

PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

SUMMER 2023

Coping With Fear of Recurrence

Among people who have been treated for breast or other cancers, the fear of the cancer often does not go away. Even after years of being told there is no evidence of the disease, you may worry about cancer progressing, returning in that breast, the other breast, or another part of the body. No matter what stage of cancer you had, it is not possible to know for sure if cancer will come back after treatment ends. Your doctor can tell you more about your risk of recurrence and coping with this fear of another diagnosis.

For Pathways Study participants, fear of cancer returning, or recurrence, is a common issue. Feeling worried is a normal part of life and everyone feels anxious from time to time. When our feelings are out of balance with how likely the feared event might be, or when anxiety is overwhelming or leaves us



feeling helpless, we may need some help.

Paula, a member of our Community Advisory Board (CAB), spoke with three others and we also heard from Joanna Hathaway

(breast care coordinator, KP San Rafael) and Dr. Samantha Siegel (internist, KP Davis) about what fear of recurrence is and how to manage these feelings. This fear can and does cause anxiety and affect quality of life; for some, more days than others. Pathways' participant and CAB member Linda said,

"The uncertainty and fear never really left me." Paula just wanted to get on with life and not think about cancer. "I tried my best to ignore that I had cancer. But it creeps into your thoughts."

It is hard to live with this uncertainty, and it is important to know that this fear is completely normal for people to experience.

When Do You Worry?

It can help to identify if there are things, times, or places when you start thinking about cancer too much. There are some common triggers.

- Pain is a strong predictor of fear for many. Maria said "The past year my body has been acting funny, more aches and pains, and it makes me wonder ... if it is coming back. So, I go into the doctor to see if anything is going on." Linda said, "If there is swelling or pain, it causes anxiety."
- Scans, such as mammograms, often cause fear. This trigger is so common that 'scan' has been combined with 'anxiety' to form 'scanxiety'. Pat told us, "My biggest anxiety is before my mammograms and waiting for the results."
- Reminders of breast cancer can happen on the anniversary of the diagnosis, in October (breast cancer awareness month), or anytime. For Linda, one trigger is "the constant commercials on TV for patients with metastatic breast cancer." When she recently lost a family member to breast cancer, "this reinforced the fears I already have."
- Reminders of breast cancer may also occur while adjusting to body changes caused by treatment.

Coping With Fear of Recurrence continued

- Thinking about family can also raise worries. Paula said, “Now my daughters have cancer in their family history.” According to Dr. Siegel, “seeing the fear in their loved ones’ faces will trigger their own fear.”

Managing Anxiety

It is useful to have multiple coping strategies in your toolkit. Here are a few:

Share and Process Your Feelings. This can be done alone (naming your fears aloud, journaling or drawing them), with another person (friend, family or professional) or in a group. Naming and expressing emotions can help. For many it is useful to talk to others. Linda said, “You need to tell them what is going on with you. If you do not let people know that you need help, then you won’t get any help or support.”



Become a Joiner: Support Groups. Many people sing the praises of their groups. Dr. Siegel said, “I was never a joiner or support group person until cancer.” For Linda, “It allows me to express myself, people are actually listening.” Some people must search for the right group or a good fit, and if you find one that you like, it could be a good place to learn about tips



and techniques for living in a post-cancer body and mind. Pat wanted to “find out what a cancer survivor should do. The meetings that were available to me were not for survivors, so I kept looking until I found (the right) cancer group.”

Deep Breathing & Mindfulness. You can relax your mind and body by doing yoga, sitting quietly, breathing deeply, or meditating. Linda has a quiet room where she meditates, or “I listen to quiet music with no words,” she said. KP members can use the Calm app for free for help with these activities. Maria told us, “My yoga instructor helped me to visualize myself healthy, breathing while I’m meditating, and a Bible verse helps me.”

Distract Yourself. Sometimes it is enough to do something or think about something else and get your mind off cancer for a while. Do something that you enjoy. Linda sits on her deck and watches the wildlife. Watch a funny or suspenseful movie. Put on lively music and dance. Catch up with an old friend.



