Pinpointing Pain: Is It Cancer or Cancer Treatment?

Distinguishing side effects of treatment from a potential metastatic recurrence can be tricky; we asked cancer experts for their best advice.

July 18, 2023 By Fred Hutch News Service and Diane Mapes

After treatment for cancer, oncologists generally send you home with a slew of surveillance appointments and a reminder to reach out should you happen to notice any symptoms that are new and different.

The only problem? Your body's been through the mill. Everything feels new and different.

Weird aches and pains abound after cancer treatment, making it hard for patients in remission to figure out whether they're suffering a treatment side effect or experiencing the first whispers of a cancer recurrence.

"I see patients with different types of cancer and a lot of the time, they want to know 'Is this pain related to recurrence or is it something else?'" said Fred Hutchinson Cancer Center's Medical Director of Cancer Rehabilitation Hanna Hunter, MD. "In a lot of cases, it's something else."

Most early-stagers know that even after systemic (or system-wide) treatments like chemotherapy and/or anti-hormones, their cancer can become metastatic, spreading from its original site to organs like the lungs, liver or brain, and triggering pain, shortness of breath, headaches and other symptoms. They also know cancer treatment can cause all manner of collateral damage.

What they often don't know is how to tell one from the other.

Worried about some strange new ache in your hip? Starting to stress out over that migraine? We turned to cancer patients and clinicians for answers on how to discern between pain and symptoms that are "normal" after treatment from those that need to be evaluated by your cancer surgeon, oncologist or primary care physician.

I have bile duct cancer. My back and kidney area hurt. Is

it a kidney infection or did the cancer travel to my kidneys. Kidney doc gave me antibiotic. Hope that's it. — TootsieRol???????? (@llldaisy) May 3, 2023

'Okay, What's This?'

"I worry about cancer recurrence every time I get a new ache or pain," said Gogs Gagnon, a 63-year-old prostate cancer survivor from Courtenay, British Columbia. "I must have called my doctor dozens of times over the years. I'm lucky she hasn't changed her phone number."

Six years out from his prostate cancer surgery, Gagnon said he's had "a few recurrence scares," including a red, painful lump he thought might be breast cancer. It turned out to be an infection, easily cleared up with antibiotics. But another lump months later — this one in his groin — caused more concern and eventually required surgery. Luckily, it, too, was not cancer.

"Another day, I woke up with severe pain in my hips," Gagnon said. "From my research, I knew prostate cancer can spread to bones, usually your ribs or lower back or hips. That pain turned out to be some kind of strain — too much work in the garden — but everything is a scare. It's always, 'Okay, what's this?'"

Marina Rockinger, a 55-year-old radio personality and lobular breast cancer patient from Seattle, said she can totally relate, as she also struggles to pinpoint what's causing symptoms.

"I get weird pains all the time and I'm constantly fatigued," she said. "I can never figure out if it's just life or all the post-cancer meds and collateral damage."

Recently, she noticed pain on her left side where the breast with cancer was removed and a new one reconstructed. Worried it might be a recurrence, she checked in with her oncologist, who suggested a CT scan.

The result? Simple post-mastectomy pain.

"It was normal and fine," Rockinger said. "But the aches and pains can be really frightening on a day-to-day basis. I try to keep in mind I'm still taking [anti-hormones] and Verzenio and the side effects of those drugs can mimic other things."

4 am thoughts: If you hated the game "Is it a cold or is it

covid?” do not, under any circumstances, unlock the advanced level “Is it osteoarthritis or is it metastatic cancer?” @ThanksCancer

— Elizabeth Fletcher (@esfletcher) May 3, 2023

How Common Is Progression?

Unexplained symptoms like pain can be especially troubling because there’s insufficient data as to how many early stagers go on to develop metastatic, or stage 4, disease.

Cancer registries like the National Cancer Institute, or NCI’s, SEER program track stage at diagnosis and biomarkers and many other crucial details regarding people’s cancer diagnoses, but they do not capture data on metastatic recurrence. Fuzziness around these numbers — and patients’ desire to better understand their cancer — prompted Fred Hutch biostatistician Ruth Etzioni, PhD, to drill down into the national cancer database to tease out actual numbers.

Etzioni and her NCI collaborators used modeling and survival data from several cancer registries to glean intel about recurrence rates, determining that 20% of early-stage breast cancer patients with estrogen-receptor positive cancers develop metastatic disease within 20 years.

