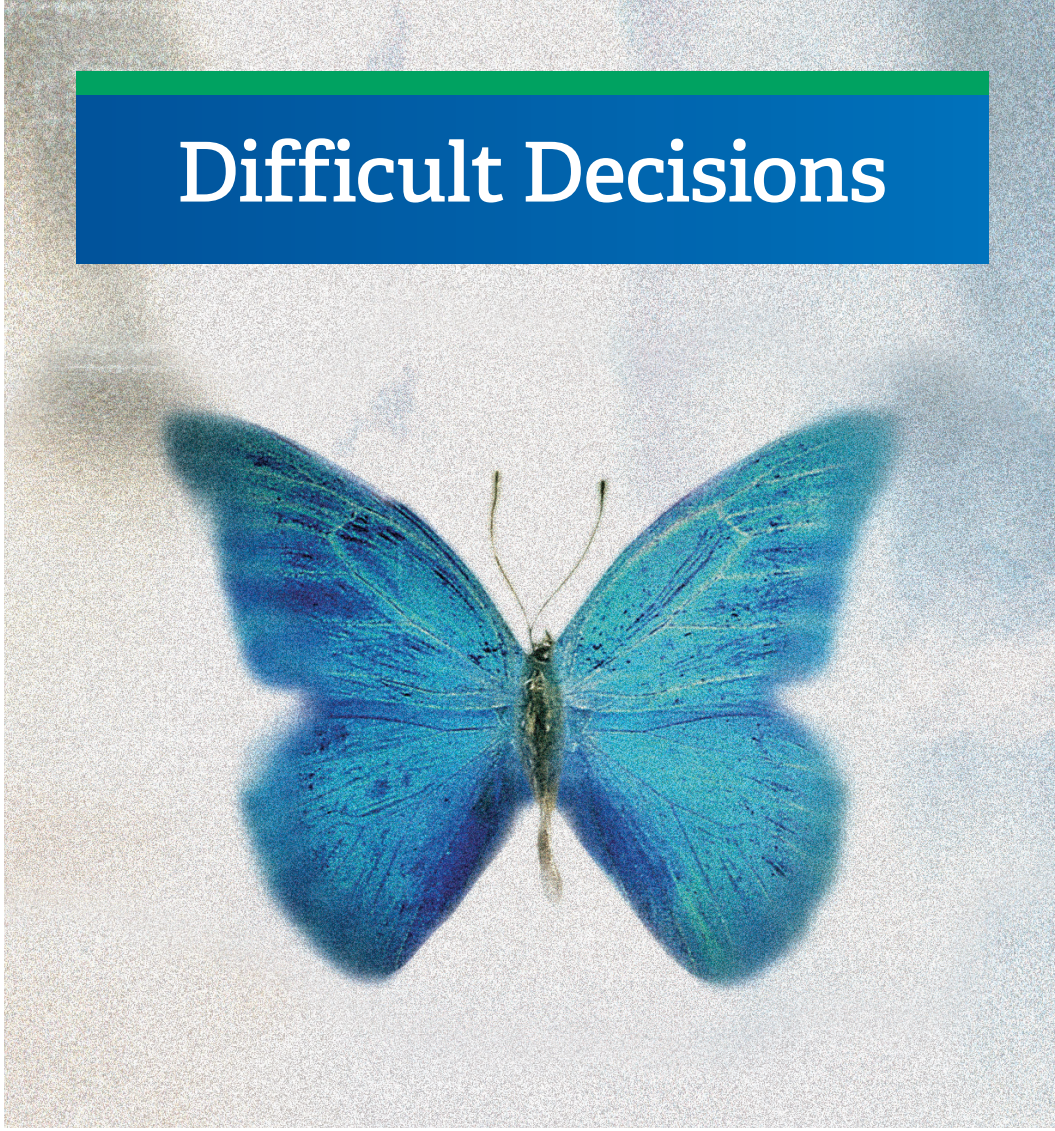
ETHCORP0136 12/20 EP

Texas Health Resources®

Difficult Decisions



Making Compassionate Choices When the End of Life Approaches

Texas Health Resources®

Difficult Decisions

DYING WELL: A Guide for the End-of-Life

"Dozens of people taught me that same lesson during my research. They did not fear death, but they feared dying badly. They did not want to live forever, but they wanted to live well for as long as possible. They did not want to die one moment too soon, but they did not want to suffer one moment too long."

