

Being an Effective Advocate For Your Loved One and Yourself:

Advice From a Physician Who Advocates for All of Us

Sandy Padwo Rogers

“You have to be prepared, polite, and persistent.” So says Dr. Ira Byock, director of Palliative Medicine at Dartmouth Hitchcock Medical Center. Dr. Byock often finds himself using this motto when helping his patients and their family members. His advice to those who are dealing with a chronic illness or disability: “Do research about the condition you are dealing with and use the resources that are available to you. Be smart shoppers in the healthcare marketplace.”

Being a smart shopper means knowing when to keep looking for help. Whenever there is a doubt, get a second opinion. This includes everything from medical advice to researching home health agencies and hospice organizations. Ask the right questions. For instance, it’s OK to ask a new physician if he/she makes house calls.

When dealing with your loved one’s physician, there is certain information you have a right to know. “Find out who the primary doctor is to go to for questions or problems whenever there are several specialists treating a person,” explains Dr. Byock. “Talk about the crisis plan: what to do after hours or on weekends if a serious problem develops. If a particular treatment doesn’t work, at the very least, your family should know whom to call to discuss the next steps.”

Dr. Byock encourages patients to bring written questions to their doctor’s visit. “If the doctor leaves the room before all of your questions are answered, you should stay put and politely let someone know you still need more information,” he says, wryly noting that they’ll need the



Dr. Ira Byock is a nationally recognized authority on end-of-life care and palliative medicine. He is the author of the following books: *Dying Well*, *Riverhead Books*, and *The Four Things That Matter Most*, Free Press. For more information on Dr. Byock, go to www.thefourthings.org.

exam room and before long the doctor or nurse will no doubt return to answer those questions.

“Families need to advocate for their loved ones,” Dr. Byock continues. He describes how certain aspects of medicine are changing rapidly

across the country, yet when it comes to areas like pain management, “our health care delivery system hasn’t moved very far. Important innovations can be found at the first-tier medical centers, but you must be really effective as a consumer to get access to these innovations.” Whether dealing with pain or any other aspect of a loved one’s chronic illness or disability, when the person’s basic needs aren’t being met, Dr. Byock has the same advice for the families of his patients: “Demand to talk to those who are in a position to help.”

Dr. Byock also stresses the importance of family caregivers taking care of themselves. “Illness and disability happen to one person, but they affect everyone who loves that person,” he says. In his practice, Dr. Byock often screens family members — particularly family caregivers — for the same symptoms that he sees in his patients. He looks for signs that they are not eating or sleeping well, signs of irritability, and signs that they are not getting joy out of life. In the patient, all of these

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FINDING HELP ON-LINE

American Academy of Home Care Physicians

P.O. Box 1037, Edgewood, MD 21040-0337

Phone: 410/676-7966 Fax: 410/676-7980

Web site: www.aahcp.org E-mail: aahcp@comcast.net

Find a healthcare professional in your area who makes house calls or access a variety of educational articles and links.

American Academy of Family Physicians

11400 Tomahawk Creek Pkwy., Leawood, KS 66211-2672

Web site: www.familydoctor.org E-mail: email@familydoctor.org

This patient-friendly Web site contains valuable information on health topics from A to Z, as well as health tools and tips for healthy living.

Caregiving Stress

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highly stressful physical, emotional, and financial issues they confront.

Solving the complex issues surrounding the role of families in providing care to the most vulnerable members of our population requires national attention from virtually every segment of our society. While effective answers will not be developed overnight, we can begin to meet this challenge by helping family caregivers self-identify and by encouraging the healthcare system to search out family caregivers, monitor them, and, if necessary, treat them for caregiver stress and its consequences. ■

Suzanne Mintz is president and co-founder of NFCA.

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symptoms are secondary to the physical symptoms that are being experienced, and they are classic signs of depression. Family caregivers suffer from the same physical and emotional effects of the illness/disability as their loved one, says Dr. Byock, and they are just as susceptible to the symptoms of depression. "As a clinician, I need to be attentive to the impact that an illness can have on the family caregiver and other family members," he says.

In his efforts to advise families, Dr. Byock strongly encourages assigning someone other than the primary caregiver to serve in the role of "project manager." This individual can help organize a support system

for the patient and the caregiver. "A family caregiver who is alone is at a high risk of suffering themselves," says Dr. Byock. "This is the time to call on others. As a physician, even when I'm faced with an apparently isolated, 'orphaned elderly' or 'unbefriended' patient, I have found that if I dig deep enough, there are almost always people in a person's life who are eager to help. If you are worried about the future, my best advice is, get yourself a community!" ■

(See the winter 2004 issue of TAKE CARE! for suggestions on how to build a care team.)

Sandy Padwo Rogers is the managing editor of TAKE CARE!

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