



THE CARE PARTNER PROJECT™

How to Get the Care You Want
for the People You Love

CHECKLIST

GET THE RIGHT DIAGNOSIS & KNOW ALL TREATMENT CHOICES

Little known fact: up to 40% of diagnoses are wrong. That's why it's so important to ask a lot of questions and see at least 2 doctors for information and ideas about symptoms, condition and treatment choices.

Getting the right diagnosis is often like solving a mystery, and it's really up to the patient and their Care Partner to dig for clues and answers. It can take lots of doctor visits and lots of research, but it's worth the time and effort.

Patients often worry that they will offend their main doctors if they get second or third opinions. Or they worry that, by consulting with other doctors, they are being "unfaithful" to their main doctor. Both of these concerns are common and understandable, but here's the truth: good doctors encourage their patients to collect as much information as they can—they know from experience, the more information, the better any health care decisions. So please don't give up! (And if your doctor is not on board with your getting different opinions, maybe it's time to give up on that doctor!)

The questions on the following pages cover important topics when talking to doctors. No doubt, you will have others. Be sure to ask the same questions for

every doctor so you can compare "apples to apples." Good doctors will support your efforts to get opinions from other doctors. Good doctors do not make decisions for their patients—and they don't push them into snap decisions, either.

Once everyone is comfortable with the diagnosis and treatment plan, the doctor and hospital provide a legal document called the Informed consent to treat. The language is not user-friendly so be prepared to slog through it. It's OK to ask someone at the hospital or doctor's office to translate it into plain words.

Make sure your special wishes are included in the Informed Consent paperwork. For example, if a certain anesthesia, or surgeon is preferred, make sure these details are shown in the Informed Consent. If not, the patient (or legal guardian for care) can write in changes, then initial and date each change noted. It's a good idea to talk about these changes with the medical team just be doubly sure everyone is "on the same page" about treatment and care.

This is a lot to handle, isn't it? That's just another reason why family members and friends are so valuable as your Care Partners!



DIAGNOSIS QUESTIONS TO ASK

- What does my diagnosis mean? (What is my problem? What do I have?)
 - Ask for the “medical name”, and then for a “regular way” to describe it.

(Note: you can use both to dig for info on the Internet later, or in conversations with other doctors when you get a 2nd opinion.)
 - What else could it be?
 - Anything else?
- How serious is this condition? On a 1-5 scale with “1” being “No worries, easy to treat/cure/live with” and a “5” meaning it’s life threatening and must be treated immediately.”
 - Why? What is your reasoning?
- How would you treat me for this condition?
- What other ways are used to treat this condition?
- What are the benefits of each way to treat this condition?
- What are the risks or complications for each way to treat my condition?
 - How common are the risks and complications?
 - What are the immediate, medium-term, and long-term side effects?
- Are there other discomforts associated with the treatments?
 - Are these permanent or temporary?
 - How can these discomforts be treated?
- How long will treatment last?
- How long before I can get back to my normal activities?

- What is my short-term outlook post-surgery? Are there long-term concerns or effects of this condition and treatment?
- What are my costs?

IF SURGERY IS RECOMMENDED, FIND THE RIGHT DOCTOR

- What is the name of the surgery? (Medical name and “regular” or common name)
- How many of these surgeries have you personally done? Don’t settle for any fewer than “hundreds,” but ideally, “thousands.”
- What are alternatives to surgery? What are some other choices?
 - What are the benefits and risks to all possible choices?
 - What are the chances for success for each choice? (What do you consider “success”?)

Be sure to share what you consider success, taking into account your lifestyle, personal goals, and anything else that would affect your long-term physical well-being and peace of mind.
 - What are the chances for risk, complications or poor results for each choice? What are the realistic risks vs. rewards?
- Who would actually perform my operation?
 - Who would assist? How many surgeries of this type have they performed?
 - Would student/s/residents be present? What would student/resident do in my surgery?
- Do you use a surgical checklist in the operating room?



