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John LeBas

The University of Texas MD Anderson Cancer Center

Joe Munch

The University of Texas MD Anderson Cancer Center

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REPORT TO PHYSICIANS

SEPTEMBER 2009 VOL. 54, NO. 9

Oncology

Addressing the Lifetime Needs of Survivors

M. D. Anderson is partnering
with physicians and patients
in the journey after cancer.



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By Joe Munch

Not only do cancer patients have to contend with their disease, but they must also endure the side effects of their treatments. Physical or functional changes, psychological disturbances, and socioeconomic burdens can persist even after treatment has been completed

and the cancer is considered “cured.” Cancer treatment can also increase the risk of second malignancies and cause chronic diseases. For some patients, then, surviving cancer means another journey is just beginning.

Recognizing the special challenges facing most cancer survivors, The University of

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THE UNIVERSITY OF TEXAS
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Addressing the Lifetime Needs of Survivors

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Texas M. D. Anderson Cancer Center is developing a comprehensive cancer survivorship program aimed at helping those who have overcome the disease. By combining research, clinical practice, and education with outreach programs designed to integrate patients' primary care with the care they receive at M. D. Anderson, the institution is striving to improve cancer survivors' quality of life long after their treatment has ended.

Survivorship 101

As the population of the United States ages, more people will be diagnosed with—and survive—cancer. The American Cancer Society estimates that the U.S. population will include more than 20 million cancer survivors by the year 2020. Those patients will have undergone therapies for cancer itself, yet many will not receive appropriate care for the various sequelae of cancer treatment.

“Once a patient completes therapy, a lot of people might simply say, ‘Problem solved.’ Conceptually and emotionally, we want to believe that,” said Alma Rodriguez, M.D., professor and vice president for medical affairs at M. D. Anderson. “But the truth is that there are some cancer patients who get lost

between the world of the cancer, where all the focus is on curing the cancer, and the world of normalcy. Many of these patients cannot make that transition because of problems arising from their treatment.”

In response to a 2005 Institute of Medicine report (please see “Toward a New Definition of Survivorship,” page 3), M. D. Anderson President John Mendelsohn, M.D., charged a task force with developing a survivorship program at M. D. Anderson. Since then, four pilot survivorship clinics—one for gynecologic cancers, one for genitourinary cancers, one for thyroid cancers, and one for breast cancers—have been established as potential models for future survivorship clinics.

According to Dr. Rodriguez, the focus of M. D. Anderson's survivorship program is on considering—from the beginning of treatment—the consequences that treatment might have on patients' lives. Preventing those consequences or managing them well early on better enables patients to recover after completing treatment. Even after cancer patients reach a long-term phase of survivorship, Dr. Rodriguez said, their care may be inhibited by a fragmented and

poorly coordinated health care system, an absence of continuity in follow-up care, and a lack of guidance on how to maximize their own health outcomes.

“The problem is that all of these services are disparate,” Dr. Rodriguez said. “At this point in time, there's no formalized integration, no well-coordinated effort to ensure that survivors consistently or at least in an integrated fashion have access to these services. It's a reactive rather than proactive approach to addressing patients' problems.”

Questioning this reactive approach—that is, addressing a patient's problems only after they have been brought to the physician's attention—is a relatively recent development in survivorship care.

“Twenty years ago, oncologists did not have a good sense of how to help adults who lived many years after cancer treatment,” said Fran Zandstra, director of M. D. Anderson's Cancer Survivorship Program. “Because of medical advances, many people are living past the first, second, and third decades after treatment.

“And it's that long-term phase that follows treatment for which we're developing the survivorship program,” Ms. Zandstra added. “We're taking the multidisciplinary care model pioneered at M. D. Anderson for the treatment of cancer and applying that approach to survivorship.”

M. D. Anderson's survivorship program represents patient-centered care moving from an illness-based approach to a wellness-based approach. The difference is an important one: What cancer survivors require after they have wrapped up their treatment is vastly different from what they required when they were still receiving therapy. Whereas in a cancer treatment clinic, cancer patients meet with medical oncologists, radiation oncologists, and surgeons, patients being seen in the survivorship clinics may consult nutritionists, who help design weight-managing strategies; social workers, who teach techniques to manage stress on a day-to-day basis; and health care professionals who identify and manage the late effects that can occur from cancer treatment. In addi-



Fran Zandstra (left), director of the Cancer Survivorship Program, and **Elizabeth Garcia**, clinical administrative director of the Gynecologic Oncology Center, say M. D. Anderson has an obligation to its patients after they have completed treatment. “We don't want them to feel as though they're falling through the cracks,” Ms. Garcia explains.

