

What You Don't Know Can Hurt You

A Guide for Patients



Help for Navigating Medical Information & Making Informed Decisions



Summary of Appendix A: The Patient Guide—Helping You Prepare for and Participate in Your Medical Information Journeys & Medical Encounters

A1: Medical Information Principles for Caring for Yourself as a Patient: A Few Core Concepts

1. **Good information increases the likelihood of good decisions.** You should be provided with **reliable health care information** when it exists. For medical interventions, with some exceptions, this should be based on **reliable science**. If recommendations for interventions are not based on quality science, you should be informed of this. You may need to ask.
2. Ask about all **alternatives** available to you. The compass for you to use are these questions—**"What is the likelihood of benefit and harm for me for each of my options—including doing nothing? What are other potential impacts including cost?"** Ask yourself how you weigh the benefits against the risks and other potential impacts.
3. **At times, you will want to ask for details about the quality of the evidence.** This involves how well the studies were done, how many studies have been done, how consistent the results are and how large the benefits and risks are. You also want to know if the patients studied were similar to you or not, because that could affect whether you can expect similar outcomes.
4. If you sense that your doctor doesn't know enough about the evidence, **be careful about accepting recommendations.** Opinions are frequently not informed by good information. At times you will need to put on the brakes and tell your physician that you need some time to "think it over."
5. You may decide to check with other people or check other sources. However, keep in mind that **much advice about health care interventions does not come from valid sources**—even if they have good reputations or the best of intentions.
6. You should be able to **understand** health care information (options, benefits and risks, cost and other impacts) without difficulty. This information should include **meaningful** and understandable **quantified**

information using natural frequencies for each studied group (potentially converted into number out of a hundred) to help you ascertain the likelihood of benefit and likelihood of risk of harm.

7. You need to **know all the steps** to take in order to apply the information—meaning, the steps you must take to obtain the care you have decided upon.
8. Sometimes you need to put a halt to forward movement and state, "**Please, to make a decision, I need a little more information...**" And sometimes best action is no action.

A2: A Summary of What I Need to Know for My Medical Information Journeys

- A. Generally with health care decisions, **I have choices**.
- B. Here are some **questions** to help me in both short and more detailed form.

The 7 General Questions Patients Want Answered = a selection of questions that patients typically want answered include—

- 1) **What**: What disease or condition do I have or what might I get?
- 2) **Why**: Why do I have it? How did I get it? Or how might I get it?
- 3) **Impact**: What might it do to me?
- 4) **Uncertainty**: What is known and unknown about it? How certain are we that I will experience an outcome?
- 5) **Choices**: What choices do I have? How will each choice affect me, including if I do nothing? Is there high quality scientific evidence available to help answer this question? If yes, I need quantified information (e.g., natural frequencies such as number out of a hundred in studied groups) about the likelihood of experiencing various outcomes so that I can weigh potential benefits versus harms. I also need to know if the patients studied were similar to me or not. If they are very different from me, I might need more information about the likelihood of benefits and harms in my case. What are the costs or other potential impacts to me of each choice? What can I expect downstream?

For a screening or diagnostic medical test, why should I have the test? If it makes sense to have it, I want to know if the test is 1) likely to be accurate, such as how likely it is to result in a false negative or a false positive outcome; 2) whether the test itself can harm me; and, 3) what might happen as a result of a test outcome—such as the need to make a decision about a treatment which will also have potential benefits and harms. I also need to know what choices are available to me as a result of the test, such as further treatments, and the likelihood of benefit or harm of those choices—which I want to know before testing. If it is a screening or diagnostic test for something for which there is no treatment or help or if there is no evidence that early detection or diagnosis results in better outcomes than later diagnosis, it may be very reasonable to decline the test.

- 6) **Advice**: What is my doctor's or other health care professional's advice? And why? What would they do? What would they do if they were a person similar to me?

