

# After the cancer diagnosis: What do you say—and do—next?

The most important thing, say the experts interviewed for this article, is for oncology nurses to reassure patients that they are not alone.



GETTY IMAGES

## DEBRA WOOD, RN

**M**ore than a million times a year, Americans receive health news they dread: *You have cancer*. This moment, although traumatic, presents nurses with opportunities to provide patients with information and support that can make the journey easier.

“For most patients, when they hear that initial word *cancer*, their mind shuts down,” says Ruth Dein, RN, nurse navigator for oncology services at Beaumont Hospital in Royal Oak, Michigan. “They cannot hear anything beyond the diagnosis. It’s so frightening for them.”

Helping them get past that requires patience and understanding. “Being open to where they are at that time and being able to read that is key to helping someone at that stage,” suggests Leslie Irving, RN, MN, OCN, a breast oncology nurse navigator for the Seattle Cancer Care Alliance, which unites the cancer care services of the Fred Hutchinson Cancer Research Center, University of Washington Medicine, and Seattle Children’s Hospital, all in Seattle. “They just need their hand held and you being there.”

## BUILDING TRUST QUICKLY

“The patient has to trust that you are doing the best you can for them,” points out Annette Dunphy, RN, BSN, OCN, manager of cancer programs at Greenville Hospital System University Medical Center in Greenville, South Carolina. She adds, “It’s just being present and not judging patients and families based on their initial reactions with you or the physician,

because when they are in that situation, they are not necessarily on their best emotional behavior.”

In general, people view nurses as trusted, competent professionals, says Teri Gilmore, RN, BSN, a breast cancer care coordinator at Adventist Medical Center in Portland, Oregon. “We’re fortunate we have that,” acknowledges Ms Gilmore. “I can expect them to be stunned. I focus first on introducing myself as a nurse.” But nurses must foster a strong relationship and get to know the person as an individual, Ms Gilmore adds.

“A good nurse builds relationships in bits and pieces,” says Barbara Henry, APRN-BC, MSN, a nurse practitioner with Psycho-Oncology Consultants and the University of Cincinnati Central Clinic in Cincinnati, Ohio and a member of the *Clinical Journal of Oncology Nursing* review board. “Nurses have to find ways to connect beyond talking about treatment and the medical aspects.”

Inquiring in a relaxed manner about family or occupations helps break the ice and allows the nurse to enter the patient’s world. Look for commonalities, Ms Dein suggests, and don’t be afraid to distract them with a little humor, such as a toy dog that peeks out from the desk or funny photos of a pet. “Humor is a de-stressor,” Ms Dein explains. “When patients leave my office, I like to get at least one smile out of them.”

### CUTTING THROUGH THE FOG

Fear and lack of understanding are the two greatest barriers to receiving information, reports Melanie Carrow, RN, OCN, ACRN, a nurse with the Ambulatory Service, Infectious Disease Service at Memorial Sloan-Kettering Cancer Center in New York City.

“When patients are shocked to the core, they are not in a state of readiness to take in information, but they know they will need some help,” Ms Gilmore adds.

The nurse must determine the patient’s emotional state, says Ms Dein, adding that such an assessment requires the nurse to actively listen rather than formulating responses or trying to move the clinical agenda forward.

“Don’t run ahead by trying to offer ‘fixes,’” advises Mary Jean Houlahan, RN, manager of the oncology navigation program at Good Samaritan Medical Center in West Palm Beach, Florida. “Just hold it, physically, mentally, and clinically, until they feel more secure.”

Nurses must find out what is most important to patients, summarize that back to ensure correct understanding, and then validate it for the patient, Ms Dein says. Patients’ worries could be as serious as role changes and job loss

fears or barriers to treatment, such as a lack of insurance, child care, or transportation. “What you think should be the priority isn’t necessarily going to be the patient’s priority,” Ms Dein explains.

Ms Dein closes her office door, turns off the telephone, takes care to project openness and relaxed body language, and gives the patient her undivided attention, making eye contact and



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perhaps holding the person’s hand. She acknowledges that often the conversation is uncomfortable, especially if the patient is crying. “They need to express that,” Ms Dein acknowledges. “But nurses often don’t have the time to give.”

Yet sitting attentively, as if you have all the time in the world, will mean a great deal to the patient. Begin by asking the patient what he or she has been told and determine the person’s understanding of what that means, Ms Houlahan suggests. “You have to assess quickly, with all of your senses—and with your heart, too,” advises Ms Houlahan.

Reinforce what the physician has said, Ms Henry adds. Never contradict the team director or greatly expand on what the patient has been told, especially about prognosis. When patients receive a diagnosis of cancer, they often assume they will die; although they might fear saying that to the doctor, they will often open up to the nurse.

“Answer their questions honestly,” Ms Henry recommends. “You can say, ‘There are so many different outcomes. It would be best to talk with your doctor because he knows your specific disease.’”

### DEVELOPING A PLAN

The cancer diagnosis triggers a series of decisions the patient must make. It also often necessitates a diagnostic workup to stage the disease and provide information for the physician to make more informed recommendations.

It’s important to make sure that before patients leave the office, they have a plan, Ms. Carrow advises. If patients have

a plan, they feel a little more secure. “That plan can be as basic as ‘I will call you tomorrow morning.’ You keep the lines open. Don’t put it in their hands because they will be quite overwhelmed.

