This booklet is dedicated to family members:

**Lawrence Good** — *Brother-in-law*, died of cancer in 1987

**Martha Neben** — *Mother*, died of Parkinson’s disease in 2007

**Tom Priel** — *Brother-in-law*, died of cancer in 2008

And to the many other people throughout the world who have an end-of-life illness or condition.

A special thank you to my good friend and advisor, Pastor Allen Anderson, Zion Lutheran Church, Boulder, Colorado, dedicated to the hospice philosophy and founder of two hospice organizations.

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**Resources:**


To order booklets, visit: www.hospice-conversations.com

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Photography: Ted G. Trainor
During my work with a local hospice organization, I had the privilege and honor of spending some time with a woman who was in her last hours. It was not common for me to attend patients, and it moved me in a way I never expected. The peace and love exhibited by this family was a wonderful reflection of the support hospice care provides to both the family and the patient. Since that time I have wondered how many more mothers, fathers, siblings and children could receive that peace and dignity given by hospice care if they only knew what hospice care could provide. Then I found out that many people don’t know because the family is hesitant to bring it up for several reasons. In order to receive the comfort and compassion of hospice care, one first has to know the option is available! By giving people ways to approach the topic, I hope to bring the message of hospice care to many more terminally ill family members in my community and across the country.

All people in every culture deserve peace, comfort, dignity and honor at end-of-life. It is my personal mission to give as many people as possible the message that they have the option of hospice care when confronting a life-limiting illness or condition.

— Gail E. Neben

Be understanding of your family member’s feelings and reactions. Fear and grief create different emotions in everyone. One might react with sadness, while another might show anger. Be patient. It might take more than one introduction before the Hospice conversation starts in earnest.

Include as many of the family in the conversation as is comfortable for your loved one. “Nobody wants to feel excluded from a discussion that affects them greatly.” Since almost half of hospice patients are cared for by family members in the comfort of their own home, the family should be part of the hospice conversation from the beginning if possible. Some might not agree with the option, but they will appreciate being a part of the decision making process.

Do not expect a decision immediately. Some people will understand that hospice care is the best for them and their family immediately. However, your loved one might have questions and want to take some time to think it over and adjust to the idea. As your loved one progresses in the illness or condition, the hospice conversation can be re-introduced.

Be sincere in the intent to give your loved one the best care possible. Most people are responsive to the intent. If hospice care is introduced with the intent of giving your loved one peace and comfort, they are likely to respond. Introducing hospice care to your loved one could be one of the most difficult situations you ever encounter. However, having a quality hospice provider help care for your loved one will be the most loving act of kindness you can give.
When your loved one is in denial

"I am afraid to bring up hospice because I don't want to jeopardize our relationship at this critical time."

Your loved one might deny their condition as a way of dealing with it. By denying the illness they do not have to face the pain of grief. Helping him/her face his/her feelings will be helping him/her along the way to a peaceful and loving end-of-life experience. Anger is temporary, death is not. Example: “Bill, before I start I just want you to know how much I love you and want the best for you. We know from the doctors what your condition means for the future. We need to talk about your options moving forward openly and honestly. I know an organization with wonderful people who know how to help us get started. Would you be open to letting the (local name) hospice help us get started...?"

Introducing hospice care to a loved one can bring benefits that are priceless. The presence of a quality hospice organization can help your family member die with dignity, honor, comfort, and love. However, according to the *Annals of Internal Medicine*, “…there is widespread agreement among experts in the field and physicians that more patients could enroll in hospice and many of those who enroll should do so sooner.”

The barriers to admitting people into hospice care early in the prognosis are varied. Often, the subject is avoided, not because the family does not believe in hospice care, but because the family is too emotional to talk about the end-of-life prognosis. Sometimes the family will delay planning for comfort care until the very end when death is imminent. However, many families state after their loved one died, that they regretted not requesting hospice care earlier. They just did not know how to start the conversation!

Hospice care, through the years, has demonstrated that the earlier it is introduced, the better the services can benefit the patient and family. But how does one begin? What is the best way to start sharing health and emotional benefits for your loved one in a way that also shares love, compassion, and dignity?

I hope that this booklet will give family members some ideas to help them get started. A few examples of early family situations are given followed by samples of how the Hospice conversation can be started. If you do not see an example that fits your situation, please feel free to call your local hospice experts to get help on how to start.

*The scenarios and subject matter introduced in this guide are derived from published medical journals, accredited hospice resource materials, my personal experience and that of Pastor Allen Anderson, Zion Lutheran Church, Missouri Synod and founder of two hospice organizations.*
**When your loved one says,**

“I’m not ready for hospice.”

When your family member has a prognosis that does not clearly indicate a specific survival time limit (such as Congestive Heart Failure or Dementia), the physician will probably find it difficult to predict exactly when the time is appropriate for hospice referral. Your loved one might believe they have a longer life expectancy than they really have and deny that they are ready for hospice care, possibly reflecting their fear. Since one of the benefits of hospice care is learning how to talk about the illness openly and helping your loved one gain peace of mind, it is better to start the conversation early.

