

Making Medical Decisions

Marcus Welby, MD, would never even get a pilot episode these days.

Recognizing the imperfections of medicine, you're no longer willing to be obedient to the advice of a kindly, paternal doctor. You want guidance, but you also recognize the important role you have to play in making decisions about your own care.

Even if you wanted to give all the control about your health care to a doctor, you shouldn't. Would you let someone else choose your spouse? Your car? Your home? Don't let someone else choose your medical care, either.

Your input is critical. Since there's rarely only one **right** answer, you need to be involved in choosing your treatment plan. Doctors know this nowadays, too. Often, your doctor doesn't tell you what to do; instead, he or she gives you information, explaining the pros and cons of various approaches.

This can leave you well informed but still uncertain about what approach would be best for you. Important medical decisions are rarely straightforward, either. How do you proceed when you need to make important decisions about your health and health care?

Perfection is not the goal

We like to imagine that medical decisions are clear and that outcomes can be predicted—even predetermined—but they can't. There's always an element of mystery. All of us, including doctors, can only hope for an educated guess about what will happen with a particular treatment.

It's important not to torture yourself trying to find the perfect plan. There isn't one. All decisions carry some risk, and the goal of making medical decisions is to balance the risks against the benefits.

So, in making medical decisions, don't strive to make a **perfect** decision. Aim instead at making decisions that take into account everything that's important to you, including your values, and needs.

Gathering medical information is an important place to start. Your doctor has left you with a stack of Internet printouts. How do you begin to make sense of what can be an overwhelming amount of information?

The very first step is to start writing everything down. Start a notebook that will include the following sections:

- Information from doctors (with a separate section for each doctor)
- The results of your research, separated into:
 - information about your disease
 - information about each treatment option
 - information about coping with the disease

- make sure to list the sources (websites, articles, books) for each piece of information in case you want to recheck it later
- Input from family and friends. Make a note of who said what. No matter how sure you are at the time that you'll remember, it's all too easy to lose track later.

As you start the process of gathering information, find good guides to help you interpret the medical world. You can use multiple guides, too, but make sure that one of the guides the 'captain of the ship.' Things fall through the cracks if there isn't one person in charge. The captain could be your primary care doctor or a specialist—it's your choice. Then ask that doctor if they would be willing to serve in this capacity for you. See this doctor frequently and keep them updated about new developments in your health and health care.

You can also consider hiring a patient advocate to help you find information and expert specialists and accompany you as you go through the decision making process.

Create a list of all your choices.

As you begin to wade through the medical information, write down every choice you discover. Without deciding for or against any of them, write them all down separately in your notebook, leaving plenty of space to add details later.

As you learn about your treatment options, you'll find that they're likely to include:

- Surgery
- Medications—write down the names and dosages of medications that are part of various treatment plans
- No treatment
- Timing of treatments—now versus later, for instance
- Experimental treatments, such as enrolling in a controlled trial
- Alternative therapies

Ask about treatment options from your doctors, both your primary care physician and any specialists you're seeing. Check with friends, support groups, books—and any other source of reliable information you find. Look on the Internet for information from national society websites like the American Heart Association, National Multiple Sclerosis Society, and American Cancer Society.

Get a second opinion, too, making sure to see a physician who's in a different practice than your diagnosing doctor. Ideally, you'd see a doctor who even practices at a different hospital.

If you live in a small town, strongly consider a second opinion at a major medical center in a larger city. The most current treatment approaches are often more consistently available in big medical centers.

Even if you live in a town with a major medical center, you might want to travel elsewhere for a second opinion. If you don't want to travel, consider an e-second opinion. The Cleveland Clinic, www.clevelandclinic.org, makes them available.

As you're looking into treatment options, be aware that things are done differently at different institutions. The 'standard' protocol at one hospital may be different somewhere else. Even if you don't plan to go there, investigate what other treatment centers do.

Get as much data as you can for each option

The kind of data you want comes in the form of hard numbers: survival percentages, years of life gained, the percentage of patients who experience important side effects, and the like.

Particularly for cancer and other potentially fatal illnesses, be aware of the difference between 'disease free survival' and 'overall survival.' Overall survival includes people who are alive after five years but may be battling end stage cancer. They weren't cured of the disease.

Both numbers are useful, but they mean different things. An 80% five year survival rate and a 50% disease free survival rate means that many people are living longer with that particular cancer but only half actually get cured.

