

# Making Hard Choices

When Patients Are Not Able to Speak for Themselves

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7/06



# Making Hard Choices

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## Introduction

Fred came to the hospital with chest pain. He got sicker. He stopped breathing. The doctors had to act fast to try to save his life.



A severe illness or injury may leave a loved one unable to make health care choices. When patients are not able to make their wishes known, doctors may turn to family members or close friends to help answer medical questions. While this booklet focuses on the times when family will be facing hard choices, sometimes the doctors are certain that medical treatment will not help the patient and will only result in longer suffering. At those times the doctors will talk with the family about how to keep the patient comfortable until he or she dies.

If you are being asked to make medical choices for your loved one, this booklet suggests such hard choices may become clearer if you answer the following questions:

- How sick is my loved one and will my loved one get well?
- What will my loved one's life be like?
- What are the risks of giving or not giving treatment?
- What would my loved one want me to do?
- What are the financial costs?
- What feelings might I have?
- What if it is time for me to let go?
- What are signs that my loved one may be dying and how can I help?



There is space at the end of this booklet to make notes. As you read, questions may come to mind. Write those questions down. You may be surprised at how quickly an important question leaves your mind when you see the doctor. It helps to have a friend or family member with you when you see the doctor. Ask that person to take notes on the doctor's comments. This will help you recall what the doctor said.

At the end of this booklet you will also find a short table. Use it to write the names, phone numbers and email addresses of family and friends that you wish to contact while in the hospital. You may want to write the room number and phone number of your loved one here as well.

## First things first: Saving life

As in Fred's case, medical caregivers will seek to save a person's life unless the patient has provided other directions. They will try to keep a person's heart beating. Doctors will try to keep a person breathing. If the heart has stopped, the person may be given a shock to try to start the heart beating again. If the person is having a hard time breathing, he or she may be placed on a breathing machine.

Fred was not able to make his wishes known. The doctors looked for written records of what Fred wanted for medical care. Fred did not have any written wishes for his medical care, like a Living Will or an Advance Directive for Health Care, so the doctors asked the family if they knew Fred's wishes.

## What came next?

What came next was not easy. Fred's doctors tried to find what caused his illness. They tried to see if and how much Fred might recover. Illness and injury vary from person to person. The doctors could not be sure if Fred would "wake up" or get better.

Special doctors were asked to see Fred. They did more tests. They were still not sure if Fred would live or get better. The family was asked again if Fred said what kind of medical treatment he would want at a time like this.

Fred's story happens every day in hospitals, only the names change. Patients become too sick to make their own decisions and families are faced with hard choices.



What Choices Might I be Asked to Make?

If the patient is unable to state his or her wishes, or has not written them, you may be asked questions like these:

- If the patient's heart stops beating or its beating is not smooth, should the doctors and nurses give drugs and shocks to try to get a normal heartbeat?
- If the patient is having trouble breathing, should the medical team put the patient on a breathing machine?
- If the patient is unable to eat or drink, should the doctor order a feeding tube?
- If the patient's kidneys fail, should the doctor put the patient on a kidney machine?

- If the patient is so sick that it is doubtful that he or she will get better, should the doctor order drugs to try to cure a germ or virus when the basic disease will not be cured?
- If the patient is so sick that he or she will not live six months, should the doctor order hospice care?

Ask the doctor about the risks and benefits of treatment. You can make a better choice when you know the hopes and the possible side effects of treatments. Knowing the patient's values and goals can help you make treatment choices.

This booklet explores a way to face these hard choices. Hard choices may become clearer if you work to answer nine questions. Let's look at these questions one at a time.

## How sick is my loved one and will my loved one get well?

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As in Fred's case, doctors are often not able to say if a very sick person will get better. The doctor may only be able to tell you that your loved one is very, very sick. It may take time to find out if he or she will get better or not.



Two things are important for you to know. First, imagine a person who has been sick at home for a long time, under a doctor's care. Now imagine that person gets another illness like pneumonia and the doctor says she should go to the hospital. Even if the pneumonia is cured, it is not likely the other disease will get any better than when she was home. The longer a person has been ill the less likely it is that he or she will return to normal health.

Second, the brain, the heart, the lungs, the kidneys and the liver are very important organs. When one of these organs is not working well, a person can be very sick. When two or more of these organs are not working well, a person can be very, very sick, and much less likely to get well.

***What if There is a Severe Brain Injury?*** (You may wish to skip this section if brain injury is not an issue.)

An illness or injury may result in a serious brain injury. Brain injuries may cause a coma. Doctors may have tests to see how severe the coma is. Talk with your doctor about the coma, what it means, and how aware your loved one may be.