More recently, she used registry data on prostate cancer to determine that there are 120,400 men living with metastatic prostate cancer in the U.S. Around 45% of those men were de novo, or metastatic at diagnosis; the other 55% progressed to metastatic disease after their early-stage diagnosis and treatment. Etzioni, who hopes to use modeling to determine precise metastatic prostate cancer recurrence rates, said the number of men living with metastatic prostate cancer is “still far outnumbered” by early-stagers whose disease had never progressed.

Colorectal cancer also progresses to metastatic disease in about 35% to 40% of early stagers post treatment.

But in the majority of patients, early-stage treatment eliminates the cancer.

Unfortunately, treatment can also take a toll, particularly on patients with existing comorbidities, or health issues. And after going through it, even the hardiest of us may require time to get back to our pre-cancer strength and stamina, said Hunter, the rehab doc.

“The body needs time and sometimes retraining after treatment,” she said. “It’s been through a marathon. We have to work on improving stamina and fitness and getting back to that baseline.

We have to come up with a return-to-play program geared towards a patient's lifestyle and goals."

Doing so can make a real difference in quality of life, she said.

"All the symptoms that patients experience — the fatigue, pain, weakness — they're very real and need to be addressed and they can be addressed by a rehab team," she said. "And that can lead to an improvement in quality of life."

Cancer or Cancer Treatment?

Hunter treats patients undergoing treatment for all kinds of cancer — everything from AML to uterine cancer — and sometimes, she's the very first stop in their therapy.

"I sometimes see patients even before the cancer treatment," she said. "I may need to treat knee pain or back pain before a bone marrow transplant. We call that prehab. We know it's going to take a big toll on their body, so we help them before their surgery or therapy."

She's also trained in treatment for lymphedema — a potentially painful condition where parts of the body swell with fluid after the removal of lymph nodes (often due to cancer surgery) — and works with people who've undergone amputations and/or reconstructions.

Fatigue, she said, can persist for months after chemotherapy or radiation and can wax and wane, depending on how much a person exerts themselves. That's normal. But if patients develop new fatigue, especially without triggers, that can be a red flag.

Same goes for aches and pains. Many patients, she said, try to do too much too soon and end up with an injury or strain.

"But when there's pain unrelated to an activity and it's constant whether the patient is resting or sleeping, that's more worrisome," Hunter said.

Cancer treatment can also exacerbate previous injuries, she added.

"We see prior injuries flare up after treatment because of decreased muscle and being a little more sedentary," she said. "If it's an injury that individuals have experienced prior, we often have to rehab that injury again."

What's 'Normal', What's Not?

Fred Hutch medical oncologist and clinical researcher Hannah Linden, MD, said she usually sees three kinds of pain in her breast cancer patients: pain due to surgery, pain due to endocrine (estrogen-blocking or -depleting) treatments and pain from metastatic recurrence to the bone.

Surgery pain could include post-mastectomy pain (an aching or burning in the surgical sites),

mobility problems like “frozen shoulder” or lymphedema.

“We often think about lymphedema in the arm but it can also be present in the breast, in the chest wall and even in the upper back,” Hunter said, adding that “normal” pain could also include nerve pain along the chest wall from surgery or radiation.

Achy joints from estrogen-squelching medications are also common.

“Aromatase-induced arthralgia happens to some estrogen-receptor positive patients,” Linden said. “It can happen to the folks on tamoxifen, too.”

Acupuncture has been shown to help with joint pain and stiffness from endocrine medications, Linden said. And rehab and physical therapy can help with post-surgery pain, Hunter added.

As for how arthralgia pain differs from bone metastasis pain, one patient called it unmistakable.

“I woke up one morning with excruciating rib pain,” said A_Research_Guru, a metastatic breast cancer patient from Idaho who asked to be identified only by her Twitter handle. “It was as though I’d been kicked by a horse while sleeping.”

Five years out of treatment for her early-stage ductal breast cancer, “Guru” first reached out to her primary care physician, then when the pain worsened and she still had no answers, went to the ER. A PET scan revealed she had metastasis throughout her skeleton.

What did her metastatic bone pain feel like?

“The pain is very complex and different from other pain,” she said. “It’s very hot, deep, and mine would throb with any strain whatsoever. And it was excruciating, pain levels around 7 to 9. Once you’ve experienced it and learn it’s from cancer, your mind just seems to know.”

