Making process. These decisions and choices pertain to more than just the disease and the treatment that might reverse, stop, or slow down the process; they also pertain to the life you want to lead with the amount of time and energy remaining. In fact, the unfinished business, your sense of self, and your relationship with others may be just as important, even more so, than focusing all your attention on the disease process. It is crucial to remember that the choices belong to you, the person with the illness. And living is a dynamic process, so you can always make new decisions and change your mind about past ones.

If you have a life-threatening or terminal illness, or if you are getting on in years and would like to have a meeting with significant people to discuss your future, the five-step process outlined below can benefit you. I have used it with many families in the hospital, in my own family, and with friends like Maggie. In many instances, dying requires a community of support. It could be years, months, weeks, or days before you die. Depending on the prognosis, you might meet regularly—every month or two or even longer between meetings.

You might feel awkward or uncomfortable, perhaps because you do not want to inconvenience people. However, my experience is that people are generally relieved when someone invites them into a meaningful conversation. It usually benefits all who participate, often strengthening friendships and family relationships. The process keeps people connected and informed about what is happening, about your wishes, and about how they can be a part of your care plan.

Family members might not be accustomed to speaking openly and honestly about wishes for health care and dying, which means others will be left to guess. So when you invite people over, make certain they understand the purpose: to have an open discussion about living with dying, about making decisions that will affect how you lead the remainder of your life. The end of life usually involves friends and family members, and your relationship with people before you die.
will effect the grieving process for them. I encourage you to participate in a process like this. You could also tape (audio or video) a message for your family and friends.

If this is something you do not want or cannot do, it would still be of value to think about the discussion topics and write down what you would like to happen in a variety of circumstances. The process I present is based on work that was taught and written about by three Americans—Albert Jonsen, Mark Siegler, and William Winslade. These three developed a decisionmaking process designed to help ethics committees in hospitals to resolve ethical dilemmas. Their work has been adapted at St. Paul's Hospital in Vancouver to include families and professionals in the decisionmaking process. Initially it was used to resolve ethical dilemmas. It has also been useful in the complex decisionmaking process at the end of life. We invite patients and those who are important to them to join the health care team in developing a plan for the patient.

Maggie made a list of all the people she would like to invite to her home. A close friend of hers phoned everyone, explaining the purpose of the meeting, and asked them to bring some food so the group could share a meal together after the meeting. All those who were invited attended. They were honored to be invited, pleased to attend.

Organizing the Meeting

In order to conduct a decisionmaking meeting, invite the people who are important to you—close family members and friends. Invite professionals who know you and are involved in providing care for you (the meeting will have value even if they are not able to attend). The meeting can be organized by you, a family member, or a friend. Set the time, date, and place. The process usually requires two to three hours. Because facilitating a meeting requires a lot of energy, it is wise to ask someone in advance to act as facilitator. (If you know of someone with experience and skills in facilitation, invite that person to act on your behalf.) That way your energy can be spent on the decisions that need to be made rather than on keeping a group of people focused and on topic. Everyone involved must understand that the purpose of the meeting is to develop a health care plan for you.

It is important for the facilitator to keep the discussion moving in a respectful manner and to make certain that everyone present is given the opportunity to express opinions and raise concerns. The goal is to develop a comprehensive plan, with those present making a commitment to the plan and therefore making a commitment to you. Once everyone is gathered, make sure they are comfortable and within easy speaking range. Sitting in a circle helps. Introduce the facilitator, explain that you invited this person, and, if you like, why you chose that person. Next, ask everyone to introduce themselves and their relationship to you.

This is a very intense process. If at any time you are too tired to proceed, ask that the meeting end and set another time. If you are too tired to concentrate, you will have trouble knowing what you really want.

The facilitator begins by describing the process and the purpose of the meeting, identifying any decisions that need to be made. It is helpful for the facilitator to set a few guidelines for the conversation:

- Be sure everyone knows that he/she can participate and will have an opportunity to speak or ask questions. Be sure they understand that you welcome and value their opinions.
- Explain that it is important to speak respectfully.
- Remind participants to be aware that communication is verbal and nonverbal; people are invited to speak clearly and simply so that all those in attendance can understand; gestures like rolled eyes, raised eyebrows, grunts of disapproval, and the like are not welcome.
- Ensure that everyone has made a commitment to stay until the
end of the meeting. If someone is called away for an emergency, ask if they have anything to add before they leave.

- If at all possible, pagers and portable phones should be turned off, you want people's undivided attention.

