

Advocating for Your Loved One

By Harriet Patterson, MPH

Having cancer in your family often requires learning a new set of skills and shifting priorities in order to leverage the best possible medical care. If you are caring for someone you love, you may suddenly find yourself in the role of that person's advocate. Here are some skills you may need to be an effective advocate.

- **Find a doctor with whom you feel comfortable.** There are as many types of doctors as there are patients. Shop around until you find a doctor who will work with you and talk openly. If your health insurance discourages this, document any problems you are having, find an ally at the insurance office, or call the insurance ombudsman and ask for a second opinion. Many policies provide for a consultation for free or a fixed cost.
- **Back to basics:** posture, eye contact, a firm handshake, and confidence. It may sound simplistic but people respond to visual impressions. When you go for a doctor's visit, project an image of confidence, just as you would at a job interview. Make direct eye contact, sit up straight, and speak clearly. Remember that you are here on behalf of the person you love and you want to get as much from this visit as you can. It's okay to say you are confused or unsure about what to do; just say it firmly and ask for what you need. For example, "I am feeling overwhelmed by all the treatment decisions we have discussed. It would really help me if you could outline the pros and cons of each."
- **It's natural to be nervous, worried or anxious.** Take five minutes to breathe deeply before your appointment. Most doctors and nurses want to help in whatever way they can, but it is your job to let them know what you need. Being confident and assertive (not aggressive) will help you get the best support possible from your health professional team.
- **Practice makes perfect.** At first, not everyone is comfortable being an advocate for the person they love, but these skills can be learned. Ask a friend to role play with you and rehearse what you will say and how you will respond to specific situations. Practice walking into the room, going through your questions, and repeating back the information. You can also call the NBTF Patient Services Line at 800.934.2873 and practice with one of our staff.
- **Be an active team member.** Good health care takes a team—and that includes the patient and caregiver as well as the doctor. Be an active participant. Share information and come prepared with your questions written down. Ask to have things explained when you do not understand or ask to slow things down. Chances are, if you don't understand, neither does the person you are caring for.
- **What about long-distance advocacy?**
These days, many families must face long-distance caregiving. It is ideal if you can physically meet the medical team caring for your loved one at least once in person when you are in town. Ask them how best to get in touch when you are not there in person. Some hospitals are able to hold a family meeting and include an out-of-town member by telephone. Others may allow you to fax questions or concerns to the nurse prior to the appointment. You also may look into hiring an advocate or case manager to fill in for you at appointments with your loved one. The Eldercare Locator is a nationwide directory assistance service designed to help caregivers find local resources for support with transportation, meals, home care, housing alternatives, legal issues and social activities. Contact them at 800.677.1116 or www.eldercare.gov. You can also check for additional resources with your local Area Agency on Aging or call NBTF for more information.

For specific advocacy questions, email patterson@braintumor.org.

NBTF National Caregiver Training Workshops

As one caregiver said, "A brain tumor happens to the whole family." November is National Family Caregivers Month. NBTF recognizes and applauds the work family caregivers do and supports them by conducting training workshops for family caregivers in conjunction with hospitals across the country, providing detailed information and referrals to resources that brain tumor patients and their families need.

January 2007, St. Paul, MN

February 24, 2007 Houston, TX

March 10, 2007 Birmingham, AL

March 31, 2007 Tampa, FL