Toward a New Definition of Survivorship

In the past, when cancer was usually considered incurable, “survivor” was used to refer to the family members of people who died of the disease. As cancer treatment improved, “survivor” came to mean any cancer patient who survived 5 years or more after diagnosis and treatment. But even as that definition has come to apply to more and more patients, it seems inadequate. Today, M. D. Anderson uses the U.S. National Cancer Institute’s definition to describe “survivorship”:

“In cancer, survivorship covers the physical, psychosocial, and economic issues of cancer, from diagnosis until the end of life. It focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to the ability to get health care and follow-up treatment, late effects of treatment, second cancers, and quality of life. Family members, friends, and caregivers are also part of the survivorship experience.”

At M. D. Anderson, the implementation of a comprehensive cancer survivorship program was prompted by an



Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (2005). The purpose of the report was to “raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment; define quality health care for cancer survivors and identify strategies to achieve it; and improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance.” The report identified three distinct stages of survival:

Identified three distinct stages of survival:

- Acute survival (living with cancer): Begins with the diagnosis of cancer and includes the period of testing and treatment of cancer;
- Extended survival (intermediate; living through cancer): Begins upon remission of the disease and conclusion of the initial treatment; this phase can include maintenance, consolidation, or watchful monitoring; and
- Permanent survival (long-term; living beyond cancer): Depending on disease type, this is the phase equated with “cure” or with long survival after remission. ●

tion, survivors receive counseling on monitoring for recurrent disease and health behaviors that reduce their risk for second cancers. Patients in the survivorship clinics may also see professionals who specialize in cancer-type-specific issues; for example, gynecological cancer survivors have the opportunity to meet with a sexuality counselor.

“There is no such thing as a one-size-fits-all survivor program. It really needs to be tailored to the particular illness and to the particular treatments given,” Dr. Rodriguez said. “The consequences of surgery, chemotherapy, and radiotherapy are all different and all different for different tumors. The long-term sequelae patients experience depend on the treatment and the disease.”

Currently, patients participating in the four pilot programs must have no evidence of disease. However, as the survivorship program grows and evolves, it will likely come to include patients who have been treated but cannot be considered cured—such as some patients with hematologic malignancies—and who

will continue to be seen by their oncologists but also need the services of the survivorship clinic.

“We have a lot of survivors who come to M. D. Anderson for follow-up visits with their oncologists, and those survivors’ needs may not be met because the needs of a survivor are very different than the needs of an active patient,” said Elizabeth Garcia, clinical administrative director of M. D. Anderson’s Gynecologic Oncology Center. “We want to make sure that, as a cancer hospital, we are addressing individual patients’ needs appropriately, and it might not be appropriate for a cancer survivor to be seen in a clinic that is seeing patients with active disease.”

Primary care collaboration

Central to the mission of M. D. Anderson’s survivorship program is not only learning more about the long-term consequences of cancer therapies, but also learning about how cancer survivors cope with the physical, emotional, and cognitive consequences of their treatments.

“As the people who give that treatment, we are the care providers who best understand the consequences of what we do,” Dr. Rodriguez said. “We have a responsibility to expand awareness and knowledge about those consequences. And as we learn more about the consequences of cancer therapies, we will be able to impart that knowledge to providers on the front lines—internists, cardiologists, or other primary care specialists—so that they can address those consequences in their own communities.”

One of the driving concepts behind M. D. Anderson’s survivorship program is that patients continue to receive long-term care from their primary care providers. “The last thing we want community providers to think is that we want to take their patients away from them,” Ms. Garcia said. “We want to provide their patients with cancer treatment, send them back with appropriate recommendations, and provide follow-up care on our end as appropriate.”

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Addressing the Lifetime Needs of Survivors

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“There is no such thing as a one-size-fits-all survivor program. It really needs to be tailored to the particular illness and to the particular treatments given.”

– Dr. Alma Rodriguez

Indeed, some issues are not addressed in a survivorship clinic. For example, gynecological cancer survivors tend to have issues that may be caused by their cancer treatment or may be the symptoms of heart disease or hypertension. While those patients might receive support and guidance in the survivorship clinic, they would have to see their cardiologist or community physician to get a prescription for blood pressure medicine.

Still, some cancer survivors may always require the services provided by a comprehensive cancer center such as M. D. Anderson.