Record everything discussed on a large flip chart so that everyone can see the information. It is also important to keep a to-do list; add to it throughout the process. One possibility is to conduct the meeting over the Internet via a chat room or e-mail. For some people, the first meeting is followed by e-mail communication.

We met in Maggie's living room in the late afternoon. The place was crowded, but everyone was comfortable and the eighteen people present could see and hear one another. Maggie introduced me to the group (her family and friends), asking me to explain how it was that we had come together. The usually take-charge Maggie was too tired to speak. She was also short of breath. She still sounded anxious but less so than she had been when we spoke on the phone two weeks earlier. After introducing myself and explaining the purpose and process of the meeting, I asked everyone to introduce themselves and explain to the other members of the group how they were connected to Maggie.

Imagine this in your living room: You are surrounded by family members and friends who care about you, who are willing to do some work on your behalf, and who want to keep in touch through the course of your illness, your remaining lifetime. You cannot predict what your needs will be or the exact course your illness will take. No one is able to do that. Unfortunately, for some the health care system will not be user-friendly. In fact, it can show indifference and even antagonism despite your circumstances. Therefore, some will need a strong advocate to speak and intervene on your behalf. The people around you are the people who will understand you, who will know what you want and how you prefer to live. Some of them will make a commitment to work with you in meeting needs, accomplishing goals, and speaking for you. Although this may be a difficult meeting, it is important.

Medical Information

You should speak first if possible. Inform the group about your health. Perhaps a close friend or family member has accompanied you to doctor's appointments; ask him or her to speak on your behalf or add to your comments. Go over the facts of your medical history and explain what has happened to you to require a meeting like this. Report on all the symptoms, the tests, and the results.

- What is the diagnosis (the name of the disease) and the prognosis (the future course of the disease)?
- Which treatments have you had to date? If you're talking about cancer, options would include surgery, chemotherapy, and radiation therapy. Inform the group about any alternative therapies you have tried. If your health care providers are present they would likely assist you in providing and explaining the information of your medical condition and history to the group. Invite them to do so.

The facilitator asks the questions. The recorder jots notes on the flip chart so everyone can see and understand the topic of discussion. Often, speaking about these issues clarifies what is important to you.

- Which therapies are you considering? What are the risks? What will your life be like if you have the therapy you are considering? What will it be like if you don't?
- If surgery is an option, how long will the recovery be? Do you want to spend that amount of time recovering, given the best estimate of your life expectancy at this point? How might your daily life improve if you have the most desirable outcome?
- If chemotherapy or radiation therapy is an option, or if there is
some medication that might have an effect on the illness, what is the time frame in which the treatment would take effect? What is the earliest point at which you might benefit? How long would you have to be on the medication until you would know whether it was working? What are the side effects of treatment? How are they managed? How long do they usually last? How soon would treatments have to begin in order to have some effect on the disease process? How long can you wait and still take them with benefit?

- Has your doctor spoken about your life expectancy? If so, be brave enough to include that.
- Is there any aspect of your illness that is reversible?
- If you are in pain, how is it being managed? What are other options? (See chapter 3.)
- And what about other symptoms, such as shortness of breath (dyspnea), constipation, nausea, vomiting, fatigue, or insomnia? What might you expect as the disease progresses? How are these symptoms being treated right now? Are there other possibilities? Every alternative you consider important should be included: physiotherapy, acupuncture, therapeutic touch, meditation, homeopathy, and so on.
- What has been your experience with the health care system? Do you usually have to wait a long time to see your physician, to have tests conducted, to receive results? Do you get information by phone, or do you have to visit your doctor for every question?
- If you are frustrated with the care you have been receiving or lack of information, what changes need to be made? How might that happen?
- Do you need someone to act as an advocate? Are you getting the information you need, and is it presented in a way that is easily understood? Do you believe that you understand all your options? How much time and energy is being spent obtaining the information you want and need with regard to your health and treatment options?
- How well are you able to live a normal life? Are you self-sufficient? Do you need help with grocery shopping, preparing meals, personal hygiene like bathing or washing your hair, getting dressed? Are you able to go out as often as you'd like? Does it require too much energy? Do you need someone to go with you? Have you noticed any changes in this regard over the past months, weeks, or days? If not now, do you think you will need assistance in the near or distant future if things progress at the same rate? Would an assessment by an occupational therapist be of value?
- What features of this experience contribute to your suffering? The changes, the sense of loss, becoming dependent on others, fears about the future? What is affecting/changing your sense of self and/or relationship with people who are important to you?

