plan of care. The patient must have input, to the extent possible, into the role that loved ones will play in his/her care. Begin early in your relationship with a patient to explore the wishes, values and beliefs that may influence how much or how little he/she wants loved ones involved.

Professional caregivers need to encourage family members and loved ones to express their concerns. Since most encounters with families will be in the context of the patient's care, you should include questions in your admission and ongoing assessments that stimulate exploration of family members' distress or anxiety.

For example, a palliative care consultant asked this question of a 79-year old woman caring alone for her 80-year-old husband with end-stage multi-system organ failure: "Can you tell me how you feel when you wake up each day?" The woman answered:

*"Some days I'm just not sure I can keep going,
I'm not sure I can do all that I need to do."*

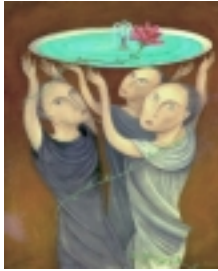
The woman's answer provided an opening for the clinician to explore the emotional and psychological stress associated with her daily responsibilities. This example illustrates the importance of asking questions that help you appreciate a caregiver's perception of the patient's illness and its impact on his/her life (Ramirez et al. 1998).

Important Messages to Remember about Emotional Assessment

- ✓ Once you have established a comfortable rapport with the family/loved one, you can begin to further assess the severity of their emotional and spiritual needs.
- ✓ *Be patient.* Family members need guidance through the emotional maze that accompanies the anticipation of and actual loss of a loved one.
- ✓ Living with the uncertainty of a life-limiting illness provokes anxiety, fears and a range of intense emotions--even in the most well supported families. Remember, *be patient.*
- ✓ When appropriate, seek the involvement of other disciplines, such as social workers, psychological counselors, chaplains and trained volunteers.
- ✓ Your assessment should include an inventory of resources available within your organization and in the family member's community that can assist with emotional and spiritual support.
- ✓ Also, don't underestimate the social fabric of the loved one. A caregiver may be connected to a garden group, a reading club, or even a card group that might be a good source of stability and emotional normalcy.



9.3b Spiritual assessment- going beyond “What is your religion?”



*Love, hope, fear, faith -- these make humanity.
These are its sign and note and character.
~Robert Browning*

When a loved one is dying, relationships with the patient and others may experience profound changes. In the face of serious illness, it is not uncommon for patients and families to reconsider their spiritual selves, their God, and their place within the universal scheme. It is important to provide the atmosphere and the resources to allow family members to pursue their spiritual questions as part of the patient’s overall plan of care.

The Spiritual History - Christina M. Puchalski, M.D., M.S.

Spirituality can be defined as whomever or whatever gives one a transcendent meaning in life. This is often expressed as religion or relationship with God, but it can also refer to other things: nature, energy force, and belief in the good of all, belief in the importance of family and community. So a spiritual history is a beliefs or values history.

The spirit is the essence of the person---what makes them unique. The spiritual part of each person can bring wholeness to the emotional, the physical, and the intellectual parts of life.

Spiritual questions of life which come up especially during illness are:

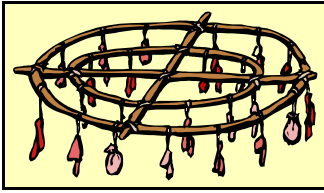
1. What gives my life meaning? 2. Why is this thing happening to me? 3. How will I survive this loss? 4. What will happen to me when life ends?

It is not our job to provide answers to these questions, but we can support and encourage people as they search for these answers. We can use people's religious faith, other spiritual beliefs or values as resources. Referral to chaplains or other spiritual directors is key, if desired by the family member.

Usually the meaning of illness or wellness relates directly to a person's perception of the purpose of his or her life. Each person's thoughts or perceptions of what is the meaning of life influences how they think about their own illness. One may have assigned certain behaviors as wrong or violating one's sense of purpose. An illness may be perceived as a form of punishment. Some patients view a return to health as a means to reaching ultimate goals in their lives. One's beliefs and values can profoundly affect how a person copes with illness and with the treatment of illness.

Spirituality is important during all phases of one's health and illness, but spiritual and religious factors play an especially prominent role in patients' experience with terminal illness, the dying process, and death. For example, a Hindu patient may see elimination of pain and suffering as a primary life goal. He believes his spirit will be passed to another life through reincarnation. Therefore, he may emphasize comfort measures at the end of life and refused heroic life-supportive measures. Discussion of beliefs is also a good lead into discussing other issues of end of life care, such as a living will. This should be done long before the person is imminently dying; therefore, when one is obtaining the spiritual history, one can then ask about preferences in end of life care.

FICA is an acronym that can help providers remember what to ask in a spiritual history.



Faith or beliefs
Importance and influence
Community
Address

There also are some specific questions providers can use to discuss these FICA issues.

