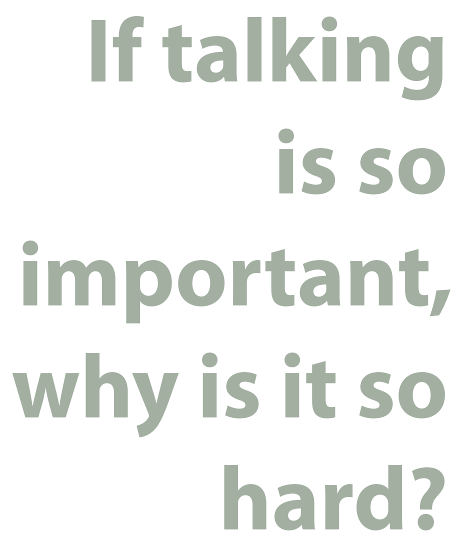

If talking is so important, why is it so hard?

Family life is mostly talk. Good talk, bad talk, talks to fill in the blank spaces, talk to express love and hurt and every other emotion. We play back certain conversations endlessly in our memories—some we treasure, some are a source of pain. From our first word to our last, the context of conversation is often our family.

Some topics are much easier to talk about than others. Even families who dive right into arguments over money, sex and politics can find themselves mute when someone brings up a topic we all need to consider. How do we feel about choices and care around the end of life? What do we want? What are we worried about? Who will decide for us if we cannot?

This booklet is a starting point for these necessary conversations. You will read about many opportunities and ways to raise the issue. Once you realize how many "conversations triggers" there are in daily life, you will be ready to start your own conversation. And starting is the most important part. Too often, these conversations don't take place until there is no time left for honest discussion, reflection and planning.

Having these conversations, "before the crisis" is not only much easier, it is much more valuable. If you can begin to talk about the end of life while people are still healthy, you will have made a significant contribution to your family, and you will discover important information for yourself. Understanding family includes understanding hopes and fears around illness and dying. Conversations before the crisis help a family cope with inevitable loss; preparing for death helps those who live on most of all.

Talk is the single most important thing that family and friends can do to prepare for the end of life of someone they love. Always difficult, the end of life can be amazingly rich. Learning, insight and love are possible to the last breath, and beyond. Talking about this time make a rich ending more likely.

You think what?

Howard McGrath and his cousin Rebecca Martin sit next to each other at the family supper following the funeral of their grandfather. Howard and Rebecca spent a lot of time together as children, but they see each other only once or twice a year now. As they talk, they both remark that their own parents are becoming frailer.

They then discuss the chemotherapy that their grandfather endured before his death from cancer. Howard feels that it destroyed the dying man's quality of life. "I don't think it would be worth it," he says. "I would rather be able to do what I want, to be with my kids, to enjoy life for a shorter time. I don't think all that treatment was a good thing."

"I absolutely disagree with you," replies his cousin. "Even one more day would be important to me; I'd do everything I could to hold onto life. I admire the way he fought, and I plan to do the very same thing."

The death of a relative is an obvious and excellent starting point for a conversation. Howard and Rebecca have discovered that they hold opposite views about a fundamental issue. A discussion about difference, and respect for choice, has begun.

We cannot assume that we know what someone else needs or wants. The object of talking is not to impose a "right choice" on others. It is to learn what each member of the family thinks about the choices, and why.

Opening up ways to talk

In today's world, there are many current events that serve the same function for us as the funeral of a family member. They help start conversations.

But first, you need to examine your own views. It is honest, and fair, to explore your desires and fears about nearing the end of life, and communicate them to your family. Too often, adult children sit down with aging parents and want to make the parents face the hard issues. It will be much more effective if you do your own emotional homework first.

There are many events and openings that can help you get started. If you want to be the conversation initiator, think about some of the issues (many are listed throughout this booklet) and then watch for a good opportunity. You will be surprised at how many possibilities you find.

Conversation triggers include:

- The death of a friend or colleague
- Newspaper articles about illness and funerals
- Movies
- Sermons
- Television talk shows, dramas and comedies
- Financial planning
- Annual medical checkups
- Family occasions such as baptisms, marriages and (especially) funerals
- Magazines and books

Families that communicate effectively—Susan and Richard

When Susan and Richard experienced the death of a friend with a small child, they immediately made their wills. Their attorney gave them a booklet about advance directives, a general term that refers to your oral and written instructions about your future medical care, in the event you become unable to speak for yourself. They talked about the end of life and decided on the basics of what they want.