Stephen P. Kiernan, *Last Rights*, 2006,

St. Martin Griffin, New York

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DYING WELL:

A Guide for the End-of-Life

Introduction

Each of us knows that someday we will die, but we don't generally like to think about it and we are uncomfortable talking about it. Consistently, those who do talk about death and dying express a desire for a peaceful, good death. They typically tell you what they want to avoid, saying things like: "I don't want to die in pain. I don't want to suffer. I don't want to be a burden on my family. I don't want to leave my family with debts or go through our savings. I don't want to die alone."

The fear of the unknown makes death all the more frightening. This booklet is designed to provide information that will assist you in making what can be very difficult decisions. With knowledge and intentionality, some even come to see that a loved one's dying can be a meaningful and memorable experience that will honor their loved one and be as special and important as it is painful.

As your hospital caregivers, we recognize that the death of a loved one is one of the most difficult experiences that you will ever face. Out of respect for you and your family and friends, it is our goal to communicate clearly and honestly at all times. We will not withhold information from you or your loved one, unless we are directed to do so. Please do not hesitate to ask your nurse or doctor any question at any time, and if your questions are not fully answered, ask to speak to a charge nurse or a chaplain. There is also an Ethics Committee available which may be consulted in particularly difficult situations. You will have an admitting doctor and 24/7 nursing care, but you will probably also have many physician specialists and staff from various disciplines caring for your loved one. Our hope is to care for our patients and their loved ones - body, mind, and spirit.

Uncertainty

One of the challenging aspects of discussing end-of-life care is uncertainty about the likelihood of death, or a feeling that there is something else that can and/or should be done. Many patients and families express a desire to not "give up," and many doctors and nurses feel that way with some patients as well. The first step in addressing these concerns is to ask your doctor if all possible treatments have been considered, and if there are others to pursue, what the likelihood of success of each of them is in this particular case. You must also be clear about what "success" means and make sure you are talking about the same thing. Please understand that it is difficult to be certain when predicting future outcomes, so if your doctor sounds a bit vague, it is because no one knows for 100% sure. This leads to the second step – if you believe that a treatment has some chance of success, ask what the treatment involves, what could go wrong, and what possible side effects might result from the treatment. Sometimes the "cure" can be worse than the disease, so make sure you and your loved one understand what the treatment will entail. Finally, ask what life after the treatment will look like – will the patient be alert and oriented, able to get out of bed, able to take care of himself/herself? Help the physician and staff identify the patient's sense of self and how important certain functions are for a meaningful life. Most people do not want to prolong dying with interventions that have little chance to actually change the outcome.

It can also be confusing when you have several doctors seeing your loved one to nail down a clear picture of what to expect. Remember that each physician speaks to their specialty and may indicate things are improving or are looking good when the overall picture may still be grim. As the eyes and ears of your loved one and as their advocate, ask questions until you get a clear understanding of the big picture. It is also your right to request a family conference to gather all of the important information at one time. One of your roles as caregiver is to express your loved one's wishes when he or she cannot.

