

FINDING A SPECIALIST OR TREATMENT CENTER

HOW TO:

- Find a Specialist in Crohn's Disease and Ulcerative Colitis
- Choose a Treatment Facility
- Communicate with Your Doctor

You've been diagnosed with ulcerative colitis or Crohn's disease. Learning all that you can about your condition and understanding your options and prospects will help you navigate the healthcare decision-making process. This fact sheet is intended to serve as a useful tool as you seek, find, and evaluate resources in light of your individual needs and circumstances.

An initial step is to find a qualified gastroenterologist who is experienced in treating people with Crohn's disease or ulcerative colitis, the two main types of inflammatory bowel disease (IBD).

Another important step is choosing a treatment facility. Although people with mild forms of Crohn's or colitis may never need to seek hospital-based care, others will go through periods when medical or even surgical treatment is necessary. That is why it's preferable to choose a hospital *before* a flare-up occurs.

Finally, you can become your own best advocate. To gain the greatest benefit from the resources available to you, don't hesitate to ask questions and express your ideas, opinions, hopes, fears, and doubts at every step—and listen carefully in turn to what your doctor and other members of your healthcare team have to say. Ultimately, gathering information and staying informed will help you make the decisions that work best for *you*.

FINDING A SPECIALTIST IN CROHN'S DISEASE AND ULCERATIVE COLITIS

As you begin your search, start with your primary care physician (PCP). Normally, he or she will refer you to a *gastroenterologist*, sometimes called a "GI" for short. A gastroenterologist specializes in the treatment of people with disorders of the stomach or intestines. If you're under 18, you'll likely be referred to a *pediatric gastroenterologist*, a specialist in digestive diseases affecting children and adolescents.

If you require surgery, your PCP will send you to a *colorectal surgeon*, a surgeon who specializes in surgical procedures involving the rectum or colon (large intestine).

Another important step is to check with your insurance company to find out about GIs who practice within your network. Once you've gathered their names and contact information, you can ask your PCP about them, look them up online, or check print directories for detailed information regarding their education, qualifications, and sub-specialties. In particular, you'll want to find out whether they are experienced in treating people with Crohn's disease and ulcerative colitis.

If you have Internet access, you can begin your research by consulting the following Web sites:

The American College of Gastroenterology
<http://www.acg.gi.org/>

The North American Society for Pediatric Gastroenterology
<http://www.naspghan.org/>

The American Society of Colon & Rectal Surgeons
<http://www.fascrs.org/>

The American Gastroenterological Association
<http://www.gastro.org/>

During your search, keep the following questions in mind:

- Where was the doctor educated?
- Is the doctor Board certified?
- What professional associations does he or she belong to?
- How many IBD patients does the doctor see over the course of a year?
- How long has the doctor been in practice?
- Is the doctor affiliated with a particular hospital?
- Does the doctor accept your insurance?

Once you've narrowed down your search to two or three doctors, the following questions can help you determine the best fit:

- Where is the doctor's office located?
- What are the doctor's office hours?
- Do I feel comfortable with the doctor and his staff?
- Do I respect his abilities, knowledge, and judgment?
- Is the doctor easy to communicate with?
- Is the doctor available to answer my questions?
- Is the doctor up on the latest research?
- Is the doctor willing to refer me for a second opinion about my care?
- Will the doctor provide references for that second opinion?

CHOOSE A TREATMENT FACILITY

Your primary care physician and your IBD specialist will likely know about the treatment facilities in your area.

Check to see whether the facility and its services are covered by your insurance policy. In addition, the following pointers will help you home in on the best treatment facility for your needs, such as:

- **LOCATION** How far would you be willing to travel? How far away is *too* far away for you?
- **ACCREDITATION** Make sure the facility is accredited by a recognized accrediting organization such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO). Visit JCAHO's Web site at www.jointcommission.org/ to confirm accreditation.
- **REPUTATION AND TRACK RECORD** Check Web sites and print directories to see what government and consumer organizations have to say about hospitals' performance.
- **RANGE OF SERVICES** Check the availability of:

- the latest diagnostic and treatment technologies
 - clinical trials
 - an onsite pharmacy
 - the full range of support services
- **PARTICIPATION IN RESEARCH AND EDUCATION** Would you prefer to be treated at a teaching hospital? The quality of care you receive is not always dependent on a facility's emphasis on research and education. By knowing yourself—your preferences, needs, and priorities—you'll be able to fine-tune your search appropriately and effectively.

Hospital information is available on the following Web sites:

Health Grades

<http://www.healthgrades.com/>

The Joint Commission Quality Check

<http://www.qualitycheck.org/consumer/searchQCR.aspx>

U.S. Department of Health and Human Services: Agency for Healthcare Research and Quality

<http://www.ahrq.gov/clinic/outcomix.htm>

After you have received treatment at the facility, you may want to think about the following questions to rate your overall experience:

- Have you been seen by the same professional staff each visit? Continuity and consistency of care are important, so this question should be high up on your list.
- Have all your questions been answered respectfully and completely?
- Does the facility have enough nurses, social workers, and other support staff?
- Are you pleased with your healthcare team? Do you consider them knowledgeable? Capable? Compassionate?
- How long does it take to get an appointment, receive treatment, and have your calls returned?
- Do the facility's services and environment suit your needs?

Choosing a treatment facility takes time. In the final analysis, it will depend on what matters most to you. How important is location? Outstanding nursing care? Leading-edge research? Ultimately, you'll base your decision on what feels right for you.

And remember: If you have any misgivings about a facility, seek a "second opinion" and keep looking.

COMMUNICATING WITH YOUR DOCTOR

Well before your appointment with your doctor, take the time to write down your questions and concerns. Some people prefer to jot them down on 3 x 5 cards, while others simply make a list. The important thing is to arrive at your doctor's office prepared to communicate.

It is also suggested to bring a family member or close friend to take notes when the doctor is speaking. A loved one can offer moral support, and also bolster your efforts to convey your symptoms, your response to treatment, and any other observations, fears, or concerns.

It's when you're face to face with your doctor that you'll have an opportunity to explore your options thoroughly. Come prepared to ask questions such as:

- What, exactly, are my options? What are the risks and benefits of each?
- Is there one treatment you'd recommend over the others in light of my individual circumstances?
- What about side effects? Will they be short-term or long-term? Could any of them be permanent?
- Could you advise me on diet and nutrition? Should I consult a nutritionist?
- How long will it take the treatment to work?
- What are my chances of achieving remission?
- Are there opportunities to participate in clinical trials? Do you consider a clinical trial an appropriate option for me?

If you want to get more out of your communication with your doctor or healthcare team, it is important to feel comfortable asking questions and expressing your needs and concerns. Through open conversations with the members of your healthcare team, you'll figure out the type of care and treatment that works best for you.

If at any time you are not satisfied with the quality of communication with your doctor or others on the team, share your concerns with them. Also, at times you may want to weigh different opinions and options. You always have the option of getting another opinion to help in your decision making process.

IN CONCLUSION

To make the best choices and get the very best results from your healthcare team, stay involved. Advocate for yourself. Know your options. And hone your skills in research, communication, and follow-through ... the skills that will empower you to engage meaningfully in your own care.

Finally, don't go it alone. The Crohn's & Colitis Foundation is perhaps your best resource of all, offering support, guidance, and the latest clinical and scientific information in the field. Take the time to learn about us at www.cdfa.org. Join your local chapter, make common cause with others living with these diseases, and get involved. Most of all, know that we're here for you whenever you need us. You can reach us at our Information Resource Center at **888.MY.GUT.PAIN**.