Susan and Richard are part of a family that communicates easily, and can have forthright conversations. When they gave a copy of their advance directives to their parents and asked them to keep a copy, the parents agreed. "So," says Susan's father, "it looks like you tow have made some important choices, and we appreciate knowing what they are. Your mother and I have been planning to make some decisions ourselves, and now that we've seen you do it, we are going to do the same thing. We'll feel better knowing that this planning is done, and that you and our doctor know our wishes. It's a hard thing to think about, but it's a relief to face it."

Few families have this much confidence, clarity and communication skill. The following conversation between Steven, a man in his 40s and his father is more typical.

. . . advance directive, a general term that refers to your oral and written instructions about your future medical care.

A difficult conversation between father and son

Steven brings up the subject of death.

Dad," he says. "I've been thinking about the end of life lately, the end of my life. I know it sounds weird. Nothing is wrong. But a friend of mine at work had a terminal illness and his family didn't know what he wanted. The family disagreed about what to do, if he should be put on a ventilator and other stuff, and it made the whole thing so much harder. I don't want that to happen if I should suddenly be in that situation."

"Let's not talk about this now," his father says. "You're healthy and young, and nothing bad is going to happen to you. Besides, if we talk about it, it could come true."

"Talking about difficult things does not make them happen. Since Deborah is my wife she'd have the legal responsibility to decide, but I would want you and Mom to understand and help her. And to be able to explain to the kids that this is the way I wanted it."

"So tell Deborah, but don't tell me. I don't want to know."

The conversation has begun. Steven and Deborah begin their own conversation and complete their advance medical directives. A few months after the first conversation, Steven gives his father a copy of his plans.

"Dad, I know that you don't want to talk about this, but Deborah and I have agreed on what we each want, and have written it down. My doctor has a copy. I want you to know that I plan to be conscious and able to communicate as long as possible, while Deborah is worried about pain and would prefer to be sedated, even if it means being out of touch. Which do you think you would want?"

"I don't want to choose. I want to die in my sleep."

"Well, that may happen, but you can't be sure of that."

This may be as far as Steven can go right now. But it is a good bet that at some point, one of his parents will raise it with the other. Over time, Steven can use current events and family happenings to restate his concern. And Steven and Deborah are clear about their choices, and have informed their doctor.

There is another benefit. Steven purposely had these discussions in the hearing of his teenage children. He did not ask them to participate, but later, when his daughter asked why he insisted on bringing this up, he said, "I love my parents and I want to care for them, just as I want to take care of you. Dad and I don't agree on much, and what I would choose may not be what he would want. But this is part of what we need to do as a family. If you have any questions about these things, I hope you will ask your mother or me."

Personal experience and current events, as well as art and culture, offer trigger points for conversations.

Seizing the moment—Using trigger points for conversations

In the conversation between Steven and his father, Steven took action after going through the death of a friend. He used the experience as a conversation starter, so that the issue did not come up "out of the blue." Personal experience and current events, as well as art and culture, offer trigger points for conversations. Here are some other possibilities.

Television Programs

"I know you saw that discussion last week on Oprah about the family who wanted to discontinue the feeding tube for the mother, but they couldn't because no one had signed the advance directive that was needed in that state. I thought that was terrible. What would you want if you were in a situation like that?"

Deaths of Celebrities

"I remember how much Paul McCartney loved his wife, Linda, and how he took care of her at home when she was dying of cancer. He had her family around her, and her pets, I think, and he sang to her. That's so beautiful. When I die, I want to be cared for at home. I know it was easier for Paul because he has plenty of money, but I think anyone can get help from that hospice group. So remember, I want you singing to me if I die. And I sure don't want to die in a hospital. Do you?"

Newspaper Articles

"I have been thinking about those young people killed and injured in that bus accident. It's so heartbreaking when children die, and we just never expect it. It made me realize that you don't know what I want if I'm in a car accident. So I'm going to write it down. And I'd like to talk with you about what you want."

Financial Planning

"I met with our lawyer last week to be sure that my will is up-to-date. I do this every three years, just in case something has changed, with me or with the tax laws. The lawyer reminded me that there will be medical decisions to make when I die, as well as financial decisions, and he asked me if I had given my doctor any instructions. I've been putting this off, but I know I need to decide. Can we talk about this? Have you thought about what you want? Will you be willing to take responsibility for decisions if I can't act for myself?"