Decision-making

When you have all of this information, the decision about whether to stop or continue aggressive medical care can be made. In every case, the decision is the patient's unless they are unable to speak for themselves. If the patient cannot decide and there is an advance directive and/or medical power of attorney, the person directed to make the decision will be asked to do so. We have these documents available if you need them. They require two

witness signatures and do not need to be notarized. An Advance Directive is a document that spells out the wishes of the patient in the event that they might not be able to speak for themselves. This document is very helpful in that it takes some of the pressure off of family members to guess what a person wants, hopefully decreasing potential feelings of guilt. If there is no advance directive or appointed medical power of attorney, the family will need to make decisions. This is generally done by group consensus, although the next of kin has the final decision-making authority. The next of kin order is the spouse, the adult children, the parents, the siblings, and so forth. The most important aspect of making these decisions is to choose a course of action that is consistent with the patient's values, beliefs, and wishes. Ask yourself what the patient would choose and try not to confuse your wishes with those of your loved one. We have some private family rooms you can use for these discussions.

What are some of the decisions you might have to make?

- Removal of ventilator
- DNR (Do Not Resuscitate - no cardiac resuscitation/chest compressions)
- Continuing or stopping dialysis
- Withdrawing nutrition and antibiotics
- Comfort care only – no intervention other than keeping a person pain free
- Hospice – here or at home

Decisions may change with a person's responsiveness or lack thereof. And difficult decisions take time, especially if your family is not in agreement or if you are awaiting test results. It is only in rare circumstances that decisions need to be made quickly, so do not feel rushed. Sometimes family members fear that removal of the ventilator is giving up. Talk to your chaplain, nurse or doctor if you struggle with this.

A difficult decision for some is to stop feeding. Please know that it is natural for your loved one to decline food when hunger is a distant memory and death is coming. Ira Byock, author of Dying Well, says that over the years he has seen that "malnourishment and dehydration do not increase a terminally ill person's suffering, and can actually contribute to a comfortable passage from life." Ira Byock, *Dying Well*, 1997, Riverhead Books, New York

Acceptance

As you come to understand and accept that the end of life is near, you may be asked to decide as a family what most honors your loved ones wishes and values with respect to certain treatment. You can also begin to consider ways to make your loved one's death as peaceful, comfortable, and meaningful as possible. If death is not believed to be imminent, your loved one may be moved out of the ICU to a room on the floor. This might feel disruptive and take you away from caregivers you have gotten to know and trust, but it will also provide you with the ability to stay together with more privacy. Some families choose to go home on hospice care, which the case manager will help you set up if desired.

A Word About Faith

Texas Health Hospitals are faith-based. This reflects our commitment to honor the diverse ways that people express and nurture their own faith. Please make staff aware of any spiritual and religious needs you have at this time. The chapel is always open to you as a quiet place to pull away, pray, and think. Chaplains are available at all times.

Creating a Legacy

We all know that we will one day die, and yet we all fear death to one degree or another. Everyone worries about dying a painful death, but much of the fear of dying relates more to our spiritual and emotional anxiety about being forgotten, or the sense that we have things left to do. In order to alleviate your loved one's fears, and to make this difficult time more meaningful, we encourage you to focus on creating a legacy to share among your family. Begin this process as early as possible and include your loved one, but even if they cannot communicate, creating a legacy will do much to help your family through the grief process and give you a beautiful memory to hold onto forever.

The key to creating a legacy is to assemble your loved one's life history. You do this by sharing stories. Our lives are made up of stories – some we discard immediately, some more slowly, and some we hold onto forever. These forever stories are the ones you want to recall. Ask the immediate family and close friends for their favorite story, and if you put those stories together, you begin to build a history that belongs to only one person who ever lived. Remember – those who are left behind are a person's true legacy. Rachel Naomi Remen, author of Kitchen Table Wisdom, believes everybody is a story.

She says, "When I was a child, people sat around kitchen tables and told their stories. We don't do that so much anymore. Sitting around the table telling stories is not just a way of passing time. It is the way the wisdom gets passed along... It's the way life teaches us how to live."

Rachel Naomi Remen, *Kitchen Table Wisdom*, Riverhead Books, New York.

