

THE PREPARED PATIENT

Chronic Conditions: When Do You Call the Doctor?

The signs are everywhere-prescriptions doled out into weekly reminder boxes, blood glucose monitors in a desk drawer, maybe even an adrenaline injection pen stashed in a diaper bag for allergy emergencies. From high cholesterol to HIV, millions of Americans have a medical condition that they manage mostly on their own.

But with so many of us acting as our own daily doctors, how do you know when it's time to call in the professionals?

"It's the level of pain that's my signal, if you will, especially in the knees," says Karen Moe, a 46-year-old Minnesotan. Moe has had chronic rheumatoid arthritis for more than a decade. She faithfully takes a combination of prescription medications and dietary supplements, but heads to her doctor when her joints become unbearably swollen.

"Expect your doctor to summarize the visit before reaching for the handle of the exam room door."

- Dr. Allen Dietrich

Feeling bad is a good sign that it's time to make an appointment, but if you have a condition like diabetes, HIV or high blood pressure, you and your doctor should discuss what sort of symptoms require a doctor's visit or how often you should be monitored to make sure your condition is not getting worse.

"If you are starting care for a new chronic illness or coming for a recheck, make sure to ask your doctor about things to report right away and not just wait for your next appointment. Activated patients, those who express their expectations about information, get better care" says Allen J. Dietrich, professor of community and family medicine at Dartmouth Medical School.

"For most conditions, your doctor will have in mind such a list," Dietrich says. "For example, with diabetes, increased urination, the need to drink more fluids, or development of sores on your feet would be part of such a list. For high blood pressure, muscle pain, reduced ability to exercise, general fatigue or weakness would be part of that list. For asthma, increased use of your rescue inhaler and shortness of breath would be included."

Your doctor may be able to provide you with written materials related to your chronic condition. Another source would be advocacy organizations, such as Families for Depression Awareness.

For some, the cue to call the doctor is the simple feeling that something has changed, says Dr. Kate Lorig, leader of Stanford University's Patient Education Research Center. "It's when all of the sudden you wake up really dizzy. Or if you haven't changed anything in your diet or exercise, and sud-

When-to-Call Websites	
<p>Arthritis www.holisticonline.com</p>	<p>Diabetes www.diabetes.com</p>
<p>Cancer (General) www.cancer.ca</p>	<p>Heart Failure www.clevelandclinic.org</p>
<p>Cancer (Lymphoma) www.lymphomation.org</p>	<p>HIV/AIDS www.positiveside.ca</p>
<p>Cancer (After Chemo) www.ufsc.ufl.edu</p>	<p>Inflammatory Bowel Disease ibdcrohns.about.com</p>
<p>Chronic Obstructive Pulmonary Disease www.cchs.net</p>	<p>Migraine www.1on1health.com</p>

denly your glucose reading is 30 points higher," she says.

The programs developed at the Stanford center help people with arthritis and diabetes manage their symptoms and solve the daily problems that can crop up. But Lorig says "self-management doesn't mean that they don't see their doctors." The Stanford programs also teach people how to get the most out their medical appointments.

"Expect your doctor to summarize the visit before reaching for the handle of the exam room door", Dietrich says. "Something like, 'My recommended treatment is as follows and this is when we should see you back. Are we clear on this? Do you have any further questions?'"

"As a patient, you should ask about things that you should monitor and that the doctor would like to know about right away," Dietrich adds. "You also want to ask them to be really clear on the side effects of your medications."

Moe sees a specialist at least three times a year to make sure her medications are working properly. "But I also do some research on my own, and there are some drugs that I've said no to. I don't have a blind faith, I have an educated faith," she says.

Carol Brown is a 50-year-old Arizonian who battled cancer and lives with severe asthma. She makes a yearly trip to her doctor and allergist to help control her asthma. "And as a breast cancer survivor, I've been seeing doctors a lot, so I have no compunction about bringing things up," she says.

"When you're feeling really lousy,
you can't adequately assess the
situation yourself."

- Carol Brown, asthma patient

Working through the challenges that come with a chronic medical condition is key to staying healthy, according to Russell Glasgow, Ph.D., a senior scientist at Kaiser Permanente Colorado. Glasgow, who has worked with people with diabetes, says successful patients tend to be good problem-solvers.

"One aspect of this is knowing when and how to bring in other resources, be it other people, your doctor, your family or even a librarian," Glasgow says.

Several studies show that people who don't learn to take care of their chronic conditions are more apt to wind up in emergency care. Twenty percent of people who came to emergency rooms in the midst of an acute asthma attack did not know that they could monitor their own asthma symptoms, a recent report found.

Brown uses a home peak flow meter to keep tabs on her breathing and to determine if her asthma medications need to be adjusted. She calls her doctor for further instructions or more steroids when her peak flow measurement falls to 80 percent or less than her high measurement.

She notes, as does Moe, that her doctors never sat down to talk about the kinds of things they should monitor. Both women took the initiative to ask their doctors directly and look for information from other sources such as the Internet. All patients should discuss "emergency" symptoms with their doctors, however, to make sure that they are alert to the most important signs of change.

Some people with chronic medical conditions are leery of taking on their own care, even for everyday problems, says Dr. Terry Porteous, a pharmacy researcher at the University of Aberdeen in Scotland, who has studied how people handle minor illnesses like a backache.

"What I would suggest, however, is that most of these issues could be addressed by professionals other than physicians," she says.

Sometimes it's not just a question of when to seek help, but who to ask. These days, patients can schedule a quick visit with a nurse practitioner or call their health insurance hotline to talk with an advice nurse, instead of going in for a full-blown medical exam.

Doctor offices vary considerably in how they handle these situations, Dietrich agrees, saying that "it's a good question to ask your doctor--how do they handle routine questions?"

When Brown had chest pains recently she called her health insurance hotline. After asking a few questions, the nurse sent Brown straight to the emergency room.

"Sometimes when you're feeling really lousy, you can't adequately assess the situation yourself," Brown says.

RESOURCES

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Health Behavior News Service

Center for the Advancement of Health
2000 Florida Avenue, N.W., Suite 210
Washington, D.C. 20009

Published by the **HEALTH BEHAVIOR NEWS SERVICE**
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Written by Becky Ham, Science Writer
Designed by Brandon Moore, IT/Communications Manager

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