Families differ. Some people value information and discussion, and like to examine expert advice. In a family like this, sharing an article or newspaper editorial might work. Some families might deal better with a movie or a story that is open-ended. This could be a better place to start. You could say something like, "I wonder if you would watch this video, and tell me what you feel about it. It made me think about some hard things." A movie, a book, a painting—works of art allow for personal interpretation. The things that your family likes most to talk about will be the best conversation openers.

After a funeral or memorial service is an excellent opportunity for candid discussions about the end of life.

Happy occasions and family memories

Birthdays and anniversaries are times when families reconnect, and present good opportunities to emphasize the family ties. Part of preparing for the end of life is valuing what has gone before. We treasure what we have in part because we will not always have it.

Joshua and Rachel celebrate their grandparents

Joshua and Rachel are 10 and 12 years old, and are close to their maternal grandparents. On the occasion of the grandparents' 40th wedding anniversary, the children made a book telling about some of the special things their grandparents had done for them over the years, including photographs and drawings. They presented this at the party, with friends and family present. Honoring their grandparents, they gave everyone an opportunity to talk about what mattered to them as a family. The events they selected for the book—special talks with their grandfather, the meals their grandmother cooked when they visited, the fact that the grandparents took them to museums—emphasized that in this family each generation shared a tradition of nurturing and education. It gave Rachel and Joshua a chance to realize that their grandparents will not always be with them in person, but will be there in memory and spirit.

This kind of activity goes beyond sentimentality. It says that each generation has a role to play. Events like this offer a good time to talk about what is most important to us. Honoring the past helps us to prepare for letting go. And it paves the way for conversations.

Reflecting on a life

When someone dies, the sense of loss is intense but hearts are open. Funerals and memorial services help everyone to understand what the missing family member meant. They are remembered from the smallest (perhaps most annoying) trait to their largest career success or civic achievement. At this time, everyone in the family reflects, either consciously or unconsciously, on how they knew and loved this person, and how the deceased fit into the family.

After a funeral or memorial service, families are often together, and this is an excellent opportunity for candid discussions about the end of life. Was this death planned for in some way? What lessons were learned? Is the family comfortable with the medical treatments and burial arrangements? For families this is a very special time and opportunity. Tears and open emotions can lead to clarity, honesty and a true celebration of life.

I've been worried lately about what would happen if one of us got sick.

After the funeral of her uncle, who died peacefully at 93, Sara sees an opportunity to talk with her mother. "This reminds me of when Grandpa died, and of how you took care of him at home for so long. That must have been hard, and I know it was difficult for you and your brothers to decide what to do. I know you wanted to care for him, but you had to give up your own plans for those years. I really admire what you did. If that happened again today, do you think you would make the same choices? Is it best to care for a dying person at home?

Biological family versus the chosen family—Make your decisions known to your loved ones

We are entitled to make decisions about ourselves as long as we are competent and can communicate. However, if we are not able to act, state law will normally assign the decision-making to our next of kin. Medical staff and others will presume, and in fact must presume, that this designation is appropriate. But sometimes people have their closest relationship with a person who is not a relative. This relationship might be friendship, or it might be something more. This distinction is sometimes called the biological family and the chosen family.

John and Robert had been partners for five years. The title to the house they lived in was in John's name, although Robert contributed to the mortgage payments. They had purchased most of the furnishings together, after combining what they owned from earlier in life.

When John suddenly had a massive stroke at age 53, Robert discovered that he did not have legal authority to determine the course of treatment. Although he and John had talked about medical interventions and treatment choices for serious illness, control slipped from Robert's hands.

After, he notified John's parents of the incident. The parents, who had a civil

but distant relationship with Robert, arrived at the hospital within 12 hours and directed the physician to maintain John on life support. Eventually they moved him to a nursing home near their residence in Atlanta. When John died, the parents sold the house John and Robert had lived in, and claimed most of the contents. Robert was not only heartbroken over the loss of John; he was left with no home and found himself in an ugly fight over inanimate objects.

The same situation can confront opposite-sex partners, even partners who have children together, if legal relationships have not been established. Anyone in a nontraditional family needs to pay special attention to decisions and arrangements for the end of life. The conversation that follows suggests a way of giving legal power to a partner or friend.

"I've been worried lately about what would happen if one of us got sick. I'd want you to make decisions about my care and help me if I needed help, but you wouldn't have any legal authority. Would you be willing to consider taking responsibility under a durable power of attorney for health care? It would make me feel better."

