

Questions to Ask from *The Caregiver's Path*

Medical Questions

Time:

- Is this an emergency, or is there time to think about what should be done?
- If it is not an emergency, how long do we have to make a decision?

Diagnosis or condition:

- What do you call what the patient has?
- How bad is the patient's condition?
- How many other things are going wrong with the patient's body?
- Are those other things fixable?

Available treatment options:

- Is this the first time I have had to make decisions about this illness or condition, or has it been going on a long time?
- What worked in the past?
- Is that still an available option?
- What are the other available options?
- What is the proposed treatment, surgery or test?
- Who will perform the treatment, surgery or test?
- How realistic is it that the proposed plan will work?
- Is the proposed treatment standard or is it experimental?
- How many times has the doctor done this procedure?
- What is the doctor's success rate?
- What has the doctor's success rate been with patients in a similar condition?
- Is there anything I can do to increase my loved one's chances of a good outcome?

Alternatives:

- What alternatives are available?
- What will happen if nothing is done?
- What will happen if we wait until later?
- Why now and not later?

Possible side effects:

- What are the possible risks and side effects?
- How often do the side effects really occur?
- What steps will be taken to minimize the risks of the treatment?

Suffering:

- How much is my loved one suffering now?
- How much will the patient suffer if he or she *does not* have this treatment?
- How much will the patient suffer if he or she *does* have this treatment?
- What can be done to prevent or decrease the suffering?

Benefits of the treatment:

- Will the treatment help the person regain or improve his or her mental function?
- Will the treatment help the person regain or improve his or her physical function?
- Do the benefits of the treatment outweigh the risks and burdens?
- Will the proposed treatment extend the patient's life, and for how long?
- What is the patient's life expectancy without the treatment?
- Will the proposed treatment improve the quality of the patient's life or only increase the length of life?

The patient's perspective:

- Would the patient want to have this treatment, surgery or test?
- Does this treatment plan fit in with the patient's quality-of-life goals?
- Does this treatment make sense in the context of this particular patient's life?
- What kind of condition will the patient be in afterward?
- What kind of life will the patient have after he or she is discharged from the hospital?

Other concerns:

- What do I *not* want to believe about what the doctor is saying?
- What do the different doctors say that is conflicting?
- Can I ask for a family conference so the doctors can explain why they disagree with each other?
- What am I confused about, and what questions do I need answered before I can decide?
- Do I need to get a second opinion to get more options or information?
- Am I reading information on the Internet from trusted sources? (If not, you need to ask the doctor which sites are recommended.)
- What do other people ask in this situation?
- What else am I forgetting to ask?

Possible restrictions:

- Are there hospital restrictions that limit what options are available here (religious restrictions, location restrictions, equipment restrictions, technical ability restrictions or the availability of specialists)?
- Are there laws that I need to be aware of in this situation? (Ask a social worker if there are any laws in your state that limit what a decision maker is allowed to agree to for the patient.)

Quality-of-Life Questions

Changes in quality of life:

- Based on the patient's quality of life before this hospitalization or treatment, how has the patient's quality of life changed?
- Is this change in quality of life something that the patient would be willing to live with?
- What would the patient say is an acceptable level of "better"?
- If I don't know, can I find out more about the patient?
- Will the patient be able to return to the same caregivers, friends and family?
- Will the patient be able to return to the same environment?
- If not, how can we help the patient adjust to a new environment?
- Will the patient be able to enjoy his or her meals as before?
- Will the patient be able to enjoy the same activities as before?

If the patient could communicate in the past:

- What would this individual consider to be a meaningful life?
- What kind of life would the patient want after being discharged from the hospital?
- What would the patient say if he or she could talk right now?
- What did the patient say to others in the past about the type of situation he or she is facing?
- What would the patient say is important to consider?
- What would I want, and how is that different from what the patient would want?

The quality-of-life goal and the medical goal:

- Now that we know the quality-of-life goal, can it be achieved medically?
- Is a time-limited trial appropriate to see if the quality-of-life goal and the medical goal can be reached?
- If the quality-of-life goal is not achievable, what level of recovery is possible?

Financial Questions

Patient finances:

- Does the patient have enough money to pay the doctors, the hospital, the X-ray department, the laboratory and the other medical bills?
- If not, can the patient get the money or is this impossible?
- Can the patient afford the medications both now and for the long term?

Cost of treatment:

- Can I get an estimate of the costs before I decide?
- Does this estimate include everything, or are there costs I don't know about?
- Who else will be sending me a bill?
- What will the long-term costs be after the patient gets discharged from the hospital?
- Will the patient have to go to a rehabilitation facility, a long-term care facility or sub-acute facility? If so, how much will that cost and who will pay for it?