- 7) **Steps:** What details do I need to know to accomplish my choice? What else should I know down the road?
- C. I need to be aware of what it means to be "**clinically useful information.**" Outcomes of importance to a patient are morbidity, mortality, symptom relief, functioning and quality of life, which are called "**clinical outcomes.**" Size of the outcomes (the difference in outcomes between the studied groups) is also important for my decision-making. These results should be provided to me in **raw numbers (natural frequencies such as number out of a hundred)** of patients experiencing each important outcome compared to those who did not, in each of the groups studied.
- D. I should be wary of outcomes that are not one of the five clinical outcomes, but which are called **proxy outcomes** (or intermediate markers, surrogate markers, etc.), unless there is reliable proof of evidence of benefit in one of these five clinical outcome areas.
- E. I should be leery of results that are not provided in **natural frequencies.** Without this information, I might make a different decision if I only know absolute measures. I may be very misled by only knowing relative measures.
- F. I need to be aware that **safety** is often unknown.
- G. I want to be aware that my medical decisions should be based on my **personal patient requirements.** These consist of my health care problems + my own special circumstances + my values + my preferences > *inform* my health care needs + wants.
- H. I need to be aware of making my decision, weighing all factors—**benefit to harm ratio** and **other considerations** that may affect me.
- I. I need to be aware of **potential problems** in the way of my getting reliable information and patient-centered care along with flags that problems might be happening. It is advised that I **be realistic** about this. Given, the realities, this advice is a suggestion only which might improve my chances of getting best care that is right for me. However, I may need to put pressure on my care providers and on the system if that is in my best interests. How can I prepare for this?
- J. I need to be aware that physicians are often limited in helping patients engage in medical decisions including **frequent communication limitations** and **underestimating patient acceptance of risk.** How can I prepare for this given my particular needs?
- K. Is **how I relate to information** helping or harming me? I need to be mindful that I can be very influenced by how information is communicated to me and my engagement. I need to be ever mindful of the **need for valid and clinically useful information** so that the communication and engagement influences do not lead me astray.

Ultimately, I need information and I need to make an assessment of the information I receive. Do I feel I am **receiving information** that I need and is it **accessible at the time** that I need it? Does the information seem **accurate**?* Does the information seem **complete**? Do I **understand** it? Does the information **fit** my personal requirements (see above)? Can I **apply** or **act** on it? Is a failure of **communication** and/or **engagement** affecting my ability to make a decision? If the answer to any of these questions is no, what can I do to improve things?

* See **Appendices D, E and F** in the book for more suggestions about this.

A3: Practical Tips for Preparing for and Participating in Your Medical Encounter

1. Use all three sections of this **Appendix A: The Patient Guide** to prepare for your medical encounter. If you are going to bring **printed copies of anything, bring two copies**, and ensure you have room to make notes.
2. **Decision support** that you seek out may be useful—remember that it is important that it is likely to be reliable.
3. If it will help you, request permission to have a **friend or loved one present or to record the encounter**.
4. Remember that you are a **customer of a business**—though it may not feel like that.
5. Be aware of the **ideal encounter format** and how you might change encounters gone wrong:
Stages of the Medical Encounter
1. Greeting; 2. Medical Interview—Listening and Inquire & Exchange Information; 3. Discussion (Determine & Decide); and, 4. Closure.

If you feel uncomfortable or believe that **communications and connectedness are not going well**, remember this key question: "Are failures of communication and/or engagement affecting my ability to make the health care decision that is best for me, and if so, what can I do about it?"

If you feel you have more information to share, feel free to state: "I have a bit more that I need to share with you before you do an exam or before we talk about my options."

Feel free to ask for more information. You might say, "Can you please tell me a little more? I'd like to know..."; "Before I make a decision, I'd like more information about alternatives and the quality of the science behind each choice for benefits and harms, and I'd like to know about costs and other impacts to me."; "I have a list of questions."; "Can you help me?", etc.

Try to ensure you understand the information shared with you. You might say, "Let me see if I understand this correctly." Or, "So are you saying that I have developed a [condition] and that means that I can expect...?"

If you feel that you have **not been heard** or are **not ready to make a decision**, express that you need to put on the brakes and slow down.

If you feel that **your care is not patient-centered**, ask yourself how you can shift the encounter to place you in the center. Sometimes it is sufficient to express your feelings about this and use the term "patient-centered care." Sometimes simply using this term can be useful, such as, "For my care to be patient-centered, I would like..."

6. **Watch out for flags** in the exam room: "*I have experience...*" or "*We've gotten good results...*" Sometimes yes, and studies show sometimes no.
7. If you will be asking for a lot of information that your doctor needs to investigate, **indicate your understanding that this may take some time** and need to be handled in a follow-up appointment.