"What about your parents? How would they feel about that?"

"I'm not certain, but I think I'd like to make this decision and then let them know. They might be relieved, or they might be angry. We could tell them about it when they come for Thanksgiving."

Certain things were just never mentioned in polite company, and one of them was death.

Talking across generations

We are products of history as well as our personal experience. Attitudes about dying, and about talking, often differ depending on our date of birth. For example, social historian Mary Pipher writes about the "greatest generation," the group now in their 80s and 90s, as people who survived the Depression and World War II, experienced enormous changes in society, and may have known substantial poverty as children. While there can be wide variation by individuals, in general terms members of this generation tend to be very self-reliant, have a strong sense of privacy, and do not like to ask for help. These characteristics must be respected.

Siblings work together—Vanessa and her brothers and sisters

Vanessa Brown and her five brothers and sisters are part of an African-American family. They are well established in careers, live in the same area, and stay in close touch with each other and their parents. In talking with their peers about the end of life, they felt that attitudes across cultures were fairly similar. But when their father suddenly became ill, they were reminded that their parents' experience represented a different history and different attitudes.

"My father died without a will, and so did my mother, even though he died first and she saw what problems it created," says Vanessa. "And they absolutely refused to talk about death. With that generation in our community, certain

things were just never mentioned in polite company, and one of them was death. My father's view was, 'Don't you try to hurry me along.' And both my parents had a distrust of authority, plus they expected the family to do all the caregiving. My brothers and I tried to get my father to see other doctors, but he did not trust the white medical establishment. He had no reason to."
Vanessa and her siblings were not able to convince their parents to act differently, but the brothers and sisters grew closer through coping with the deaths of their parents. Eventually they helped one another prepare wills, designated responsibility for raising the nieces and nephews should a parent die young, and talked about end-of-life interventions and wishes. Through the loss of their parents, they were strengthened as a family

When Siblings Disagree—Elizabeth's Family

Elizabeth's parents, now in their mid-70s, are reluctant to talk about the end of life. She has tried to engage them more than once, using her own plans as an example, but is making no progress. A keen observer, Elizabeth is aware that through her parents are living independently and doing well, change has begun. They tire easily, have increasing difficulty with stairs, and her mother seems to be acting strangely in social settings.

Elizabeth and her brother and sister do not live in the same area, each has problems and difficulties, and they are not close. Elizabeth knows that there will be conflicts over caring for the parents, making decisions, and about finances. With some dread, she decides that it's better to talk about the future than pretend it's not coming. She arranges a three way phone call.

"I've asked you to be on the phone with me because I think we need to start getting ready for big changes with Mom and Dad. They are starting to have trouble managing. Mother seems confused, and Dad is just not himself anymore. They feel insulted if I offer my help, they don't want anyone else around the house, and I'm going to be traveling more this year. So I really need your advice and your help."

"Do they need to move?" asks Elizabeth's brother. "Is there a nursing home or someplace they can go? Do they have insurance? How much is the house worth? Have you talked to the doctor? Exactly what is wrong with them?"

Elizabeth's sister has her own agenda. "I think you need to plan to be home with them, not start traveling more. I can't help out, and they've always liked you best anyway. Did they ever finish their wills? Mother promised me that the house would never be sold. Why didn't you call us before things got to this point?"

This family has work to do to avoid major conflicts over the next few years. The siblings do not have a good base of information about the affairs and attitudes of their parents, each is making assumptions about what the others should do, and all are preoccupied with their own problems.

How can Elizabeth direct this conversation constructively? Because she has thought about this and prepared by talking with friends and doing some reading, she might suggest a plan.

Elizabeth could say something like this: "I think it's important that we try to work together and figure out what each of us can do, and how to think about this, so we don't have a family disaster. If they both continue to decline and we do nothing, it will be terrible for us, as well as for them. I could try to talk with the doctor to see if he has any insights on their medical situation, and check on their insurance. What can you two do? Is there anyone else who can help us? Whom do we know with experience?"

Nothing has been decided, but each sibling now realizes that things are changing, and that they lack critical information. Progress from this point may be bumpy, but cooperation is still possible. At least Elizabeth has raised the issue, and is making clear that she is not going to do all the practical and emotional work for the family.

Adult children need to respect the dignity and privacy of their parents. But it can be a gift, if parents allow or accept help.