At that follow-up call, Ms Carrow will review what has been discussed and may talk about the testing required, future appointments, and symptom management. She adds that good information gives power to the patient. “Our role, as nurses, is to make sure that happens,” Ms Carrow points out.

Jane Edelman, RN, OCN, breast health nurse at Southampton Hospital in Southampton, NY, tries to ensure that patients understand the pathology report on the first visit. She also gives them a handbook, so they can read more about breast cancer after they go home, and a special gown. “The education and support are the most important things for these patients, and realizing that they are not alone on this journey,” emphasizes Ms Edelman.

When coming up with a plan, Ms Houlahan asks patients what is most important to them during the next 24 to 72 hours. “Break it down into small, manageable parts,” she advises. “That can ease their anxiety.”



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### **DISPELLING MYTHS**

Often nurses find themselves in a position of dispelling myths about cancer. Ms Dein inquires about patients’ experience with cancer, either personally or with a family member or friend. “That can taint their concept of what they are facing,” argues Ms Dein, explaining that someone whose mother died quickly of cancer will have different expectations than someone whose loved one survived. “Their experience may make it easy to deal with them or very difficult.”

Nurse navigators provide accurate information from an experienced professional. For additional support, Ms Dunphy suggests referring patients to hospital or community cancer support programs.

### **VALUING CULTURAL DIFFERENCES**

Although nurses should never stereotype a patient on the basis of ethnicity or religion, they should remain mindful

that in certain cultures, accepted practices, such as eye contact, may make the patient uncomfortable and adjust accordingly.

“Nurses use a lot of touch, and it’s appropriate,” Ms Henry says. “But if you put your hand on the person’s shoulder and he or she recoils—do not touch the person again, at least not at that moment. A lot of it is intuition.”

Ms Henry adds that nurses should always identify themselves and ask how the person would like to be addressed. When working with an interpreter, Ms Dein recommends that the nurse face the person and direct the conversation to the patient, not the translator.

### **HEARING THE NEWS BY TELEPHONE**

In some cases, nurses follow up by telephone after a physician, sometimes a radiologist the patient does not know, has informed the patient by telephone about the cancer diagnosis.

“Hearing the message on the phone is rather cold; I’d much rather do it face-to-face,” emphasizes Maureen Lockwood, RN, BS, OCN, clinical coordinator at the Women’s Health Center at Saint Clare’s Health System in Dover, NJ. But logistically, that doesn’t usually happen. Radiologists call as soon as the pathology report comes in, and then Ms Lockwood follows up.

“Compassion, patience, listening are the things I use,” Ms Lockwood says. “A lot of it is instinct and awareness that no two women accept the diagnosis in the same way.”

Telephone consults present additional challenges to good communication. “You can imagine how hard it is over the telephone to get a feel for this person,” Ms Gilmore suggests. “I cannot see them. They cannot see me. I use a lot of silence and reflecting.”

Ms Gilmore may have access to the medical record but no personal knowledge about the patient. She starts by asking if it is a good time for the person to discuss the “difficult news,” and then she just pauses. She finds most people want to talk.

Yet patients often try to dismiss Ms Gilmore’s concerns, telling her they are fine. Even on the telephone, the experienced nurse can pick up subtle clues indicating that may not be the case. She might repeat, “It must be hard news to take,” and let that hang in the air.

Ms Gilmore notes that patients will often tell her they are fine and then suddenly they start to cry. Then, she says, “we will talk about what it feels like to get that phone call.”

Sometimes all Ms Gilmore can accomplish during the first interaction is to set up a second meeting, preferably in person, with a goal of providing more information about the diagnosis so the patient can better discuss options with the physician. “If they understand the diagnosis well, they are better able to choose

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than if they are still at the point where they don't know what's wrong," Ms Gilmore maintains. "I try to help each patient be ready to get the most out of time with the specialist."

### **CARING FOR CHILDREN AND THEIR PARENTS**

When the patient is a child, the provider must inform both the patient and the parent. At The Children's Hospital at Montefiore Medical Center in Bronx, NY, nurses are in the room with the

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family as the attending physician gives the news. This approach reinforces the team concept, and all the clinicians know what has transpired. Often a child-life specialist will stay with the child while the providers talk separately with the parents.

"The parents can be a little more open with how they are feeling and with questions they wouldn't want to ask in front of the child," offers Joan O'Hanlon Curry, ANM,

CPNP, CPON, administrative nurse manager of outpatient pediatric hematology/oncology at Montefiore. Parents more than children, she says, get that "deer-in-the-headlights" look. At that point, Ms Curry will schedule another visit to discuss testing, treatment, and "softer issues," such as symptom management, school, and treatment logistics.

"The most important thing is to reassure them that they are not alone," Ms Curry says. "That's your biggest job as a nurse—to make this as tolerable as possible, for the family and the patient."

### **DISPENSING HOPE**

Nurses often encourage patients to call them with questions and allow them to serve as a resource. For many patients, just knowing the nurse is there and can offer guidance throughout testing and treatment is reassuring.

Cancer patients "are alive and need to be treated like they are alive and going to have a life," Ms Houlahan says. "Give them hope. It may not be hope for long-term survival, but it can be hope for control or comfort care and that they will never be abandoned." ■

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**Debra Wood** is a medical writer in Orlando, Florida.