Sometimes an illness or injury causes severe brain damage resulting in "brain death." When a person is brain dead there is no medical treatment that can make him or her better. If a person is brain dead and on a breathing machine it looks like he or she is breathing. But when a person is brain dead and the breathing machine is removed, the body does not breathe. When a person is brain dead there is no reason to continue treatment. If organs are to be donated, the body will remain on life support until the organs are taken. This gives the organs the best chance to serve the person who will get them.

Another form of severe brain injury is called "persistent vegetative state" (PVS). The brain stem, a "basic" part of the brain that helps a body breathe, is still able to work, but nearly all the rest of the brain dies. When a person is in a PVS, the brain stem may control waking and sleeping cycles, so it can appear that a person is "awake" but although the eyes are open they do not focus and the body does not respond normally. The body may appear to smile and make other movements. The body may even grimace, cry, or laugh. Many people believe that even with PVS a person is somehow present in that body. However, the brain stem is not the part of the brain where people think, feel or remember. Many people believe that when severe brain damage results in PVS, the person who thinks, feels or remembers is no longer there.

## What will my loved one's life be like?

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Of course, you want to know what kind of life your loved one might expect if he or she goes through long and at times painful medical care. No one can say for certain. Sometimes days or weeks pass before the doctors are able to predict the most likely outcome of medical care. At times doctors will only be able to tell you the chances a person will recover. "There is a 25% chance that Fred will be able to breathe without a breathing machine and get well enough to go home." Or, "There is a 60% chance that Fred will never be able to leave the hospital."



However, even getting well enough to go home does not mean the person will be the same as when he or she came to the hospital. He may need continuing therapy. She may not think as well. She may not be able to drive. He may need additional caregivers. Fred's family asked the doctor what Fred's life would be like if he got well enough to go home. The doctor said he would not be the same, that he might need nursing help at home too.



## What are the risks of giving or not giving treatment?

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Each treatment is to help the patient, but each treatment has risks. Drugs, surgery, chemotherapy, and radiation all have strong impacts on the body. No one can be certain of how each person will react to these treatments. Each treatment may have serious side effects. And just being in

the hospital brings added risks of infection.

Ask the doctor about the risks of treatment. You can make a better choice when you know the hopes and the risks of treatments. Knowing the patient's values and goals can help you make treatment choices.

## What would my loved one want me to do?

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This may be the most difficult question to answer. You are not being asked to state your needs. You are being asked to state your loved one's needs, desires and values. You are being asked to say what your loved one would say if he or she could speak. As you search to know what your loved one would want consider the following.

- Does your loved one have a Living Will or advance health care directive? These papers may tell you what your loved one would want at this time. Has your loved one named someone to speak for him or her in such a time as this?
- If your loved one, like Fred, does not have these papers, ask yourself if your loved one has ever told you what kind of medical treatment he or she would want. He or she may have said, "No matter what, never leave me on one of those machines," or "Whatever happens, do everything you can to keep me alive," or "I never want to be a vegetable." The person may have made comments about religion, such as "I think putting people on machines is just playing God," or "I think God will take me when God wants me." Such phrases may have different meanings in different situations.



- If your loved one has not made such comments, ask yourself if your loved one ever made comments about someone else, such as, "I would never want to be like that woman on TV. Her family never let her go," or "I think they should keep that person alive as long as possible, even if he never wakes up." Comments such as these may help you know what your loved one would want.
- If you cannot recall comments from your loved one, ask yourself what you know about your loved one's values. Did he or she like to be in control, like being active, like being able to communicate, like being able to see others, like being able to touch or hold loved ones, or like to have fun with children or grandchildren? How likely is it that your loved one will be able to live in the future as he or she did in the past? How would your loved one feel about issues of privacy and modesty in the hospital? Do these questions help you know what your loved one would want now?
- While you are asked to speak for your loved one, the choice may not be fully yours. If doctors feel that medical treatments are not going to help your loved one, they may feel it is only right to stop or not start treatments and still do all they can to keep the patient free of pain. If the doctors believe that life saving treatment has no benefit, they may refer your loved one to palliative or hospice care. Families and patients are often greatly comforted by the kind and warm caring they find in hospice or palliative care.

## What are the financial costs?

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While some people have health care plans that cover their medical costs, the costs of medical care may be more than dollars. Some treatments may cause pain and suffering. The longer the treatments, the more patients may suffer. Of course doctors and others will do all they can to reduce pain and suffering. Yet you should think about the benefit of treatment versus the pain of treatment.