It's not just logistics

In addition to understanding what treatment choices a person wants, and who is going to make those choices, conversations about the end of life—because they are difficult—are also opportunities to explore family issues. The job of the adult child and the aging parent is to heal and appreciate their relationship, to acknowledge love and caring.

It is often easier to give help than to take it. When adults refuse help, it may be because they have long been givers, not takers. They do not want to be a burden. This can apply to advice and conversation as well as care in the home help with travel, etc. Adult children need to respect the dignity and privacy of their parents. But it can be a gift—a created state of grace—if they allow or accept help.

It is important to think through why you want to have this discussion. Here are some good reasons, incorporated into conversation.

The true objective of family conversation is more than a simple package of papers with advance directives and estate details.

"Dad, you know I've mentioned some things about the end of life, and that I've wanted to talk with you more about this. I want to be sure you understand why. We never know what is going to happen and you could outlive me, but if you are very sick I want to take the best care of you that I can, and I want to respect your wishes. Over many years you and I have worked hard to understand each other, even though we've had differences. I don't want to make any assumptions about what you want. I want to make sure your wishes are honored. So I would be grateful if we could talk about this—not in so much detail—but just in general."

"Richard, as your sister I've seen you operate on your own for years, and I know it's important to you to make your own decisions. Control means a lot to you—I guess it runs in the family. I'm like that myself, as you know better than anyone. Now that I've turned 50, I've realized that I'm possibly, just possibly, not going to live forever, and I want to ask you to assume responsibility for me by naming you on my advance directive. But since we are both so strong-minded, I'd like to tell you what I think I would want, and I'd like to know your thoughts. I appreciate your counsel, and I trust you. So could we talk about this?"

"Mom, I have watched you care for people all your life. You are a born caregiver. But someday you may need some care yourself. It would mean so much to me to be able to help you, and help you decide about things as our lives change, and I'd like to start now by asking you a few questions. Could we do this?"

The conversation continues

It's only in the movies that everything is neatly wrapped up in a package. The real world is much more complicated. Family conversations stop and start over time. Conditions change, new information makes a difference, and relationships shift.

After you complete your advance directive and have discussed it with your family, be sure to talk to your physician. Sharing this information with your doctor increases the likelihood that your wishes will be honored, and it can ease the burden on your family members because they're not left guessing about how much treatment you might want.

The true objective of family conversation is more than a simple package of papers with advance directives and estate details. Those things matter, because they will guide final actions. But what matters most is to talk with the people you love about decisions near the end of life, to come to terms with inevitable loss, and thus to honor the cycle of life.

RESOURCES

Caring Connections

800-658-8898

www.caringinfo.org

We provide free resources, information and motivation for actively learning about end-of-life resources; promote awareness of and engagement in efforts to increase access to quality end-of-life care; help people connect with the resources they need, when they need them; bring together community, state and national partners working to improve end-of-life care.

Helpful Books

Greenberg, Vivian E. *Children of a Certain Age: Adults and their Aging Parents* (Lanham, MD: Lexington Books, 1994).

Morris, Virginia. *Talking About Death Won't Kill You* (New York: Workman, 2001).

Nuland, Sherwin B. *How We Die: Reflections on Life's Final Chapter* (New York: Vintage Books, 1995).

Rosen, Elliott J. *Families Facing Death: A Guide for Healthcare Professionals and Volunteers* (San Francisco: Jossey-Bass, 1998).

NHPCO Marketplace

The *NHPCO Marketplace* brings you a comprehensive selection of resources on advance care planning, decision making, grief, caregiving, hospice and other end-of-life issues. This selection of products will provide you and your loved ones with valuable information and resources. *NHPCO Marketplace* book prices are lower than any on-line book retailer.

You can visit the **NHPCO Marketplace** at **www.caringinfo.org.**

Resources include:

BROCHURES

What is Palliative Care?

Loss & Grieving Series:

Advice for Healthcare Providers

Helping Caregivers

Helping Children

Helping the Elderly

Helping a Friend

BOOKLETS

End-of-Life Caregiving

Conversations Before the Crisis

Questions & Answers Series

Advance Directive & End-of-Life Decisions

Artificial Nutrition and Hydration and End-of-Life Decision Making

Cardiopulmonary Resuscitation, Do-Not-Resuscitate Orders & End-of-Life Decisions

Dying At Home

Health Care Agents: Appointing One and Being One

OTHER RESOURCES

Ask Tough Questions Information Sheet

Helping Employees Deal with End-of-Life Issues: A Tool Kit