First, establish the known options with your loved one. Then, in light of the options, recognize and include hospice care as one of those options, now or in the near future. It is never too early to introduce the topic of hospice care with uncertain survival time, even if your loved one is not yet ready to be admitted for hospice care, medically or emotionally. Remember, this is only the first conversation, not a decision. Hospice medical directors and registered nurses (RNs) are skilled in making assessments. If your loved one agrees to an early consultation (usually at no charge), then the RN can determine, in accordance to Medicare regulations, if and when your loved one is physically appropriate for hospice care. Example: “Mom, the doctor says that you have congestive heart failure. Moving forward, we need to discuss your options. While some people live many years with this condition, others decline more quickly. I want you to have the opportunity to live a full life for as long and as comfortable as possible. While we treat your symptoms, there is another organization I would like to introduce to you which has experts in treating symptoms and helping people live a full life at home...”

**When you say,**

“My parent (grandparent) is fiercely independent and refuses to accept help.”

In many cultures, asking for help is either putting a burden on someone else or admitting to weakness, and both options may be unacceptable to your loved one. Being able to carry one’s own weight in life is a source of pride and a show of strength. In this instance the family member is the key to their end-of-life care. When approaching an elderly family member who prides him/herself on their self-sufficiency, it is important to respect the patient’s feelings. Example: “Dad, I am so proud of the way you have worked for everything you have and supported us through the years. Now I would like to take my turn and help you. It breaks my heart to see you in pain and alone at this time. I know an organization that can help me be with you and enable you to stay here at home...”
You as family or the caregiver, can approach your loved one with first asking what his/her desires are. After making certain the desires are clear, hospice can be introduced as an organization that can help. Some benefits of the hospice care that you can mention are:

1. Hospice will help your loved one stay at home as long as possible; 2. The medications required and all equipment needed to achieve comfort at home can be delivered to them as needed; 3. Their symptoms and comfort can be managed with home visits by a team of caring professionals; 4. The organization can teach the family how to safely care for the patient 24/7; 5. One of the most important benefits is that the organization can help the family as much as the patient!

Example: “From what you have just told me, you would like to stay in your home instead of moving to a nursing home or hospital for care. You would also like to have us nearby to help you. Even though living like before is no longer an option, I can recommend an organization that can help you remain at home with us. You will be able to have your family near you…”

Some people who have lived a private life are not comfortable with outsiders in their home. They might be distrustful, or they might not want people intruding on a very private and emotional time in their life. You as the family member can be reassuring about their feelings of privacy and still introduce hospice care as though they are friends who want to help. In this case his concern for you might override his need for privacy. Example: “John, I know you prefer not to have other people here at this time. However, it is getting increasingly difficult for me to help you out of bed and keep track of your medications. I know some very nice people who like to help when people are dying. We both know the doctor has said your condition will not get better. Would it be ok if I asked hospice to help me care for you…?”
When the grown child says,

“*My mom is so despondent, I am afraid that if I introduce hospice care, she will think I have given up helping her and sink into a deep depression.*”

When your loved one says,

“I want to seek a cure no matter what it takes.”

When your loved one considers comfort care as ‘giving up’, he/she might think seeking a cure is their only option. The physician will continue curative treatment as long as possible, but a gentle suggestion in the light of ‘what if’ can be mentioned early. Consider hospice care as an option when a cure is not an option. Introducing the hospice conversation early gives your loved one time to adjust to the idea. Exploring options also gives him/her control over their care when the time is right. Their physician should continue to let the patient know how the treatment is progressing, then the patient can re-evaluate the possibility of hospice care at any time. “People are seldom, if ever, offended by being given choices.”

Example: “Gail, we have discussed your illness and treatment options with the doctor. We can begin aggressive treatment for the cancer with (radiation) if that is what you want. However, I want you to know that there are other options available that we can talk about at any time if the treatments no longer help. Hospice care can help us go through this together. They are experts in helping people like us. If, during the treatment you decide to change to comfort care only, just let me know. It is your choice of how you want to proceed.”

When your loved one receives a terminal prognosis, he/she will often start the grieving process immediately. Even though it is painful, the family must help them face their situation in order to obtain peace. A quality and compassionate hospice organization will help your loved one communicate their fears and anxiety in an open and loving way. Bring up the topic in a way that lets your loved one know you love them and you want to help. Example: “Mom, I talked to the physician today about your illness. He told me everything about what you are experiencing and what options are available. I love you and I want to help you get through this. Can we talk about getting someone to come into your home to help us talk about this openly? They can help us deal with this together…”
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When your loved one says,

“I don’t want hospice care, I just want to be at home and go back to living like before.”

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When your loved one says,

“My husband will not agree to strangers in our home.”

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Dedication

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