Becoming a caregiver for a loved one with cancer may be one of the most important roles in someone’s life. It may also be among the most challenging, often because it comes without warning, preparation or prior experience. Many times, when a loved one is diagnosed with cancer, the caregiver is thrust into the role with no training on what it means to be a caregiver or how, exactly, to provide that care.

If you or others you know are filling this critical role, it’s not too late to prepare for the road ahead. In this issue, we focus on the caregiver, by sharing tips from three caregivers on what they learned on the cancer journey with their loved ones.

Dig for information.

Becoming as educated as possible about his wife’s cancer was key for Nathan Jones, caregiver and husband of invasive ductal carcinoma breast cancer patient Viola Jones. “I remember it was important for me to understand the kind of breast cancer my wife had,” he says. “It was triple-negative, so it was very aggressive.” Jones adds that after he and his wife shared her diagnosis with family and friends, many of them suggested a wait-and-see approach to treatment because she didn’t “look sick.”

“Because I had learned everything I could about Viola’s cancer, I understood that even though she wasn’t sick in bed or even in pain, her cancer was going to grow fast and we needed to be proactive,” he says.

Learning about available resources for caregivers—not just cancer patients—helped Ken Owenson, caregiver and husband of breast cancer patient Sue Owenson. “There are so many resources out there for patients and caregivers alike,” he says. “Some are geared toward the patient, some are geared toward the caregiver, and some are geared toward both.”

Encourage the patient to get a second opinion.

Owenson and his wife were shocked when they were told she had cancer. “We decided to seek a second opinion,” Owenson says. “We’re so glad we did because Sue’s new oncologist told us he was confident he and his team could help us.

“Don’t accept the first diagnosis and treatment plan if they don’t feel right to you,” Owenson adds.

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The Essential Caregiver, Continued from Page 1

“You have some time, and it’s a good idea to think it through. It’s really important to go to a facility with a caring atmosphere and staff.”

Carry a notebook with you. “You think you’re going to remember everything the doctor tells you, but you don’t always,” says Michelle Turner, caregiver and wife to renal clear cell carcinoma patient Ed Turner. “There are a lot of things thrown at you at once, and it can seem overwhelming.” To help remember the important takeaways from appointments, Turner began to carry a notebook so she could write things down. Jones carried a notebook with him, too. “If something was really important, I’d even ask the doctor to repeat it or spell it out for me,” he says. Jones also used the notebook to keep track of how his wife was feeling each day. “Her aches and pains, if she had a headache, etc.,” he says. “It worked really well because that way, her doctors always had a good idea of how she was doing.”

Owenson says he came to each appointment with a list of questions. “It got to the point where the doctor would look at me each time and ask if I had my list,” he says. “I learned that caregiving isn’t a spectator sport. It’s very important for the caregiver to go with the patient to as many appointments as possible.”

Share your cancer journey with others. “We always share Ed’s story with everybody,” Turner says. “Our philosophy is the more prayers, the better.”

Owenson and his wife say they benefited from talking to people during their cancer journey, and now they like to talk to others going through a similar experience as a way of giving back. “We find a lot of strength from sitting down with patients and giving them a place to vent some of their anxiety, and it also gives us a chance to clear our minds, too,” he says. “It’s not good to internalize it because that just makes it worse.”

Take care of yourself. “As a caregiver, you really have to step up,” Owenson says. “But you have to be careful that you don’t wear yourself out, too. If you’re rundown or sick or really depressed, you’re not able to do much for the patient.”

Turner says she felt guilty at first when she would leave her husband for short periods of time to take time for herself, but she eventually grew to realize how important it was.

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Don’t take things personally and practice patience.

Sometimes, when people are sick, they’ll take out their frustrations, fatigue, fears and pain on the ones they love most. “Every now and then when I’m trying to do something for Ed, he’ll snap at me,” Turner says. “I have to remind myself that it’s not personal, though. He’s not feeling well, and that’s the way we all act sometimes when we’re not feeling well.”

Jones adds, “Sometimes, my wife gets emotional about certain things or forgetful, and I just have to be patient with her.”

Understand that caregiving doesn’t end when treatment stops.

Treatments may continue to cause side effects for months or even years after they’re completed. “I learned from the radiation oncologist that it was very normal for my wife to feel tired after completing radiation therapy, because the treatments have real, depleting effects on energy stores for a long time,” Owenson says. “Caregivers really are called to step up for a long time, not just give lip service to it.”

Signs of caregiver stress

As a caregiver, you may be so focused on your loved one that you don’t realize that your own health and well-being are suffering. Watch for these signs of caregiver stress:

- Feeling overwhelmed or constantly worried
- Feeling tired most of the time
- Sleeping too much or too little
- Gaining or losing a lot of weight
- Becoming easily irritated or angry
- Losing interest in activities you used to enjoy
- Feeling sad
- Having frequent headaches, bodily pain or other physical problems
- Abusing alcohol or drugs, including prescription medications

Resources that can help you anytime from anywhere

Webinars about caring for a loved one or friend with cancer

Caregiver Support: Where Do I Fit In?
https://thecaregivernetwork.ca/event/session-four-caregiver-support-fit-needs/

Spotlight on Cancer Caregivers
https://www.oncolink.org/blogs/2014/01/focus-cancer-caregivers-webinar/

Caring for the Caregiver: Bladder Cancer Advocacy Network
https://www.youtube.com/watch?v=NZIXkJQtk1I&feature=youtu.be

Cancer Care Connect Caregiver Support Workshops (Click on “Caregivers” under General Topics)
https://www.cancercare.org/connect_workshops#!past_workshops
Support for you in November

**Integrative Oncology Clinic Activities: Every Thursday**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
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<tbody>
<tr>
<td>Meditation*</td>
<td>8:00—9:00 am</td>
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<tr>
<td>Reiki</td>
<td>9:00—11:00 am</td>
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<tr>
<td>Arts in Medicine</td>
<td>11:00—11:45 am</td>
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<tr>
<td>Yoga**</td>
<td>12:00—1:00 pm</td>
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<tr>
<td>Nutrition</td>
<td>1:15—2:00 pm</td>
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<tr>
<td>Meditation Clinical Study</td>
<td>2:00—5:00 pm</td>
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<tr>
<td>Pastoral Care</td>
<td>Various</td>
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</tbody>
</table>

* $5.00 fee for meditation session; ** $10 fee for each yoga session.

**Location:** Educational Counseling Center. Patients check in at Guest Services desk on 2nd floor of The Kirklin Clinic across from the coffee bar, near the parking garage crosswalk. Appointments are necessary and small fees may apply. To learn more, call (205) 801-8415. Or, if you are not a UAB patient, call (205) 934-5077 to schedule a consultation with Dr. Carolina Salvador.

**Gentle, Restorative Yoga**

Join us for a flowing sequence of supported yoga postures, breathe work and meditation designed to help manage the side effects and stress of cancer. Cancer patients and survivors are welcomed.

**When:**
- Wed 12:15-1:30 PM
- Thurs 5:45-7:00 PM

**Where:**
- Embody Practice Center
- Embody Practice Center

For more information: dianewood@uabmc.edu Or call: (205) 934-4462

**Have questions and concerns about managing your physical, emotional and spiritual health while going through cancer treatment or after treatments end?**

There’s help. Make an appointment for our support concierge service designed to help you get the information or support services you need. This services is brought to you by the UAB Comprehensive Cancer Center’s Patient and Family Resource Center. For more information, call (205) 934-5772 or email tgw318@uab.edu.