Here are some typical questions to get the stories and memories flowing:

- What were your parents like? Your brothers and sisters?
- What kind of student were you in school? Did you have a favorite teacher? Did you play sports or do other activities?
- What was your first job? Best job? Worst job?
- How did you meet your spouse/partner?
- What do you recall about the day that each of your children was born?
- Who is (are) your best friend(s)?
- What is your proudest accomplishment?
- What is still on your bucket list (something you'd really like to do before you die)?
- What is the funniest thing that ever happened to you? The most embarrassing?
- How has faith been a part of your life?
- How do you want to be remembered?

As you begin to gather the answers to these questions, put together the stories that form the legacy of your loved one. You can tape it or write it, and be sure to include pictures and favorite songs, verses, poems – whatever will make it meaningful to your family. This is something you can hold onto and pass down to others. Creating a legacy says to the dying person "we will be with you. We will bear witness to your pain and your sorrows, your disappointments and your triumphs; we will listen to the stories of your life and will remember the story of your passing." Ira Byock, *Dying Well*

What Else Can You Do?

"Caring for someone who is dying is never easy and can be enormously taxing. But you can turn the burden of care into an opportunity to express love, heal old wounds, change flawed ways, and discover hidden strengths. At some level, it is not what you do but rather how you are with a person who is dying that seems to matter most." People who pride themselves on being doers and givers find illness and dependency something they are utterly unprepared for and, typically, they resist and protest." Ira Byock, *Dying Well*

With this in mind, remember that it is important to take care of yourself. Be a good receiver by allowing others to help. Take time to eat, go home to sleep, take care of pets, keep an appointment of your own, etc. knowing that you can trust your loved one to our continuous care. We promise to call you as soon as possible should there be a need or change.

Do what you need to create a healing, personal atmosphere in the patient room. Bring pictures, brush hair, paint nails, massage with lotion, play favorite music, bring a personal blanket or pillowcase, etc. If you have something you think would be meaningful to a person – ASK! Invite your clergyperson to come and pray or a priest to administer anointing of the sick. A chaplain is available at all times to assist in your spiritual needs.

Continue to talk to your loved one and touch them. It is believed that hearing and touch are the last senses to go. Remember this as you are in the room and be sensitive with what you say and the amount of noise. Many sit vigil and believe that presence and love communicate in ways we cannot explain. Some feel they must be present when a person dies and others do not want to be there. Since we can't predict the time of death, accommodating these wishes can be difficult. Our staff will do the best they can to help with this. Some people are caretakers to the end and choose to wait until the moment they are alone so as not to burden loved ones with witnessing their death. This is sometimes a concern when death lingers – when it has been accepted and anticipated and does not happen quickly. Some find it helps to verbally tell someone it is OK to let go and assure them you will be alright. Some deaths happen suddenly and there is no time for goodbyes. Having time can be seen as a gift to say what you need to say. Express love. Forgive and be forgiven. Give thanks. Being with someone as they die is a holy moment.

There are times a person will seem to rally before death. It is difficult not to see this as a reversal of the dying process. These rollercoaster changes can be emotionally and physically exhausting for loved ones.

If you decide to remove a person from life support, please know that there is still no timetable for death. You can choose to be present when a ventilator is removed or step outside the room. You might also choose to have prayers around the bedside at this time. Death may come quickly, or it may linger, which may require resisting thoughts that you made the wrong decision. Reflexive movement and an appearance of struggling to breathe are common. There may even be a period of what appears to be no breathing only to have breathing begin again. The staff will monitor vital signs and let you know when death has occurred. An official pronouncement by a medical staff member or nurse is required.

Normal Signs and Symptoms of Dying

While there is no way to say exactly what to expect as your loved one dies, here are a few of the things to look for (if you have questions at any time, please ask your nurse or physician):

- Sleepiness
- Confusion
- Vision changes
- Decreased appetite/refusing food and liquid
- Decreased urine output
- Periods of apnea (no breathing)
- Gurgling or rattling breathing
- Cool skin; skin color changes
- Increased body temperature
- Jerky movements
- Out of character requests or statements
- Withdrawal from world
- Reports of "seeing" deceased loved ones

What Happens After Death?