“There are some survivors who are basically healthy, who have a low risk of recurrence, and who had treatment with few consequences, and transitioning those patients to mainstream health care is completely appropriate,” Dr. Rodriguez said. “But then there are patients who have had more complex and more toxic treatments or who may be living chronically with their cancer for whom we will continue to be part of their care. Depending on the severity of the consequences of their treatment, there may or may not be providers in the community who are informed enough about cancer treatment to address those questions well.”

Passport Plan for Health

After patients have completed treatment, M. D. Anderson must align with the community physicians upon whom it relies to continue the care of survivors once they leave the institution. To accomplish this, M. D. Anderson did a qualitative survey of

community physicians to look at the themes surrounding survivorship and what community physicians would like to receive in terms of support and education. Surveys were also mailed out to 20,000 community physicians to get feedback to help improve communication with physicians.

“The community physicians we surveyed said, ‘You know, we love M. D. Anderson, but when you send us a patient with 300 pages of their records, we don’t have time to read all that. We want a page or two that tells us what happened to the patient, what to look for, and what to do going forward,’” Ms. Zandstra said.

Hence, M. D. Anderson created the Passport Plan for Health, a two-page medical summary of care that explains the cancer diagnosis, the treatment(s) that the patient received, potential late effects of the treatments and recommended monitoring, and follow-up care recommendations. The document is given to the patient and sent to the survivor’s identified community provider(s). In addition, passports are uploaded to the Internet, where they can be accessed via secure connection by survivors and their health care providers. Physicians can log onto myMDAnderson.org to follow their patients as they are treated at M. D. Anderson. When a patient sees a new medical care provider, he or she needs only to log into the site to give the attending physician an accurate snapshot of his or her medical needs as a cancer survivor.

“Today, patients are a lot more
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Renal Tumor

Treatment advances reduce

By John LeBas

Just a decade ago, localized renal tumors were almost always treated with radical nephrectomy. Today, surgery for localized renal masses can be much less extensive or even avoided altogether, yielding a higher quality of life for patients with cancerous and benign tumors confined to the kidney.

Renal cancers are most effectively treated before they metastasize, and benign kidney tumors may also require removal because of their potential to affect function. Multiple kidney-sparing options, from maximally invasive to non-invasive, are available to patients with localized renal masses. Because of increasing incidence partly owing to early incidental detection, the majority of kidney cancers are now found in the early stages.

“Ten years ago, we would have performed radical nephrectomy for almost all patients with localized renal masses. However, there are now very convincing data showing that removal of part of the kidney is just as effective as radical nephrectomy for such tumors,” said Surena F. Matin, M.D., an associate professor in the Department of Urology at M. D. Anderson. “Therefore, open partial nephrectomy has become our gold standard for curative treatment. And for older patients with very small and slow-growing tumors, we may be able to simply monitor the tumor without performing surgery at all.”

Partial nephrectomy

Also known as kidney-sparing surgery, partial nephrectomy is less disruptive to the patient’s system than radical nephrectomy. After radical nephrectomy, the patient is left with only one

the extent of surgery for masses confined to the kidney.

kidney (which may not function well, depending on other health issues) or no kidneys. When 50% or more of a person's kidney function is removed, other conditions such as heart disease can accelerate.

Partial nephrectomy was first used to treat patients with tumors smaller than 4 cm who would have been left without a well-functioning kidney if treated with radical nephrectomy. "However, it's becoming increasingly clear that 4 cm doesn't really mean anything. In fact, the size of the mass matters little to the outcome of the operation when it is performed correctly," said Christopher Wood, M.D., an associate professor in the Department of Urology. Recent data suggest that partial nephrectomy can be successful for tumors up to 7 cm, and M. D. Anderson surgeons will consider partial nephrectomy whenever possible, regardless of tumor size.

What matters more than size is the location of the tumor. Tumors that are at the center of the kidney are more difficult to treat with partial nephrectomy, but with a good operative strategy even these can be effectively removed while preserving the kidney. Tumors invading the renal sinus or vasculature present a higher risk of positive surgical margin and are better treated with radical nephrectomy. Tumors in the upper or lower pole of the kidney and those that are primarily exophytic—the majority of renal tumors—can usually be treated with partial nephrectomy.