For those patients whose treatment must be paid for by family savings, other choices may need to be considered. Fred saw his best friend receive costly, long-term treatment and never leave the hospital. Fred told his wife, "If that ever happens to me, let me go, save the money for the grandchildren and for your own health care." On the other hand, Fred's wife had an aunt who had costly treatment that saved her life and she still enjoys her loved ones.

Some families face another problem about costs. You may receive benefits from your loved one's pension or disability payments. If you decide to stop treatments and your loved one dies, you may not have the money to live as you have in the past.

### **Remember:**

Your first duty is to do what the patient would want.

### **It may be helpful to know these things:**

- The family's first duty is to the patient. The patient has counted on the family to say what the patient would want for medical treatment. Families often know if a patient would want to continue or stop treatment.
- Nearly all hospitals have social workers who can talk with families about financial resources. Social workers can help families think about moral and ethical questions.
- Many hospitals have chaplains who can help families think about the moral, ethical and spiritual issues of making choices that affect both the future of the patient and the family.
- Ask the nursing staff to contact a chaplain and/or social worker to come see you.

### **What feelings might I have?**

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Fred's family was faced with hard choices that raised difficult feelings for them. This was a very hard time for them. If you are facing hard choices too, be gentle with yourself. Listed below are some feelings you may have. These are normal feelings for a hard time.

- You might not be able to believe what you have been told. You may hear yourself saying, "This can't be true...this can't be real...how could this happen...there must be some mistake...I feel like this is a bad dream and I'm going to wake up and all will be fine."
- You might have a sense of panic and fear. You may have a higher heart rate, rapid breathing, and upset stomach. You may be less or more hungry, and it may be hard to calm yourself or to sleep.

- You might have feelings of guilt. You may hear yourself saying, "I should have made him come to the hospital...I should have known he was this sick...I am not sure what's the right thing to do." You may feel guilty for what you did or didn't do in the past, even though what you did or didn't do has nothing to do with your loved one's sickness.
- You might be angry. You may hear yourself saying, "Why couldn't the doctor have done something about this...Why did God let this happen...Why didn't she take care of herself like she should have...Why can't the doctor tell me more?"
- You might be sad. You may hear yourself saying, "I feel so empty...what will I do if I can't be with her...I'm not sure that I can go on...it should have been me instead."
- You might be tempted to cut yourself off from others. You may want to be left alone. You may not feel comforted by the presence of others. While it is normal to need time alone you should avoid pulling into a shell. Others want to help make a hard time a little more easy. Let people whom you can trust help you.

All these feelings are normal during times of stress. Your whole system may be in shock: body, mind, feelings and spirit. Being in shock is a way we protect ourselves from knowing too much too soon. We deny what we know is true to protect ourselves from very strong feelings; however, strong feelings of guilt, anger, sadness and fear are normal for such a hard time in your life.

These emotions may make it hard to keep in mind what you are told. You may find yourself asking the same questions over again. Your own feelings may make it hard to consider what is best for your loved one. You may find that you cling to a few words or phrases of hope, when you know that the main message is that you need to prepare yourself for letting go.

You may need some time to absorb what has happened. Sadly, some choices cannot be put off, so you may find yourself faced with choices you do not feel you are ready to make. You may need to ask for support from other family and friends. Remind yourself to use the help of chaplains, nurses, social workers, and doctors. These caregivers are there for you as well as for the patient. Tell yourself: "I do not have to go through this alone."

## What if it is time for me to let go?

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You may be confused about what to hope for. Keeping hope alive is important. Knowing what to hope for is harder. "Do I hope that she will get well...do I hope that he wakes up so I can talk with him one more time...do I hope that she can be kept free of pain...do I hope for a miracle...do I hope the children can get here before he dies?"

Facing the death of a loved one is one of the hardest things you may have to do. Your mind may know that your loved one might not live and yet your heart may not be able to let the person go. Why do we try to hold on when it is time for a loved one to leave us?

- You may have had such a rich and loving bond that you cannot and do not want to imagine what it would be like to live alone.
- You may feel guilty about something you have done or not done, and may feel the need to make it right. In such cases, it is good for the family member to go to the bedside and confess real or imagined failures and ask forgiveness, even though the patient is unable to respond. Then you will have done all that you could do.
- You may hold on because you feel the patient owes you something. Maybe the person has been less of the mother, father, son or daughter than you wanted. Facing his or her death means to let go of the hopes and dreams that someday you will have a better bond. It is sad to admit those dreams will not happen.