Once your loved one has died, you will be offered the opportunity to see and spend as much time with them as you need. You will not be rushed during this time – it is your time with your loved one. Some decide to gather around the bedside and have a prayer committing their loved one to God. Eventually you will need to gather any personal belongings and decide what funeral home you want to use. Our staff has a packet of grief resources to assist you in these decisions. The hospital will make the initial contact with the funeral home when you are ready to leave, although some families decide to stay until they arrive to pick up the body. The funeral home will call you to set up a time to meet. If a death has occurred less than 24 hours after admission, we are required by law to notify the medical examiner to determine if he/she will want an autopsy. You might also decide to request one even if it is not required to answer nagging, unresolved questions.

You will then begin to make phone calls and plans, if you choose, for a service. Delegate what you can as everything seems to take more energy than you seem to have. When people offer to help, let them. You might put a message on your phone or internet page telling what has happened and what the plans are for the next few days so you don't have to repeat it over and over. Several web pages are designed for this purpose and are a good resource to keep people updated during an illness and in the time immediately following a death.

Contrary to what you might have thought, there is no appropriate way to grieve and no timetable to know that grieving is finished. Everyone grieves differently. It seems to come in waves and is more like a spiral than an ordered path. Grieving is in no way to be seen as a lack of faith or a sign that you are not coping. You are rightfully sad when someone you love is no longer here. Your tears are a sign of your deep love and sadness. However, if your grief is ongoing and impairs your ability to find any joy in life, or you notice a change in eating or sleeping habits, you may want to talk to your doctor or minister about depression. There are many groups of people who are also trying to go on after a loss that you could consider joining. You might also consider a personal counselor if you need more privacy. Your loved one would not want your life to end just because they are no longer physically present. A list of resources is included in the family resource packet you should receive from our staff. Ask for one if it is not offered. Gerald May wrote: "Grief is neither a disorder nor a healing process; it is a sign of health itself, a whole and natural gesture of love. Nor must we see grief as a step towards something better. No matter how much it hurts – and it may be the greatest pain in life – grief can be an end in itself, a pure expression of love."

There will undoubtedly be many other decisions to make in the months ahead. It is recommended by most professionals that you not rush into major changes but give yourself time to begin to get over the initial shock and sadness in order to make good decisions. If possible, most recommend waiting up to a year to make major changes.

Elizabeth Kubler Ross, who was a pioneer in writing about grief in her book *On Death and Dying*, said "someday, perhaps, we will understand why there was once this overwhelming fear of death, which, for so long, covered up the fear of living." As you go on with living, we know you will take many things from this experience. We hope that includes a new decision to live each day to the fullest, to love and be loved, to find time for noticing beauty and giving thanks, and a commitment to be who you were created to be.

You might find the following prayer meaningful by John O'Donohue taken from his book *To Bless the Space Between Us*.

Prayer at the Death of a Loved One

Though we need to weep your loss,
You dwell in that safe place in our hearts
Where no storm or night or pain can reach you.
Though your days here are over,
Your spirit here was alive, awake, complete.
We look toward each other no longer
From the old distance of our names;
Now you dwell inside the rhythm of breath,
As close to us as we are to ourselves.
Though we cannot see you with outward eyes,
We know your soul's gaze is upon our face,
Smiling back at us from within everything
To which we bring our best refinement.
Let us not look for you only in memory,
Where we would grow lonely without you.
You would want us to find you in presence,
Beside us when beauty brightens,
When kindness glows and music echoes eternal tones.
May you continue to inspire us;
To enter each day with a generous heart.
To serve the call of courage and love
Until we see your beautiful face again
In that land where there is no separation,
Where all tears will be wiped from our mind,
And where we will never lose you again. Amen.