F: What is your faith or belief? Do you consider yourself spiritual or religious? What things do you believe in that give meaning to your life?

I: Is faith or spiritual belief important in your life? What influence does it have on how you take care of yourself? How have your beliefs influenced your behavior during this illness? What role do your beliefs play in regaining health?

C: Are you part of a spiritual or religious community? Is this of support to you and how? Is there a person or group of people you really love or who are really important to you?

A: How would you like me, as your healthcare provider, to address these issues in your care?

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Important Messages to Remember about Spiritual Assessment

- ✓ A spiritual history is nothing more than talking with your patient or their caregivers about his or her beliefs and what is important to him or her. So in getting a spiritual history, you are simply listening to that person's story.
- ✓ During a history or admission assessment, you can ask about beliefs during the social history section.
- ✓ One can get basic spiritual history at the first visit and then follow-up in subsequent visits as appropriate.
- ✓ Consider spirituality as a potentially important component of every person's physical well-being and mental health.
- ✓ Address spirituality at each complete physical exam and continue addressing it at follow-up visits, if appropriate. Spirituality is an on-going issue.



- ✓ Respect a person's privacy regarding spiritual beliefs; don't impose your beliefs on others.
- ✓ Make referrals to chaplains, spiritual directors, or community resources as appropriate.
- ✓ Be aware that your own spiritual beliefs will help you personally and will overflow in your encounters with those for whom you care to make the doctor-patient encounter a more humanistic one.

Turning back to Gloria's story



Gloria's condition begins to decline quickly. She is spending most of her time in bed, and Mary finds that her care is actually less demanding than it was when her mother was more active. Gloria's sons and their families have gotten more involved in helping Mary with Gloria's care, often bringing food and even staying the night.

The hospice nurse discusses Gloria's declining condition with Mary and offers to meet with other family members to talk about the physical changes they can expect to see as death nears. Mary tells the hospice social worker that she is finding it hard to be with her mother without crying and that life will be very hard to imagine without her mother.

Although Gloria is quite sleepy, she still enjoys conversation and prayers. She asks her son to call her parish priest to ask him to make a visit for confession. Gloria's son dismisses the need for confession, only to have Gloria react quite strongly that she must make a final confession.

About 45 days after leaving the hospital, Gloria began to experience some agitation and shortness of breath. Her family panicked one night and called 911 but quickly realized they should have called hospice first. By the time the emergency squad arrived, Mary had spoken with the hospice triage nurse who advised her to administer the ordered medication and then she dispatched a visit nurse. As instructed Mary, showed the EMT Gloria's Comfort One which contained her advance care planning documents, including her out-of-hospital Do Not Resuscitate order. When the hospice visit nurse arrived, the patient was more comfortable and the EMT staff was leaving. By this time, the family was much calmer and able to talk about contingency plans in case Gloria's symptoms recurred.

The following evening Gloria's breathing seemed different. Mary realized that her mother's breathing seemed just as the hospice nurse had described a few days earlier. Gloria appeared comfortable, but Mary decided to call her brothers to tell them about the changes. Gloria died about an hour later.

Case study



continued

Gloria's story offers many opportunities for clinicians to connect her and her family with needed services and resources.

9.3c Bereavement- One Journey's End... ...Another's Beginning

*I carry your heart in my heart
I carry your heart in mine*
~e. e. cummings



Serious illness involves multiple losses for everyone involved. The death of someone close often begins one of the most painful times of a person's life. Yet, many people don't understand that their bereavement journey may begin long before their loved one dies. It is not unusual for a family member to experience some of these feelings during the period of anticipatory grief.

*Anticipatory
grief*

Sadness. People may experience an intense sadness knowing that someone they love is dying and that some of their plans will go unfulfilled.

Frustration. One day a person may be in denial. The next, they may be hopeful their loved one will beat the illness. This ambivalence can be very frustrating.

Guilt. A family member or close friend may have said or done things that make them feel guilty.

Anger. A person may display anger toward the doctors and other health care providers, the one who is dying, or God.

Loneliness. Some people feel extreme loneliness because the dying person is no longer part of their everyday life.

Fear. Loved ones are entering unknown territory and may be afraid of how the disease will run its course or what life will be like after the person dies.

Hope. Some people find a great well of inner strength; some may call it faith. This strength may come from spirituality, friends & family, or life experience.

*Losing a loved
one may give
rise to many
emotions --
some of which
may be
unexpected or
surprising.*

Following the death of a loved one, people may experience many of these same feelings. Grief is the combination of sorrow, strong emotion, and the resulting confusion that comes from losing someone important. They mourn not only the loss of that person but also others they have lost in the past.

*Grief has no
timetable.*

The journey through grief is as individual as the journey through life. Yet, there are opportunities to use the intensity of bereavement as a time for personal growth and understanding about relationships, meaning and transcendence. Some family members may benefit from a support group or individual counseling to assist in their bereavement journey, before or after the death of the loved one.