> Is it a herniated disc or is it a relapse of aggressive B cell lymphoma?
>
> — Dr Vaguechera (@vaguechera) May 3, 2023

Empowering the Patient

Prostate cancer patients out of treatment often have “normal” pain and side effects, as well, including back pain or decreased musculature that can contribute to incontinence.

Pelvic floor muscle and abdominal exercises often help, Hunter said.

“Some exercises are for strengthening and relaxing and some are to retrain the muscles to work and coordinate again,” she said. “There’s been a drastic change to the body. We need to get those complex, intricate muscles to work together again.”

Fred Hutch urologic oncologist Yaw Nyame, MD, MS, who cares for people with prostate, kidney and other urologic cancers, said providers can sometimes forget how “routine symptoms” can feel to patients.

"To cancer patients, they’re absolutely jarring,” he said. “They’ve never seen this before. It’s important we don’t dismiss symptoms or questions that are presented.”

That’s why Nyame does everything he can to empower and reassure his patients, including managing expectations.

“It’s really helpful for individuals to understand what’s to be expected,” he said. “What is normal and what is not. And that starts even before treatment. I usually write down a list of things that can happen, explaining how in the first 30 to 90 days, they may experience X, Y or Z. That’s the pre-education side. On the post-treatment side of things, it’s all about availability.”

Nyame said his patients always have a direct line of communication to him and that his care team is equally accessible.

“We have incredible nurses and practitioners who can also answer a lot of questions that come up,” he said. “The conversations can be very short, but they’re reassuring to patients. Or sometimes, there is an issue and we’ll tell them to head for the ER.”

Many genitourinary surgeries, he said, are minimally invasive with some expected side effects, like muscle soreness, shoulder pain or even blood in the urine. But if pain is severe and symptoms like blood in urine persist, it’s time to call the doctor.

“I always tell my patients it’s not just the presence of blood; it’s that plus something else,” he said. “Blood in urine plus difficulty urinating. Blood in urine plus feeling faint. Or some pink urine but a lot of pain. These raise a concern. Reach out.”

Rachel Becker, a 38-year-old librarian from Madison, Wisconsin, diagnosed with early-stage breast cancer last year, said she doesn’t really understand what she’s supposed to look for.

“It feels like you’re abandoned in a way,” she said. “They said if I had any new symptoms, to call after two weeks. But it would be helpful if I could hear from people who’ve experienced pain that turned out to be a cancer recurrence. I honestly don’t know what it feels like.”

A lack of clarity about symptoms of metastatic recurrence is one reason metastatic breast cancer patient advocates like Joanne Taylor of ABC Diagnosis in the U.K. have created resources to help

early stagers better pinpoint advanced cancer pain.

Taylor commissioned infographics for the two most common types of breast cancer — ductal and lobular — to help patients identify "mets" symptoms. Her infographics, translated into a number of different languages, are available on her website and are used within the U.K.'s National Health System.

A Slow Onset of Symptoms

Unfortunately, symptoms of metastatic disease can sometimes be hard to recognize. Especially when they come on gradually.

"I ignored my symptoms for six months, attributing them to allergies or getting old or being out of shape," said Courtney Preusse, a Fred Hutch program operations director from Frederick, Maryland who was treated for breast cancer at 31, then progressed to metastatic disease 13 years later. "It was largely because I thought I was cured. Cancer was no longer on my radar."

Preusse first developed a cough, she said. Weeks later, she started to "huff and puff" going up hills.

"I still remember walking up a hill thinking, "I am so out of shape, I've got to get back to the gym!'" she said. "I did the same thing hiking on Mount Rainier. I thought 'I must be slightly anemic. I don't breathe well at high altitudes.' I told myself all these lies month after month."

Her coughing eventually got so severe she woke up to a sharp pain. Assuming she'd broken a rib, she went to an urgent care clinic and asked the doctor for an expectorant and an X-ray. Instead, the doctor noted her history with breast cancer and begged her to go in for a scan. Preusse reluctantly agreed and when she arrived at the ER, the person at the front desk took one look at how hard she was breathing and called for a bed — STAT!

"I was looking over my shoulder to see who was sick," Preusse recalled. "It was me."

Preusse spent the next few days in the hospital; one of her lungs was full of fluid and needed to be drained repeatedly. An analysis of the fluid found metastatic breast cancer cells.

"I was like the frog in water that doesn't notice as it heats up," she said. "It came on so slowly. It never even dawned on me, even as they were draining fluid from my lung. I kept thinking, 'It's pneumonia. I was cured.'"