You may not have all the answers to these questions. You may have additional questions. But if these questions have sparked a desire for more information from your doctor, who may not be present, invite someone along to your next visit with your doctor. Make a list of the questions you would like to ask (see the discussion in chapter 2 about visits to the doctor). Make sure the facilitator invites people to contribute or ask questions at specific points, especially if some people are shy.

Maggie spoke of how the diagnosis was made, how she had gone for radiation and for chemotherapy, and how the symptoms were recurring. It was a rare form of cancer. She admitted to a sense of desperation—she didn’t want her doctors to give up on her, surely there must be something else that could be done. She felt that her doctor was giving her the information he had, but it seemed that there ought to be something else. Surely there was something someone could do somewhere. Her doctor was now
on a leave, and she was uncertain about where to go with the questions she had. She didn’t have the energy to go through it all again—meeting a new doctor, telling her story, waiting for appointments and for another opinion, another treatment plan.

Why was the system so poorly organized? Maggie didn’t want to wait, she felt she didn’t have enough time. She talked of her increasing shortness of breath and her inability to do anything other than basic activities around her home. A friend of Maggie’s spoke, as she had accompanied Maggie on a few visits to the clinic.

Maggie’s biggest concern was her three children, none of whom were living at home. And though she wanted them to know the truth, she found it hard to speak to them about how sick she felt, her fatigue, and her fear that she was dying. She couldn’t bear to speak about those concerns at this point in the meeting. She was also concerned about her youngest brother who had recently been ill. She knew her mother would have a particularly difficult time with the truth.

success, simply because you are someone who doesn’t quit?

How might that affect those who care about you with regard to your physical, emotional, and spiritual energy?

Most people begin with the wish for a cure, even when they know that the disease is incurable. Working toward a cure can include one more effort with a particular therapy. Some people place a lot of hope in that magic cure, the one with a 5 percent chance of reversing the disease process.

- Are you focused on that magical cure because that’s what you want or because that’s what your partner/spouse/children want you to do? Is your focus on the magic cure distracting you from other important issues that require your time and attention right now?

It is of value to dream out loud about what you would like to do in the time you have left. Although this can be a rewarding process, it is usually an emotionally painful process. Your preferences in this regard will reflect who you are as an individual (activities you would like to enjoy one more time, something new you have not tried before), your relationships with others (special events such as birthdays, graduations, and weddings, conversations that you need to have, time with favorite people), and your sense of spirituality (meaning, forgiveness, meditation, self-reflection, worship). And while you are expressing your dreams and desires, you may also experience a sense of grief because you recognize some potential losses.

- What are some of your other goals? Are there things you really want to do or see? Some people want to travel to a particular place because of certain memories. Some want to travel to visit family members or friends. Sometimes there are conversations
people want to have while they have enough energy to do so. You might want to divide these goals into personal goals, goals that relate to family and friends, and goals that pertain to the spiritual domain.

- How might your health care team help you achieve these goals? If they are not present at the meeting, tell everyone about your entire health care team—all those that provide physical, spiritual, and psychological care and support—family members, friends, volunteers, and professionals. In a way, you are introducing them to the people who will likely meet through the course of your illness.

- Have you considered palliative or hospice care? Do you want those services, and are they available in your community? How might you get information about the hospice/palliative care program in your community? Is there anyone who does home visits from that organization?

- What about advance directives (documents outlining your wishes for health care decisions if you are incapacitated)? The intent is to give you control over decisions in the future.

- Do you have a health care proxy or a durable power of attorney (a document that names someone to make decisions in the event you are unable to do so) or a living will (which states what type of treatment you would like to have or refuse to have given various health situations)? Someday someone may need to speak for you or to make decisions on your behalf. Who is most able to act as your advocate? Who is most able to think like you do and take action accordingly? Who is most able to give voice to your wishes about end-of-life care? This might be a friend more than a family member. Some people choose a family member as a matter of loyalty, but a friend might be better. Advance directives are legal in every state, though laws in each state can vary. They are also legal in most provinces in Canada. Do you know the laws in your state or province pertaining to advance directives, health care proxies, and living wills? Who might help you get this information?

This whole process might be very new for you. If it is, there is value in discussing how you make these decisions. Who do you include in the decision-making process? Again, at the end of this discussion, the facilitator goes around the circle, asking each person whether they have anything to add.