- You may hold on to a loved one because you are concerned for his or her soul. Some people's faith teaches them that unless a person makes a specific faith statement, he or she will go to hell. Such a belief may cause great spiritual and emotional suffering for the family member who believes that he or she may never see a loved one again. This person may wish to look at his or her faith and scriptures again. The hospital chaplain is a good person to talk to at such times and can be reached by the patient's nurse.
- At other times you may hold on to loved ones when it is time for them to die because you fear that you cannot live without their presence and their support. Sometimes these fears grow because of the worry of loss of income.



There are many reasons to deny the reality of death. The fact is that we all die. Trying to hold on to a loved one by insisting upon health care that you know in your heart is futile is really an effort to soothe your emotional and/or spiritual needs at the expense of your loved one. Letting go at any time is not easy, but it is harder when your own needs stop you from doing what is best for the patient. Holding on too long increases the patient's and family's suffering and prevents the healing that comes through grief. Though it is very hard to imagine, nearly everyone who faces grief comes to have new life after a time of grieving.

## What are signs that my loved one may be dying and how can I help?

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You may see signs that show that your loved one is near the end of his/her life. The nurses may say that his "secretions", that is body fluids, are building up. You may begin to hear a rattle when he breathes. You may notice her jaw moves as she breathes through her mouth and that the rhythm of her breathing is not regular or easy. You may see his skin getting blotchy. You may feel her hands getting cold. His fingernails may look more purple than usual. Her heart rate may go up and her blood pressure may drop. You may see some or none of these signs. Many of these signs only occur the last day or the last few hours of a person's life.

Letting go is hard, but you can help make it a little easier for your loved one and for yourself.

- Even if your loved one is not able to speak to you, you can speak to her. She can likely still hear you.
- Even if your loved one is not awake to see you, you can still touch him. He can probably still feel your touch.
- Even if your loved one cannot drink or eat, ask the nurse if you can use a swab to keep your loved one's mouth moist. Consider putting a cool washcloth over your loved one's forehead and notice if this seems to comfort him.
- You may know other things that provide comfort for your loved one, such as music, a certain odor, a certain fabric, scripture, poems or voices. Work with nurses to help provide these items of comfort.

- If your loved one found religious or spiritual rituals helpful, ask a person from your faith group or the hospital chaplain to provide those.
- If it is time to let go, suggest to the nurses that the monitors be turned off so you can focus on being with your loved one. Suggest that the television be turned off and the lights made more pleasant. Perhaps you would like a private room and ask that the door be closed. Think of making the room a place of peace for you and your loved one.
- **When you talk with your loved one, consider:**
  - ♦ Saying “Thank you.” Thank your loved one for every way he has been good for you, for his kindness, his care, for the times she stuck with you, for the times she forgave you, for vacations, birthdays, trips, holidays that you shared.
  - ♦ Saying “Forgive me.” We all let our loved ones down at times. Ask your loved one for forgiveness, even if he is not able to respond. If it is important to you, ask forgiveness of God or your Higher Power as well. Then believe that you have been heard and forgiven.
  - ♦ Saying “I love you.” Tell your loved one all the ways that you love him or her. See how many time you can finish the sentence, “I love you for....” Finish by saying “I just love you.”
  - ♦ Saying “It’s OK to go.” Tell your loved one that you will be OK. Support him in the next steps of his journey. “It’s OK to go now. I will be OK. You will know when the time is right. We will miss you, but we will be OK. You need to do what’s right for you. Go with our love and our support. It is OK to let go. You will be safe.”
  - ♦ Saying “Goodbye.” Finish saying, “It is OK to go” by saying goodbye. You may wish to squeeze your loved one’s hand, and kiss him or her as you say goodbye. You may wish to say that you will see him or her when your turn comes to die, but for right now you are saying, “Goodbye,” or, “God bless you,” or “God be with you,” or “I will always love you,” or what ever feels right to you.

If you sense your loved one is dying, and you feel you can't let go, ask your nurse to contact the social worker and/or chaplain. They are there to help you with the hard feelings and thoughts that we all have to face from time to time.

### **How can I care for myself at this hard time?**

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Thinking about yourself when your loved one is sick or has an injury may seem selfish. It is important that you take care of yourself so you will have the strength to make hard choices and face the difficult times ahead.

- Do the basics: eat well even if you don't feel hungry; drink lots of water even if you don't feel thirsty; try to rest and sleep, even if your mind keeps thinking; take deep breaths; get some exercise; practice your spiritual or religious life. These will all give you the fuel you need for a hard time.
- Form a support network. Let friends, family and your religious leader and/or social group know what you are facing. Ask for their support. Accept their help. Let them provide meals, watch the children, do the laundry, provide travel. Ask for hugs and prayers when you need them. Ask your boss for the time and support you need.
- Name one person to be the “contact person.” You can tell this person once a day of your loved one's condition. Your contact person can then inform everyone else.