However, all else being equal, par-

tial nephrectomy is more difficult than radical nephrectomy. During partial nephrectomy, the unresected portion of the kidney must be reconstructed to retain function and prevent postoperative bleeding and urine leakage. Reconstruction involves three main steps. First, vessels that have been transected must be suture ligated. Second, any defects in the urinary collecting system must be closed. Third, a compressive bolster must be sutured into the kidney to ensure complete hemostasis. Each of these steps requires fast and precise work.

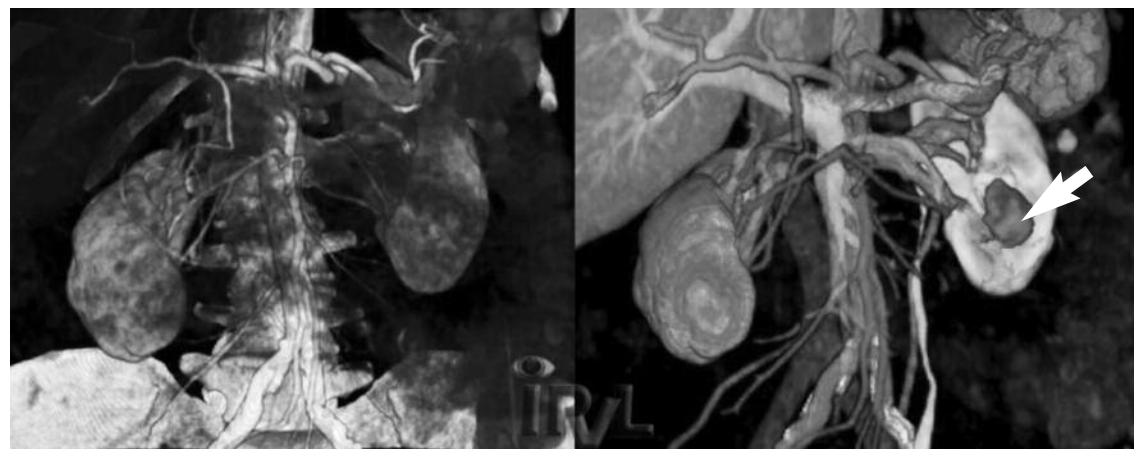
"Every time the heart pumps, 25% of

the blood flows through the kidney," Dr. Wood explained. "To perform renal surgery, we therefore have to clamp the renal artery, which temporarily stops the blood flow and allows relatively bloodless surgery. But we only have 30 minutes before the kidney begins to show signs of irreversible ischemic damage." This time limit can make radical nephrectomy more attractive to the surgeon. Thus, despite the prevalence of tumors that can be treated with partial nephrectomy and the benefits of partial nephrectomy compared to radical nephrectomy, partial nephrec-

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Visualizing renal tumors: Above, the patient's right kidney has a tumor, shown in a mesh pattern and designated by the arrows. The urinary collecting system is shown in white, and the vasculature is shown in medium gray. These images helped physicians determine that there was no invasion of the urinary collecting system, contributing to the choice of partial nephrectomy for treatment. Below, the overall anatomy in another patient is shown in the left panel. On the right, the liver, veins, kidneys, and tumor (designated by an arrow) have been enhanced to help in treatment planning.



Renal Tumors

(Continued from page 5)

tomy is still very much underutilized worldwide, Dr. Wood said.

Other surgical options

While most of the partial nephrectomies performed at M. D. Anderson are open surgeries, about 200 patients have instead undergone partial nephrectomy via traditional laparoscopy. Those patients generally have had very good outcomes with much less pain, shorter hospital stays, faster recovery, and better cosmetic results than patients who undergo open partial nephrectomy, Dr. Matin said. “International data suggest that laparoscopic partial nephrectomy carries an increased risk of bleeding and urine leakage after the surgery. But we have not seen this increased risk, likely because we carefully select patients who have favorable anatomic features.” The major downside to partial nephrectomy via traditional laparoscopy is that it is more difficult to complete the resection and reconstruction in the time allotted.

Newer robotic-assisted laparoscopic techniques for partial nephrectomy are now being tested. But with fewer than 100 patients worldwide having undergone robotic laparoscopic partial nephrectomy, it is too soon to say whether any benefit will be realized. “Robotic laparoscopy may help improve outcomes and it may help more urologists perform laparoscopic partial nephrectomies, which are very complicated when done with traditional laparoscopy,” Dr. Matin said. “But we have only short follow-up for the patients who have undergone robotic laparoscopic partial nephrectomy, and the early data don’t suggest a benefit. I suspect this is because it is early in the learning curve, but this learning curve is much less than with traditional laparoscopy, so it may be just a matter of time before we see a benefit.”