Maggie needed more information about treatment options before deciding what she would do. She asked whether one or two people might accompany her to her physician. She also said that she would feel more comfortable if she had a copy of her records, she would ask for a photocopy of her medical records, knowing that she would have to cover the cost of photocopying. She did say that she would like to go on a family vacation as well as to spend time individually with each of her three children. She hoped to have more energy so that she might be able to take each of them away for a weekend. Her wildest dream was to take all of them on a trip to England. Maggie did not speak about a living will or an advance directive. She had mentioned before the meeting that she was not ready to discuss those topics in a large group. In fact, she acknowledged that she was hardly prepared to approach those topics on her own or with her children.

Describing What Quality of Life Means to You

At this juncture, consider your quality of life—physical, emotional, mental, spiritual, financial, and social. This is often the most difficult and challenging part of the process. Frankness and honesty are especially important. Only you can define or describe what 'quality of life' means to you. Your definition might be very different, not only from those in the room but also from your own in the not-too-distant past. That is one of the reasons this process is important. It gives you the opportunity to let other people know your wishes.
What is important to you at this time in your life? What would "quality of life" mean if you had five years of life left? (Five years seems to be forever for most people. To imagine that you only have two years to six months of life remaining is more difficult.) What does quality of life mean to you if your life expectancy is two years? Six months or less? A few weeks?

How are you living now compared to before this illness? Your answer might help others understand the changes in your life and might also provide a reference point as to how quickly changes are happening.

In my experience, this is where the group can differ in perspective. In some instances, the patient has begun a process of confronting mortality even while friends and family members still hope for a cure and don't want to address end-of-life issues. Therefore, at least one or two people need to know your decisionmaking background and be willing to back you up. So encourage discussion, invite people to ask questions, and express what they can do to help you achieve your goals—but make sure this is what you want.

Up to this point, we have been reviewing your past, your choices for medical treatment, and your wishes for the time you have left. Now, the discussion moves toward the actuality of your life.

• What is realistic? What is desirable? What is possible?
• How has your definition of "quality of life" changed with the knowledge that you have a terminal illness? What brings meaning to your life?
• Consider physical, social, psychological, and spiritual issues. What has sustained you emotionally and spiritually in the past? What sustains you at present?
• Are there circumstances under which you would consider stopping all medication or treatment? Given the preferences you have expressed, which of the above are feasible, and how might they best be achieved?

As this part of the meeting draws to a close, the facilitator asks if anyone has anything to add before moving on to the next section.

It was difficult for Maggie to speak about all the possibilities that might result from her illness, especially the likelihood she might die as a result of the cancer. She felt overwhelming grief at the thought of saying goodbye to her three adult children, whom she dearly loved. As the facilitator, it was my responsibility to introduce the topic.

"While we have looked at all the favorable outcomes, we have thus far avoided one possibility. It is the most difficult of all to talk about, but we have decided that we must also talk about what will happen if all the remaining options are unsuccessful. We are told that if the cancer does not respond to treatment, it will likely cause Maggie's death." There was a silent pause. Then her eldest son blurted out, "What a relief, mom, now we can be honest with each other! There's a lot to say and we want to say it."

The other two children agreed—it seemed to be the moment they had been waiting for. We needed the previous hour and a half to get to that point. That was the beginning of greater intimacy within the family. Maggie's breathing improved as her stress decreased. She seemed to sense that her children wanted to share her pain, her loneliness, her anxiety. Her journey was less lonely than it had been once she was able to speak the unspeakable and begin to express some of her inner feelings.

Assessing Practical Considerations

The facilitator continues to raise issues and ask questions. Do you have one health care provider who acts as an advocate for you? Do you have someone who understands you and works with you? If not, is there anyone in the group who knows of such a person? If so, how might you be linked to that health care provider? If not, are there other people you could ask in order to find someone like that? The
greater the ambiguity about the disease process, the more stressful the end of life will be.

Maggie felt there was a lot of ambiguity about her illness. She felt that she did not have a clear understanding about the natural history of the disease. Neither did she know what treatment options remained for her and how she might get the information she needed and her children wanted. Someone in the group knew of a physician in another city who had already provided some information about the disease to Maggie. He offered to make another contact; another person offered to accompany Maggie on her next visit to her cancer doctor to ask questions about the disease and treatment options, a third person was eager to surf the Internet for information.

- Where might you receive care during the course of your illness—at home, in a hospital, in an extended care facility, in a hospice? Although care at home is often a first choice, it can be taxing on you as well as your care provider(s). The good moments are certainly good, but the bad times can be very bad. It is great to be around for the intimate moments, the meaningful conversations, the time of shared quiet. It is more difficult during times when pain is poorly controlled, when diarrhea means frequent diaper changes, when wretching doesn’t end.