9.4 **Defining an overall goal for addressing family members' emotional and spiritual needs**

Take a look at your audit results concerning support for family members' emotional and spiritual needs. 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.

Where are we?

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

Where would we like to be?

*What is our overall goal?
How will we know when this goal is achieved?*

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)."*



STEP III



9.5 **Key Item - the kinds of interventions that are appropriate and measurable for attending to emotional and spiritual needs of family members**

Raise awareness about the importance of rituals. Conduct a PDCA cycle to raise cultural sensitivity about the importance of various rituals at the end of life. Involve clergy, medical interpreters, and others that might share an interest in promoting greater cultural awareness. For some patients and families emotional and spiritual support is closely linked to certain cultural, religious or spiritual rituals. It is important to honor these rituals, to the extent possible, within your care setting. Don't underestimate the significance of rituals – without them some family members will have a very difficult time achieving closure. In fact, interference with rituals can leave a family member feeling guilty or worried that their loved one will not achieve an eternal peace.



Build emotional and spiritual needs of family members into the admission and discharge processes. For example, add questions corresponding with *FICA* to your admission form. Consider adding a question about special needs, such as



religious or spiritual sacraments or ceremonies, to your initial assessment. It may be helpful to with discharge planners, many of whom are nurses as well as social workers, about family support needs they struggle with when planning for the patient's transition from one care setting to another.

Develop a Palliative Care Kit (Lynn et al. 2000). One health care institution developed Palliative Care Kits that included:

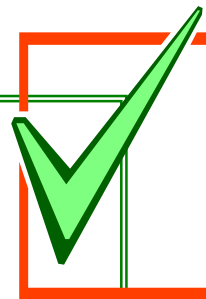


- prayer book with a variety of readings, including poems and scripture;
- oils for rituals and blessings;
- music therapy with CDs and tapes;
- potpourri/sachets for aroma therapy;
- lotions for massage therapy.

Other items you might want to consider for your patient's family members include coloring books for children, disposable cameras to capture family moments, and journals for writing.

When developing your 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



See [Chapter 6](#) of this guide for more on using the quality improvement tools.

More ideas for addressing emotional and spiritual needs of family members

Form an interdisciplinary team. Improving how your organization attends to the emotional and spiritual needs of patients and family members requires careful consideration of your resources. Clinicians may feel uncomfortable with these issues or may lack confidence in their ability to do a good job. Seek guidance from social workers, chaplains, physical therapists, and volunteers within your institution. Consider ways to bring these resources together to support mutually beneficial collaborations. For example, consider developing a model for interdisciplinary rounds that can meet with sufficient regularity to be meaningful to your patient population.



Utilize resources outside your institution. Hospice is a framework that considers the patient *and* his/her loved ones as the unit of care. The hospice framework also uses an interdisciplinary team model to assess and manage patients' and family members' changing needs. Since hospice programs routinely incorporate psychological, spiritual, and emotional assessments in their plans of care, consider inviting a local hospice team to a brainstorming session on methods to improve how your staff assesses patients using an interdisciplinary approach. Other resources outside your facility to consider are community clergy groups, parish nurses, community wellness centers, bereavement professionals, school guidance counselors, mental health professionals, and various support group networks.



Develop or expand family support groups. Assess the family members of the population that you serve for unmet emotional and spiritual support needs, and consider developing a support group to address those needs. Think about potential bereavement support groups that are in keeping with the population your organization serves. For example, an extended care facility that specializes in Alzheimer's disease and other forms of dementia might offer a support group for grieving spouses. It may be helpful to look to other disciplines within your organization for assistance. In addition, look for ways to collaborate with outside groups, such as the Alzheimer's Association and your local hospice.



Explore non-pharmacological therapies. There are numerous resources available--including relaxation exercises, yoga, aromatherapy, and expressive therapies--that could offer a new dimension of support. Seek input from wellness specialists on ways to incorporate some techniques into your practice or opportunities for complementary therapies to be offered to patients and their families in your institution. Music, art, movement and other methods of expression can provide a valuable outlet for emotional and spiritual suffering.



Institute bereavement follow-up. Consider ways that you can follow-up with families and staff after the death of a patient. Whatever you choose to do, make it a routine practice that becomes part of your care plan.

- Send a sympathy card from unit staff immediately following the death and at the one-year anniversary.
- Develop a packet of information for family members regarding internal and external support groups, counseling, and other bereavement resources.
- Encourage family caregivers to schedule a visit with their physician for a routine check up to support their own wellness.
- Consider establishing a memorial program that is appropriate to your setting to remember patients who have died. This might be annual or more frequent, depending on need. Invite family members and staff to participate.
- Support your staff's bereavement needs by providing opportunities to discuss difficult cases and losses. This will strengthen their abilities to be present to family members who are grieving.



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