Less-invasive ablative therapies, in which the tumor is heated (radiofrequency ablation) or frozen (cryoablation), may be offered to some patients with small kidney tumors. These therapies can be delivered percutaneously or laparoscopically, depending on the lo-



cation of the mass. Radiofrequency ablation and cryoablation for renal tumors appear to be less effective than surgery, but they also carry a lower risk of complications. Thus, these less-invasive therapies may be appropriate for older, sicker patients, according to M. D. Anderson specialists.

For all of the above-described procedures, M. D. Anderson urologists work closely with imaging specialists to develop the treatment plan. “With imaging, we can noninvasively assess key characteristics and extent of a growth in regard to the kidney’s most critical structures and therefore infer its potential evolution and impact on biological and physiological functions,” said Luc Bidaut, Ph.D., associate professor in the Department of Imaging Physics and director of the Image Processing and Visualization Laboratory. “With high-quality datasets, we can visualize the surrounding anatomy as well as a lesion’s vascularity and feeding vessels. All this information is key for the surgeons to decide which approach is best and then for planning the chosen intervention.”

Said Dr. Matin, “It’s no longer about doing an ‘exploration’ and seeing what we can do on the fly, like in the old days. It’s about having a good road map, planning a strategy based on accurate imaging, and then executing that strategy.”

Active surveillance

Imaging is also very important to the least invasive of treatment options—active surveillance. Usually offered to patients who are older, as many at M. D. Anderson are, active surveillance relies on computed tomography in combination with other imaging modalities to

“There are now very convincing data showing that removal of part of the kidney is just as effective as radical nephrectomy for localized renal tumors.”

– Dr. Surena F. Matin

determine whether a tumor evolves and may require surgery at all.

To qualify for active surveillance, patients generally must have a kidney tumor that is smaller than 3 cm and asymptomatic. Such tumors carry an extremely low risk of local or metastatic progression, Dr. Matin said. Following the initial imaging assessment of tumor location and grade, follow-up imaging is used to monitor tumor growth. Usually, therapeutic interventions are triggered only if the tumor shows rapid growth or reaches 3 cm.

“We’ve learned that patients with small or slow-growing tumors can be safely observed for disease progression and potentially avoid surgery,” Dr. Matin said. “We can really individualize the therapy and perform surgery only when it is necessary, which is also good because many of these patients are undergoing therapy for other cancers as well.” What is difficult, said Dr. Matin, is that imaging does not predict which tumors will grow and which won’t. But the ones that behave aggressively are more unusual.

So far, only 10% of kidney tumor patients in the active surveillance program at M. D. Anderson have had to undergo surgery, and only half of those had a malignant tumor. Another 10% of the study participants have died of conditions unrelated to their renal mass. These statistics support the theory that most people with small and slow-growing kidney tumors do not need immediate treatment, Dr. Matin said. ●

For more information, visit the Genitourinary Cancer Center at www.mdanderson.org.



Preparing for a Hospital Stay

No one likes to stay in the hospital, but bringing a few personal items can make the experience much more pleasant. Many members of the Anderson Network, a support group for cancer patients and their caregivers, have experienced at least one hospital stay themselves, so we asked them to suggest a few of those comforts.

Here is a sampling of things they found useful in the hospital—or what they wished they had brought.

Your own clothes. Bring a bathrobe, nightgown, pajamas, underwear, shorts, and perhaps an athletic suit. Take “anything you feel comfortable in,” one Network member advised. “You don’t need to wear that gown that the hospital gives you.” Others suggested comfortable slippers with non-skid bottoms, socks with rubber on the bottom, or slip-on shoes such as Crocs to make walking easier.

Warmth. Many Network members remembered being cold in the hospital. They suggested bringing socks to keep feet warm and perhaps a special quilt. “I really enjoyed having a bed jacket. It kept me warm when I sat for visitors and looked a lot nicer than the hospital gown,” one woman said. Another said she wished she’d brought a “soft, fuzzy shawl” with her. A fleece blanket or piece of fleece from a fabric store, she wrote, would have fit the bill. And while it may not provide much warmth, a pillow from home can make a hospital bed much cozier.

Decorations. “Any decorations to help make your room your own will really help,” one Network member wrote. “I decked the walls with cards from well-wishers so I could always see my support network.” Make your room

more homey by bringing a couple of knickknacks or a silk plant. Just be sure not to bring anything expensive or irreplaceable.