Look at survival numbers both ways, too, to get the full meaning behind them. An 80% survival rate is also a 20% death rate, for instance. Inverting the numbers like this helps you get a better feel for what they really mean.

Gather as much research as you can, while recognizing that even medical research isn't perfect. Two studies may present totally different answers to the same question. If most of the studies agree, though, you might ignore the few that don't. If the research truly lacks any consensus, you might need a doctor who specializes in the area to help you interpret why the research doesn't point in any clear direction.

Gathering data is much harder than it may seem at the outset. The data you find from one source will often conflict with what you learned somewhere else. The Internet, in particular, is an endless source of data that seems like a hodgepodge of varying numbers. One expert offers one set of numbers; another says something different.

While searching the Internet, stick to a few reliable websites and use them repeatedly as you search for information. Here are some of the most trustworthy sites available:

- **PubMed** lists presents summaries of many thousands of medical articles and is searchable by topic. PubMed listings contain links to sites where the articles can be viewed for no charge or purchased.
www.pubmed.com
- **MedLine Plus** contains credible general medical information.
www.medlineplus.gov

- To find out if there's a research study for your condition in your area, look at this list of many clinical trials organized by topic and area.
www.clinicaltrials.gov
- American Academy of Family Physicians presents general medical information on multiple topics.
www.familydoctor.org
- For cancer-related information, here are three credible resources:
 - National Comprehensive Cancer Network
www.nccn.org
 - National Cancer Institute
www.cancer.gov
 - Susan G. Komen for the Cure® focuses on breast cancer
www.komen.org
- Heart disease information can be found at the American Heart Association site.
www.americanheart.org
- Information on rare diseases can be especially hard to find, but this site provides reliable data.
www.rarediseases.org
- The National Institutes of Health presents information on complementary and alternative medicine on this site:
www.nccam.nih.gov

In addition to the Internet, medical textbooks can be a good source of information. They're usually unbiased, meaning that the information is presented objectively. However, textbooks are quickly out of date, so they're not a good source for the most current treatments. They can be found in hospital medical libraries, to which the public usually has access at no charge.

Good medical textbooks that can provide a wealth of information about your condition include:

- *Harrison's Principles of Internal Medicine*
- *Sabiston Textbook of Surgery*
- *Novak's Gynecology*
- *Williams Obstetrics*
- *MD Anderson Manual of Medical Oncology*
- *Physicians' Desk reference (PDR)* for drug information
- *Merck Manual of Diagnosis and Therapy*

Medical articles are a good source of more current information. They're not written for laypeople, but, if you're willing to work at locating and understanding articles that pertain to your condition, you can get good information. Most articles begin with an abstract, which is a summary of the article. Skim the abstract and, if the findings seem valuable to your specific needs for information, read the article

Articles are more likely to be biased than textbooks. If, for instance, you've found an article about a particular medication, check to see what the funding sources were for the study. Medical journal articles are also often narrowly focused on one aspect of a condition or treatment. Look for 'review' articles, which tend to include more aspects and often present the most reliable results from other articles.

Be especially wary of articles that present 'case reports.' These typically describe experiences and outcomes for one or two patients—you can't generalize from case reports to your own situation. Also be aware of the article's publication date. Cancer treatment articles from five years ago are already out of date.

What else should you be wary of when you're gathering information? Be skeptical about medical information presented by laypeople. Although other patients with similar diagnoses can be good for learning how to deal with an illness, getting support, and the like, take any data presented with a large grain of salt. Also be cautious about doctors who are recommending a product that they sell. Information from television, advertisements, or newspapers is often suspect, too. It's often presented in a biased way, to attract as many viewers, readers, or customers as possible.

Be aware of how information is presented. This can affect how you interpret the data. For instance, the statement that, "this treatment has a 75% chance of curing you and returning you to completely normal functioning," presents essentially the same information as, "25% of the people who try this therapy either are not helped at all and some may even be harmed." While these statements agree, they come across quite differently.

When evaluating a research study, be sure it applies to you. If the study subjects were all men over the age of 70 and you're a 40-year-old woman, the results might not apply to you. Statistics for stage III cancer don't apply to stage I disease.

Be aware of how the source of the information might bias what is being presented. Recommendations made by an insurance company sponsored website might be biased towards minimizing cost. A research study conducted or funded by a drug company may be biased towards showing that the drug works. Don't discount the information entirely if it seems like there might be bias involved. Just be aware that the findings might be slanted.