- What is your infection rate for this kind of surgery?
 - Do you recommend showering and or shampooing with Hibiclens (similar) prior to surgery? If so, for how long? If not, why not?
 - Do you prescribe a prophylactic antibiotic prior to surgery? If not taken in advance of admission, would I get at admission or just prior to surgery?
 - Will I get a pre-op MRSA test? (If “No”, will you order?)
- Do you lead a “time out” for everyone on the surgery team to introduce themselves?
- Will you provide me with all Informed Consent papers so I can study them and make sure everything we’ve discussed is covered?
 - Append your notes and agreements with your doctor to your Informed Consent.

**IF YOU DECIDE ON SURGERY,
KNOW WHAT TO EXPECT**

- How long will the surgery take?
- What kind of anesthesia will be used?
 - Are there other kinds of anesthesia to consider?
 - If so, what are the positives and negatives of each type?
- How much pain can I expect?
 - When will I have it?
 - What will you use to help control my pain?
 - Any alternatives pain management resources to consider? (I.e. other meds, biofeedback)
 - Will pain management be self-administered via IV that I control—or by prescription and given by nurses?

- Do I have a choice? (Note: studies show that, when patients self manage, they take lower doses of pain meds than are typically prescribed.)
- How long will I be in recovery?
 - How will I be monitored after the surgery? For how long?
 - May I have a family member sit with me in the recovery area?
 - Will I get supplemental oxygen after surgery? Why? Why not? What is the standard of care?
- How long will I be in the hospital?
 - What are the signs of recovery?
 - How will we know when I’m ready to go home?
 - May I have a family member stay with me 24/7?
 - What are sleeping provisions for my family member who stays with me?
- Where will I go after leaving the hospital? Home? Rehab? Assisted Living? Other?
- What care will I need after leaving the hospital?
 - Medications?
 - Therapies? (I.e. Physical therapy, Occupational therapy)
 - Wound care?
 - Daily living support?
 - In-home nursingcare?
 - Other:
- Will I need to make any changes to my
 - Diet? What can I eat? What should I not eat? Why? For how long?
 - Lifestyle? Changes to plan for/accommodate? Why? For how long?



QUICK TIPS

- Look up ratings for hospitals. It's a good idea to check all three.
 - Hospital Safety Score
 - Hospital Compare
 - Consumer Reports
- The safest time to schedule surgeries is mid-week during a "regular" business week—not around or near holidays, which is when senior hospital staff tends to take vacation time.
- Doctors who have performed thousands of your planned surgery, use checklists and take a "time out" to make sure the surgery team knows one another, tend to have the best results.
- In general, it's a good idea to call the insurance provider to learn as much as possible about the cost of care and your estimated share.
- Find out if all the doctors, therapists and others care providers—as well as all hospital services — are covered by your insurance. Ask if they are "in network" or "out of network".
 - You always have the choice to select other care providers who are in your network
 - You can also appeal to the insurance company to cover an out-of-network doctor you've chosen on an in-network basis -- especially if this doctor a special expert on your condition or treatment.

Be prepared to take your appeal up the chain of command with your insurance company, if necessary.

- From your doctor, get a list of medicines likely to be given in the hospital or prescribed for recovery after going home – again, find out if your insurance covers them. If not, ask the doctor to help figure out alternatives or other ways to cover the costs. Some drug manufacturers offer discounts to patients in special situations.

- If you do not have insurance, let your doctors and the hospital know. They will do their best to help you get the care you need.

REMEMBER

- There are a lot of details to cover! Patients need a Care Partner with them at every appointment to take notes or record conversations (most cell phones have this feature). Informed and proactive Care Partners are a must for every hospital treatment—whether an Emergency Room visit, outpatient surgery or inpatient care.
- To help doctor visits go more quickly, print this list of questions and bring them so everyone will literally be "on the same page"—a great way to start the conversation!
- Talk to as many doctors as needed to feel comfortable with a treatment plan and surgeon that feels right.
- Still having trouble understanding your condition and treatment options? That's common! Health care is complicated so don't hesitate to ask your doctors for more of their time and help. You may want to consider talking to a professional patient advocate, too.
- It's OK for patients to refuse treatment at any time, for any reason. . . even up until the last minute.