Meaningful photos.

Over and over, Network members suggested bringing “pictures of things you love,” such as your family, friends, home, or pets. “I brought a framed picture of my child,” one wrote. “I would look at it several times a day to remind myself of why I was fighting to get well. It made me feel like he was there with me even when he couldn’t be.” One former patient enjoyed a digital photo frame, while another assembled old photos into an album during her hospital stay, helping her “make good use of the time and enjoy the memories.”

Distractions. Many Network members recommended bringing a good book and magazines, though one advised, “If you’re having chemotherapy or surgery, you may find that you can’t focus as well as you normally can. A book with beautiful photos or a simple plot line may be better than a complex book.” Other favorite distractions included Sudoku, crossword and jigsaw puzzles, audio books (“it’s much easier to ‘read’ when you don’t have to hold a book”), a deck of cards, and games.

Music and movies. Many Network members enjoyed listening to music and suggested bringing an MP3 player, a satellite radio receiver, or a portable CD player (including spare batteries and headphones). Soothing music, relaxation tapes, and comedy albums were listed as favorites. Others liked watching movies on a portable DVD player (also with headphones). Bring funny DVDs to lighten your spirits, one former patient suggested.

Tools for staying in touch. Suggestions included stationery, stamps, a pen, thank-you cards, an address book in-



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cluding phone numbers of friends and family, and—if it’s allowed in your room—a laptop with a wireless networking card to access the Internet and e-mail. One Network volunteer found that “a journal or notebook can help you keep track of the days and help you see progress.”

Your own toiletries. People liked having their own soap, shampoo, makeup, skin care products, remedies for dry lips and hands, and baby wipes.

Whatever reassures you. Reassurance means different things to different people. One member suggested bringing “a book of faith, even if you can’t read it.” Others found comfort in listening to “healing-type tapes” or reading books with devotions and positive sayings. A grandfather was cheered by listening to a recording of his grandson’s voice. Another Networker found comfort in the small stuffed bear a friend had brought: “I was too sick to want visitors, but it reminded me of those who wanted to visit.” ●

An expanded version of this House Call is available online at www.mdanderson.org/oncolog.

For more information, talk to your physician, or:

- visit www.mdanderson.org
- call askMDAnderson at 1-877-632-6789

OncoLog, September 2009
K. Stuyck

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Addressing the Lifetime Needs of Survivors

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savvy than in the past, and they know a lot more about their own health and the treatments they've had," Ms. Garcia said. "But you still need provider-to-provider communication. Patients can generally remember the kinds of cancer they have and their treatments, but they may not remember how many rounds of treatment they went through, they may not know all the drugs they've had, and they may not recall their most recent lab values."

Even when patients are in active treatment, their community physicians will be able to see the dictated physician notes, test results, radiology reports, and other pertinent information in real time. This is one way in which M. D. Anderson hopes to collaborate with community physicians to provide their common patients with exceptional care.

"There needs to be a partnership," Ms. Garcia said. "That's why we produce tools like the Passport Plan for Health and myMDAnderson for communication with community providers, to make sure that we're partnering with them and that together we're taking care of these survivors in the best possible way."

On down the road

In the gynecological cancer survivorship clinic, patients are given a "Survivorship Award" to commemorate their transition from active cancer care to survivorship. For many patients—and their M. D. Anderson physicians—the moment

is a bittersweet one.

"Our patients develop relationships with their providers that go on for years—literally, for 5 years—and then their providers need to send them on. Even though these providers are still involved in their patients' follow-up, they no longer actually provide hands-on care, and that's difficult after having established a relationship that is so special and deep-seated," Ms. Garcia said. "But it's also difficult for those same providers, when they are already seeing 30 active cancer patients in the clinic each day, to make the time to address survivors' needs as well."

Although the emotions surrounding a patient's transition to long-term survivorship may be mixed, the motivation behind M. D. Anderson's survivorship program is not.

"We want to be the benchmark for survivorship care," Ms. Zandstra said. "And we have an obligation to the patients we've treated—we were there with them through their diagnosis and treatment, and we don't want them to feel as though they're falling through the cracks after they've completed treatment." ●

For more information, contact Dr. Rodriguez at 713-792-2860, Ms. Zandstra at 713-745-8717, or Ms. Garcia at 713-792-6864, or log on to myMDAnderson.org. Parts of the Institute of Medicine report mentioned in this article can be found online at <http://www.iom.edu/?ID=30869>.

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