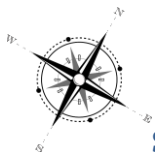
8. There are **three decision-making options** available to you: 1) shared, in collaboration with your care provider; 2) independent; or 3) physician-directed. In most cases, you should have a choice of your preference. If you wish your physician to make a decision on your behalf, help him or her understand your personal requirements to help your clinician make the best choice for you. And we would recommend asking the reasons for his or her opinion.

Some phrases that may help you: "Well, maybe we can discuss this a little more. I'd like us to share in the decision-making. I want to make sure I am making the right decision for me."

"I appreciate your advice and recommendations. I need some time to think about this, and then I will let you know my decision, and we can talk about next steps."

"What option would you choose and why? What would you choose if you were a person similar to me?"

9. If you feel that you need **another opinion**—or even **another care provider**—you should not hesitate to act on this.
10. If you anticipate that you will feel shy about expressing your feelings, it can be **useful to practice** a little script or to write down what you want to convey.



Summary of Appendix B: Supplement to The Patient Guide—More Details and Suggestions About General Questions For Which Patients Need Answers

In preparation for your medical visit, you may wish to elaborate on the general questions we have provided to you. Here is a sampler for some more questions. This list is not intended to be complete, but only to generate some ideas of your own. (If you research any of these questions in advance, you will want to note your sources of information.)

1. What do I have or what might I get?

- If this is for screening in an attempt to find a disease at an early stage—meaning that I do not currently have symptoms or any obvious indications of a condition or disease—should I have this screening test?
 - 1) How likely is this test to result in a false negative or a false positive outcome? 2) Can the test harm me? and, 3) What might happen as a result of a test outcome—such as the need to make a decision about a treatment which will also have potential benefits and harms? 4) Is there good evidence that early diagnosis results in better outcomes than later diagnosis? As with other therapeutic interventions, I also need to know what choices are available to me as a result of the test and the likelihood of benefit or harm of those choices.
- If I have been given a diagnosis, how certain is this diagnosis?
- What observations or tests were done to make the diagnosis?
 - Test 1
 - Result?
 - Reliability?
 - Test 2 (etc.)
- Do I need additional tests?

Additional Test 1

- What is the test?
- What is involved?
- What is the reliability?
- Will the diagnosis be more certain?
- What are the potential risks?
- What will it cost / insurance coverage?
- How might it affect me?
- Et cetera...

Additional Test 2 (etc.)

- What do I need to do?
 - Now (e.g., am I contagious?)
 - Short term (e.g., more tests?)
 - Longer term (e.g., life style changes?)
 - Et cetera (assume etc., after all questions in this section as this is just to be a sampler of some ideas...)
 - Anything I should be on the alert for?
 - What is a normal course of timing?

2. Why do I have it? / How did I get it? / Or how might I get it?

- Genetics, exposure (viral, food-borne bacteria), lifestyle etc.
- Is there agreement between information sources that are likely to be reliable?

3. What might it do to me?

- If I do nothing—
 - Will it go away on its own?
 - How long would that take?
 - Will it get worse?
 - How bad will it get?
 - How will it affect my life?
 - How will it affect those around me?

4. What is known and unknown about it? How certain are you that I will experience an outcome?

- How certain is this information you are now providing?
- Where can I learn more about it / keep up on new information?

5. What choices do I have?

- What are my treatment options?

Option 1

- What is the option (e.g., medication)?
- What is involved?
- What can I expect to gain (e.g., will the problem go completely away)?
- What is the evidence/reliability?
- How will this outcome affect my lifestyle?
- How will this outcome affect those around me?
- What are the risks?
- What are the costs (insurance coverage)?

Option 2 (etc.)

6. What is my doctor's (or other health care professional's) advice? And why?

- What is the advice?
- Why is that the advice?
- Does it fit with my priorities?
- ***Is this MY choice?***

7. What details do I need to know to get this done?

- ***Are you certain in your choice of options?***
- How do I make arrangements for this option?
- What will I need to do?
- What will my doctor do?
- What other doctors / professionals will be involved?
 - How can I contact them to discuss your case?
- Are there insurance issues (coverage, notification, referral or network needs)?
- How long will treatment last?
- How long will recovery / rehab last?
- Where will all of this take place?
- What kind of transportation assistance will I need?
- What kind of home support will I need?
- What other questions do I have?
- What are the final comments from your health care professional before proceeding?

And more...