Don't expect to get perfect data, the numbers that point clearly to a particular decision. Just do the best you can. It's impossible to find data that resolves all the uncertainties. Accepting this will keep you from driving yourself crazy. You won't become an expert, but even getting imperfect information still helps you make better decisions.

Be willing to look at depressing information, in addition to numbers that make you feel hopeful. Looking at data that doesn't bode well for your health can be very hard, but you need balanced information to make a good decision. For instance, don't avoid realistic information because you found a small study showing that lemon juice cured cancer in one small group of people.

Use your doctors as a source of information, too. Ask questions—and keep asking until you understand. Push your doctors to give you real data, not just general impressions like one therapy is ‘more effective’ than another. Tell them it’s fine if they don’t know the numbers right off the top of their heads. Ask them to look it up for you or tell you where to look it up yourself.

Consider bringing someone with you to your doctor visits. When you’re stressed, it’s hard to remember what the doctor said. Your partner can make sure you get it right. If your doctor agrees, tape the visit so you can listen later. At the very least, your partner should write down everything your doctor says.

Get expert opinions

To get an expert opinion, find a doctor who has particular interest and experience in your condition. For instance, if you need breast surgery, consider seeing a breast surgeon, who only operates on breasts, rather than a general surgeon, who also does gallbladder and appendix operations.

To find an expert, start by asking your doctor and any other doctors you know which doctor in your town specializes in your condition. You can also search university hospital websites. Physicians often list their areas of special interest and experience under the ‘physician profiles’ section.

For cancer diagnoses, search the National Comprehensive Cancer Network website (www.nccn.org); it lists national experts. You can also use PubMed (see below) to look at research articles published about your condition in major journals (*New England Journal of Medicine*, *Journal of the American Medical Association*, *Archives of Internal Medicine*). Make a note of the authors’ names; they’re likely to be experts in the field. The articles often list the institution where the research was conducted, too. You can then use Google to locate them.

Identify the pros and cons of each option

No single option will be perfect. You’ll have to weigh the benefits and risks of each one. Work through your list of options, thinking of as many pros and cons for each choice as you can. Consider questions like these:

- How likely is this to work?
- What are the risks?
- How important are the risks to you? For instance, how difficult would it be for you to lose your hair or your sexual function? Judge the efficacy of the treatment against its impact on the quality of your life.
- What’s the worst thing that could happen if you make this choice?
- What’s the best thing that might come of out choosing this option?
- What good might come out of that choice?
- What else will happen if you choose this option? Take into account things like expense and inconvenience, recovery time, loss of daily functioning, and impact on family members.

Write the answers down for each choice even if you think you already know what to do.

Explore your beliefs & goals

Gathering data is only part of making health care decisions you can live with. You must also assess your emotions and fears and interpret the information you've gathered using your personal values and beliefs. The more your choices are in line with your beliefs, values, and needs, the more comfortable you'll be with them over the long run, despite all the uncertainties involved.

To understand how your beliefs, values, and needs interface with your illness, start by considering your overall goals. Do you want to live as long as possible or maintain a good quality of life? What determines good quality of life for you: being able to communicate with your loved ones? Enjoying a beautiful flower or the sunshine on the grass? Being as pain-free as possible?

As you consider your beliefs, you may become aware of fears. Are you terrified of major surgery, because you're convinced that you wouldn't survive it? Then maybe a less invasive procedure, if one is available, would be better for you. You also have to balance your beliefs with medical science. You may believe that chemotherapy is poison, but, if it's likely to be your best option, don't discount it. Taking a clear-eyed look at your beliefs and fears will support your decision-making process.

Assess your values, too. What is most important to you? Knowing what your values are helps you make the choice that is right for **you**. The next page is a values assessment exercise that can help make your priorities clearer.

When you've completed this values clarification tool, write in your notebook or a journal about it. Write down each value that's important to you, then make a list of which types of options seem to best support that value. This might look something like the following example:

FAMILY

Because of my young children, I want to choose whichever treatment has the best chance of cure, even if I feel terrible while I'm getting it.

Or....

INDEPENDENCE

Because I live alone and have to care for myself, I don't want to choose a treatment with a significant chance of leaving me disabled.