Insurance coverage:

- Does the insurance company cover the proposed test, treatment or surgery? (Any time a person goes to get medical care, call right away to make sure the insurance company will approve and pay for the visit.)
- What will the insurance company pay for? (When you call the insurance company, make sure you write down whom you talked to, what was said, and what time you called. Ask the person to send you the information in writing.)
- What percentage of the bill is the patient's responsibility?
- Do I need to call the insurance company to get a pre-authorization for the test, treatment or surgery?
- If the insurance company says it will not pay, can I appeal the decision?
- What will happen if the patient has the treatment but I didn't get a pre-authorization from the insurance company?

Financial distress:

- Is it cheaper to go somewhere else for the test, treatment or surgery?
- If the patient doesn't have any insurance, are there any programs that he or she may be eligible

for that can help cover the costs?

- Have I talked to the billing department to see what other options are available? (It is better to talk to the billing department right away, because they will be more willing to help you before you get into financial trouble. You may need to ask for the supervisor of the billing department to get the help you need.)
- Does the patient need to apply for Medicaid or MediCal because he or she is out of money?
- What will happen if the patient can't pay the bills?
- How will all of these costs affect the patient's family?
- Is the patient going to need to declare bankruptcy?

Religious or Spiritual Questions

The patient's religious beliefs:

- What is the patient's faith or belief system? (It may be a traditional religion, a personal spiritual connection or no religion.)
- Is the patient actively practicing his or her religion or spirituality?
- Are the doctors aware of the patient's beliefs? If not, what do I need to tell the doctors?
- Does the patient's belief system play a role in his or her other life decisions?

Religion and healthcare:

- Does the patient's belief system play a role in his or her healthcare decisions?
- What does the religion say about the obligation to keep fighting?
- Does the patient's religion say what can and cannot be chosen when it comes to healthcare decisions?
- Does the patient's religion have rules about how the body can be treated?
- Are there certain fasting or food restrictions in the religion?
- Do I need to ask questions about what services may or may not be provided at a religiously affiliated hospital or clinic?

Religious community:

- Can the religious community provide comfort and support for the patient?
- Do I need to call in the patient's religious leader to help make these decisions?

Religion and death and dying:

- What gives the patient's life meaning or purpose?
- What does the patient's religion say about death and dying?
- Does the patient's religion have certain rituals or prayers that are part of the healing or dying process?
- Before the patient dies, should certain things be done in preparation, either spiritually or physically?
- After the patient dies, should certain things be done to prepare and respect the body?
- Is there a hospital chaplain that I can turn to for help?

No religious beliefs:

- How can I show this person respect without using religion?
- How can this person be comforted while dying, without using religion?
- What values and personal beliefs of the patient can guide me when making these decisions?

Religious beliefs of the decision maker:

- When I am making decisions for the patient, how does my religion affect my decision making?
- Am I remembering to respect the beliefs of the patient and to not impose my own religious beliefs? (It is your responsibility to make sure that others involved in the person's care are not imposing their own religious beliefs on the decision making process.)

Cultural Questions

The culture of the patient:

- How much does the patient follow the rules of his or her culture?
- What would the patient say about his or her cultural values and how they would apply in this situation?
- What is the patient's view of the illness in the context of his or her life?
- How would a doctor from the patient's culture handle this situation?
- How would a doctor from the patient's country handle this situation?
- Are there fears, concerns or misperceptions about the proposed treatments because of cultural beliefs?
- Does the patient want to be told the truth about the illness or would the person rather not know?

Choosing the decision maker:

- What does the culture say about who should be the decision maker?
- Should the decision maker be one person or a group of people?

Family involvement:

- What does the patient or the family say would help in this situation?
- Are there community resources available to help the patient when he or she is discharged?

Alternative medicine and healers:

- Is the patient going to a healer, herbalist, spiritual healer or other person for help?
- Do you need to call in a healer or someone to pray?
- Does the patient trust Western medicine?
- Does the patient want to receive the medicines or alternative medications that are used in the patient's country or culture?
- Is the patient taking alternative medications?
- Do I need to tell the doctor the truth about the alternative medications or treatments the patient is receiving outside the doctor's care? (I would recommend telling the truth so your doctor can keep your loved one safe from any side effects of combining what your loved one is taking and what the doctor is prescribing.)

Culture and healthcare:

- Are there certain things the patient can do or not do to get better because of the rules in the culture?
- Are there certain things the patient can eat or not eat to get better?
- Does the patient typically show pain, or does this individual prefer to be brave and accept suffering?
- Are there gender restrictions on who can take care of or touch the patient? If so, what would be okay?

- How would this person want to be shown respect?

Language barriers:

- Does this person speak the same language as the healthcare team, or should a trained medical interpreter be used?
- Are the forms and written information available in the patient's language?
- Can the patient read the forms and the written information about the disease and treatment options?

Culture and death and dying:

- Are there cultural healing or dying rituals that need to be performed?
- After the person's death, are there rituals that need to be performed or are there certain ways that the body needs to be treated?

The decision maker's cultural beliefs:

- When I am making decisions for the patient, how does my culture affect my decision making?
- Am I remembering to use the culture of the patient and to not impose my own cultural beliefs?
- What else do I need to understand about this person's culture so that I can make good decisions?