After going back into treatment, her symptoms subsided. But following a move across the country, they came roaring back.

"My tumor markers doubled, then doubled again and again," she said. "I demanded a scan and

when I had it, all of a sudden, I had all of these tumors. I thought I was going to die."

Thanks to genomic sequencing and a clinical trial for a drug that targets one of her tumor's mutations, FGFR1, Preusse is back in remission. And like many cancer patients who become metastatic, she wants to help others help others avoid her mistakes.

"Nobody told me the ways cancer might recur," she said. "I thought I might find a lump in my breast or I'd get a tiny spot on a scan. I didn't know that I would almost drown in lung fluid."

Hunter, the rehab doctor, said patients should report symptoms even if they're mild.

"Even if it doesn't feel like severe pain but if it seems out of the ordinary, a work-up may be warranted," she said. "Or if there's a new neurological symptom like weakness or numbness or discomfort, we'll want to package it together with the imaging we have to find out what is causing the symptoms."

Persistent and Progressing? Call the Doc!

Rachel Issaka, MD, MAS, a gastroenterologist who often sees cancer patients undergoing gastric symptoms, agreed it can be hard to differentiate symptoms of treatment from those of recurrence.

"There are a lot of GI symptoms associated with side effects of treatment like nausea and vomiting and they're sometimes hard to tease out from recurrence," she said. "We want patients to at least communicate with their health care team if they're experiencing them. Especially if the symptoms are persistent and progressing and not responding to anything."

Side effects from treatment can also last for months, she advised. And patients who are immunocompromised due to treatment or stem cell transplants, are vulnerable to infections, which also cause GI symptoms. New drugs, such as checkpoint inhibitors, can also produce symptoms that can be confused with recurrence.

Holder of the Kathryn Surace-Smith Endowed Chair in Health Equity Research, Issaka said that when the GI tract is not working well, the effects are "profound and immediately noticeable." Luckily, she and colleagues have multiple options to help with these symptoms. She also emphasized that not everyone has unpleasant side effects from cancer treatment.

"A lot of people have no symptoms at all at the end of their treatment," she said. "And that's awesome."

Others, like Gagnon, continue to monitor their post-treatment aches and pains, checking in with their oncologist when necessary. And doing their best to be at peace with uncertainty.

"I've had rib pain for over a year now," he said. "My oncologist sent me for all kinds of tests — X-ray, CT scan, bone scan, ultrasound and MRI — and everything came back normal but the pain's

still there. So I'm wondering, 'Is it cancer?'' If I knew that it wasn't cancer, I would be able to live with the pain a lot more comfortably. If it is, it's not at a detectable point yet."

Gagnon, who's met many patients with prostate cancer through the book he wrote about his experience, said one story has stayed with him.

"One of my friends' cancer came back after ten years," he said. "He told me before he died, 'I wish I would have gotten my secondary treatment sooner' and that haunts me. He had to wait — same thing as me. We have to wait for it to show up on scans."

Etzioni, who recently received a large grant to evaluate the efficacy of several multi-cancer early detection tests, thinks this will change shortly.

"We now have liquid biopsies that can be used for detection of minimal residual disease or for recurrent disease," she said. "They're not yet established and widely available, but there are tests out there that have been approved and they'll be folded into cancer treatment guidelines and clinics soon. Much is going to change in the next few years."

SIDESTORY

Top Tips for Dealing With Post-Treatment Pain

Wait two weeks and see if it goes away. That helps me relax about whatever I'm feeling so I'm not so reactive. — Rachel Becker, 38, librarian and breast cancer patient, Madison, Wisconsin

Talk yourself through it. Did you do something recently? Work out? Fall down? I asked myself the questions the doctor would ask. If it doesn't go away, I'll go in. — Marina Rockinger, 55, lobular breast cancer patient, Seattle, Washington

Do not suffer in silence. There are many available treatment options to manage nausea, acid reflux, abdominal pain, diarrhea, constipation and other issues. — Dr. Rachel Issaka, Fred Hutch gastroenterologist

Acknowledge your pain. I know so many men, including prostate cancer survivors, who won't admit they have pain or discomfort — and it's really important to get that message out there. — Gogs Gagnon, 63, author and prostate cancer patient, Courtenay, B.C.

Don't gaslight yourself. I ignored my symptoms for 6 months telling myself it was other things, like getting old. It was metastatic breast cancer. — Courtney Preusse, 43, metastatic ductal breast cancer patient, Frederick, Maryland

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