Values Assessment

Circle the 5 values that are most important to you

Helping others	Inner peace
Having an impact on the world	Humor
Connecting with others	Independence/autonomy
Honesty	Life balance
Loyalty	Personal growth
Love	Logical thinking
Trust	Concern for the environment
Belonging/being accepted	Beauty
Relationships	Trust in God
Sex	Having time for yourself
Being part of a community	Having new experiences/discovery
Friendships	Achievement/accomplishment
Family	Recognition for accomplishments
Mastery/excellence	Competition
Financial security/prosperity	Love of nature
Power	Creativity/imagination
Being responsible & reliable	Stability
Social justice	Vitality
Expressing your feelings	Searching
Refinement/elegance	Inspiration
Visiting new places	Creating
Innovating	Being the best
Belief in a higher power	Excitement & adventure
Safety	Privacy
Having a relationship with God	Self expression
Serenity	Wisdom/knowledge
Feeling in control	Having fun/pleasure
Improving yourself	Traveling
Keeping things the same as they are	Avoiding risk
Taking risks	Learning new skills

The final piece of considering your beliefs, values, and needs is to examine the meaning of your illness in your individual circumstances. Do your symptoms make your life unmanageable? You may be willing to accept more risk. For instance, a math professor might accept a hand tremor and be unwilling to risk the side effects of a medication, while a surgeon might find the tremor completely unacceptable. What symptoms would make your life unmanageable? Are there treatments that reduce the risk of these occurring?

Eliminate totally unacceptable choices

After exploring the pros and cons of each available option and assessing your goals, values, and needs, eliminate any totally unacceptable choices. For instance, if 'no treatment' is not acceptable to you, eliminate it from your list.

Incorporate the wisdom of others

Dealing with medical issues is lonely, because illness isolates us. Reach out to other people as you make decisions about your health care. In addition to asking for your doctors' input, ask for the counsel of other people whom you respect. Be aware that it's hard to be objective about yourself, especially when you're under stress. Very close family members may also have trouble evaluating the situation objectively

Ask friends/family who know you well but are slightly removed. These might include close friends, cousins, and the like. Give them the pros and cons of the choices you're considering and then record their thoughts in your journal. Go beyond asking, "What would you do?" to include "What are your thoughts about the situation?"

Consider asking others who you think of as wise: pastor, rabbi, or professor. Again, ask, "What are your thoughts about this?" not just, "What do you think I should do?"

Record their thoughts in your information notebook or ask them to do it for you.

Reassess the pros and cons of the remaining choices

Once you've educated yourself and mulled over the options, sometimes taking a break from thinking about it will allow a new insight to present itself. Think about something else for a few hours or days. As much as you can, drop the burden of needing to make tough decisions.

When you return to the process, use your imagination to help you decide. Look at your list of all the possible results of each choice, including no treatment, and actively imagine each outcome. This will be hard and scary, but imagine living with one breast if you decide to have a mastectomy without reconstruction or imagine your cancer progressing if you decide not to pursue chemotherapy.

You can't know which complications will occur, of course, but imagining the worst-case scenario of each choice can help you eliminate options that would be totally unacceptable to you. Some people want to prolong their lives at all costs, while others are willing to sacrifice longevity for quality of life. And quality of life means different things for

different people. For some, losing a limb would be totally unacceptable. For others, the loss of a limb would be tolerable if it prolonged life.

Review your information notebook and answer the following questions in writing:

- What am I most afraid of?
- What is the worst thing that could happen to me?
- What questions do I still have about my disease or its treatment?
- What qualities do I have that will help me get through this?"
- What qualities do I have that will make this challenging for me?

Also write down any other thoughts or feelings you have about your illness or your treatment choices. Reviewing these may give you some insight about yourself that can help with making your decision.

Two final caveats: don't assume that the most aggressive treatment is necessarily the best choice and don't be unduly swayed by inconvenience. Illness is always inconvenient. Don't accept an inferior option just to avoid driving to a farther hospital or enduring more frequent treatments

Take a leap of faith

You can only control the decision, not the outcome. You don't have a crystal ball so you simply can't possibly know what the future will bring. You must do your best with the information that you have. At some point, you just have to rely on the awareness that you've done all you could to gather information, make sense of it, and assess your values, goals, and needs.

You have to just make a choice.

There is no 'right' decision. There's just the decision that seems best under the circumstances. If two choices are equally compelling, then either one is an acceptable path. Trust that you'll have the strength to deal with whatever your decision brings.

For more information, read *Port in the storm. How to make a medical decision and live to tell about it* by Cole A Giller, M.D. Ph.D.

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