- What are the financial costs? Are the costs of treatment covered by insurance? If not, what does insurance cover? What about medication through the course of your illness? What are other options for payment? In the United States, it is important to ask how Medicare, Medicaid, and private insurance differ. Because terms of coverage can change, it is imperative to ask your social worker, nurse, doctor, or case manager to assist you in determining what the costs will be and who will cover them. Can someone at the meeting agree to act as a financial advocate, research the options, and then deal with insurers should that become necessary?

- How important is the treatment to you? Is it based on a “last hope” because dying is simply something you’re not ready for, or is there a likelihood that the treatment will reverse the disease process or prolong your life? Where would you have to travel in order to get treatment? Who might be affected by your choices? How convenient is the location? Do you know of anyone who has received care at that facility? What was their experience? Are there other facilities to be considered? Who in the group can help you gather information about them?

What are the resources available for optimal care? This includes, first, financial resources:

- Is there money available for equipment (e.g., rental of a bed, commode, wheelchair, etc.), for assistance (e.g., homemaking, nursing care, assistance with activities of daily living, etc.), or for care in a particular facility?

- What is the response of your health insurance company to your needs, to your desires? Who might help you with the mountains of paperwork your insurance company requests from you, or with the interaction that needs to take place between you and the insurance company?

- As you get sicker you will have less energy for all of this, and your family will want to be with you rather than fighting with an insurance company. Who might help your with the work?

Second, there are emotional resources. The emotional energy of the people providing physical, emotional, and spiritual support is a limited resource. It is important for them to be honest and to make commitments only if they are realistic. Some may want to give the idea more thought, and that’s okay. Others might want to commit for
a shorter period, after which you meet again and review how everyone is doing. At that time, some people may ask for a break to recharge their own batteries. Ask them to speak honestly about their commitments and limitations, and respond in kind. Some people have a tendency to overcommit, and everyone at some point will likely experience a degree of anger, frustration, guilt, or fatigue. Some people will remain stoic in the face of tragedy, unwilling to express their true emotions. But if stress is building, it’s important to express it. Speaking openly helps everyone come through the experience healthier, stronger, and with a better understanding of themselves and one another. The burdens—and the rewards—are being shared.

Third, consider societal resources. In my experience, individuals often worry that someone else, a sicker person, might need the facilities more they do. That worry increases if financial resources are being drained. Be honest about your own needs and the needs of those who are supporting you.

What does the law say about your wishes? This is especially important with regard to euthanasia and physician-assisted suicide. It might be valuable to have a discussion about the topic. Many people want to talk about it, even if it’s not an option for them. Physician-assisted suicide and euthanasia are against the law in Canada and in most U.S. states (Oregon is the exception). In Canada, it is against the law to counsel anyone toward either euthanasia or physician-assisted suicide. It is not against the law to discuss the topic.

That ends the series of questions. There may be other topics of interest or concern. The facilitator then invites everyone to make comments. The to-do list becomes the plan of action.

Once all the topics are discussed and recorded, look at what needs to be done—review the to-do list. This might include a visit to another specialist for a second opinion, assistance with regard to an activity (to go skiing one more time, to visit a friend in another city, to explore alternative therapies), a visit to a potential hospice, or the drafting of a living will. It is important for the facilitator (or, even better, you) to acknowledge the varied emotions triggered by the process. Be honest; talk about your loss of independence, about your appreciation for everyone’s efforts. The plan will work better if people don’t overcommit. Review each item and ask who will assume responsibility. Write down that person’s name next to the item. Set a deadline for each task. Once the list is complete, set up a second meeting. There is often merit in setting priorities or checking the burdens and benefits of each item on the list. Is everyone who might be affected by this overall plan comfortable with it and able to contribute? If not, why not? What needs to change to enable everyone to put the plan into effect? Some may have to agree to disagree. How much effort (e.g., time, energy, money) will need to be invested to make the specific event happen? What happens if it cannot happen? What is the desired outcome? How will the person’s life be enhanced if the item can be achieved?

Maggie’s shortness of breath was evident through the meeting. We went through the issues and concerns. People were eager to help her find the information that she wanted and needed, to accompany her to physician visits, and to provide emotional support. There was a significant sense of relief in the room. Conversations continued after the meeting was ended. Everyone stayed to enjoy a meal together. It was the beginning of a community of caring established specifically for Maggie, a community of people who would keep in touch with her and with each other in order to make certain that she would receive the best possible care.