- Use a notebook to keep track of what happens daily. Days in the hospital often blend together. Without a written record you may not recall what happened. Writing down key events and feelings is one way to help provide self-care. Keep phone numbers in your notebook, ready for use.
- Keep a written list of questions for the doctor. Unless you have them written down, you may be amazed at how many questions leave your mind when you see the doctor.
- Invite a trusted family member or friend to be with you at the hospital. Ask him or her to be there when the doctor speaks with you. Ask them to take notes and to repeat to you what was said. You are under stress. You may find that you don't recall what was said to you.
- Take breaks. Ask trusted friends or family to take turns at the bedside so you can take breaks. Walk, exercise, leave the hospital, get outside, and if possible spend time at home every day and/or night. Waiting in a hospital is very tiring work. You may be surprised at how weary you are from "just sitting around." To renew your energy, get away for a while.
- Ask the nurse to contact the hospital chaplain and/or social worker for you. The chaplain is an expert at providing emotional and spiritual support. The social worker can provide emotional support and help you with financial and medical benefits. Applying early for benefits may be important in some cases.

- Know that you are grieving. You are facing a change in your life. Much will change. Keep to your regular routines as much as possible. Know that you may feel empty - or in shock, as if you are outside your body. You may feel angry, downcast, depressed, sad, and tearful. You may have a number of feelings at the same time. It is OK to laugh or find humor in each day. You may be tempted to bargain with and make promises to God as a means to convince God to restore your loved one to health. All these feelings can be a part of grief work. Whatever you feel, have compassion for yourself. Treat yourself as you would your best friend under the same kind of stress.
- If you have not written an advance care directive, think about doing this for your family. Giving your family a written paper that tells what your medical choices would be is a very loving act. Social workers can help you get the forms.
- Keep in mind that you do not have to do this by yourself. Ask for help. If you do not know whom to ask, seek out the nurse, chaplain or social worker. They will be glad to help you with your questions and will listen when you "just need to talk."

## Summary

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Making choices for a loved one faced with illness or injury may be one of the hardest times of your life. Take time to think about written or spoken words that your loved one may have made to help guide you in your thinking. Think about the kind of life your loved one enjoyed living. Use doctors, nurses, social workers, and chaplains as well as family and friends to talk about your concerns, questions and feelings. Know that help is ready for you.

In the end, the question is: "What would your loved one want?" You will be asked to make the best choices for your loved one. Sometimes this will be hard because you may have fewer facts than you would like. At those times, be gentle with yourself, knowing you are doing the best you can at a very hard time. As hard as it is, no one may know your loved one's wishes and values better than you do.

## Appendix

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### What Are Some More Resources?

If you would like more to read to help you think about hard choices, there are many resources. Consider the following:

*Hard Choices for Loving People*, 7- 1-1999 by Hank Dunn. Published by A & A Publishers, Inc., P.O. Box 1098, Herndon, VA 20172-1098. **Voice mail** - (703) 707-0169. **Fax** -(703) 707-0174. **Website** [www.hardchoices.com](http://www.hardchoices.com)  
**Email** AAPublish@aol.com

If you can access the Internet, use a search engine to identify other resources.

Many hospitals have libraries, some of which are available to family members. Check with your hospital library to see if you can use it to get more facts about your loved one's illness or injury.

There are many public service groups such as the American Cancer Society, the American Stroke Association, the National Stroke Association, the National Institute of Neurological Disorders and Stroke, and the American Heart Association. Your library can provide phone numbers and addresses of these and other helpful groups. Many groups offer free brochures.

## Notes on key questions

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The space below is for notes and additional questions you may have as you think about the key questions.

1. How sick is my loved one and will my loved one get well?

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2. What will my loved one's life be like?

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3. What are the risks of giving or not giving treatment?

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4. What would my loved one want me to do?

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5. What are the financial costs?

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6. How can I deal with my feelings?

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7. What if it is time to let go?

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8. What are signs that my loved one may be dying, and how can I help?

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9. How can I care for myself at this hard time?

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### Contact Information

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Patient's Room Number: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Patient's Doctor: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Patient's Unit Number: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Nurse Manager: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Patient's Chaplain: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Patient's Social Worker: \_\_\_\_\_

Phone Number: \_\_\_\_\_

Visiting Hours: \_\_\_\_\_

Cafeteria Hours: \_\_\_\_\_

Patient's Clergy: \_\_\_\_\_

Phone Number: \_\_\_\_\_