Make Your Follow-up Care Plan. Some people seek reassurance from having more tests and appointments, while others want to avoid seeing a doctor and skip or delay visits. Talk with your health care providers about what your recommended schedule for follow-up visits and tests should be, such as mammograms, and at what age you might stop having scans. Ask questions so



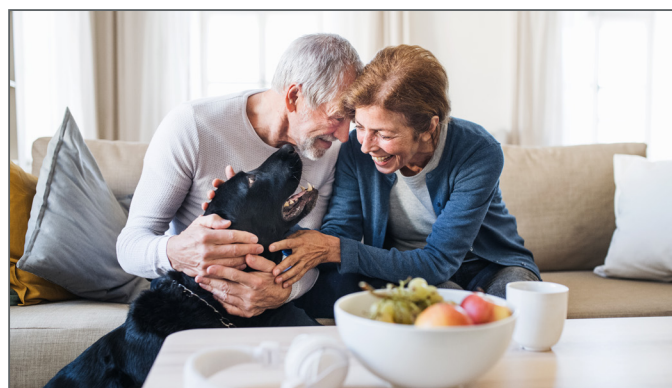
you understand why those specific recommendations were made. Maria was offered annual visits with an oncology nurse practitioner, so she spaces those with her yearly mammograms and primary care doctor appointments about four months apart, and it keeps her anxieties in check.

Control the Things You Can. Dr. Siegel likes to help people see that there are things they can do to support their health and healing, besides waiting for the next scan, such as exercise, healthy eating, massage, and acupuncture. For example, in the Pathways Study, we found that women who increased their physical activity after breast cancer had lower mortality rates than women who did not (Troeschel, et al., Cancer Epidemiology, Biomarkers and Prevention, 2023). Linda suggests managing your diet and your life as best you can. “Educate yourself to know your diagnosis and how to manage it. The more education you have the more you can alleviate some of your anxiety.”

Meaningful Activities. A new activity or a new goal can provide a sense of purpose. Gardening can be great if you have containers or space. How many steps do you want to walk, maybe with a friend? For some people, cancer

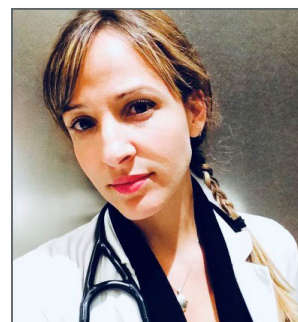
sets their life in a new direction. Stacey, diagnosed at 40, has made cancer patient advocacy her life’s work and her career. For Pat, “Doing something for someone else takes my mind off of my own fears.” Helping can be informal, with family, friends and neighbors, or volunteering online or with a local organization.

Remember, some fear is normal. The important thing is to manage it in healthy ways. If worry or anxiety gets in the way of your relationships and daily activities, prevents you from going to your follow-up care appointments, and/or leaves you feeling hopeless about the future, you may want to seek additional help.



Keep in mind that you are a cancer survivor and remember the good news: You are one of millions of Americans alive today who has had cancer, and the survival rate is still improving. Like most of them, you, and the people around you can adjust to and continue to lead a fulfilling life after cancer. www.cancer.org/cancer/survivorship/be-healthy-after-treatment/life-after-cancer.html

Special thanks to Dr. Samantha Siegel, Internist at KP Davis, cancer thriver, survivorship advocate and integrative medicine enthusiast for her contributions to this article (pictured here). ☒



ADDITIONAL RESOURCES

Developing Resilience

Some women benefit from building up their resilience. This can be by accepting the fact that things change and we can't control what happens, only how we feel about it; looking for the big picture to learn from our experiences; developing a strong support network of people that are stable and loving; learning to believe in ourselves and how to approach difficult situations; or taking good care of ourselves and developing habits to improve our health and decrease the risk of a recurrence.



Individual KP facilities may have different support programs. Joanna Hathaway (pictured here), a Breast Care Coordinator at KP in San Rafael has offered Expressive Arts workshops and is creating a new, 6-week course on fear of recurrence for breast cancer survivors.

You Are Contributing

Many of you reading this newsletter may find comfort in participating in research such as the Pathways Study. Knowing that the information collected from the surveys answered by you and the 4,503 other women that joined this study is used to find ways to improve the length and quality of life of future patients brings a sense of satisfaction to many. We hope this is also a motivator to continue your participation in Pathways; even after so many years of participation, we continue to need your input.



Mental Health Services

No matter where you are on your journey, many mental health services and resources are available to you, including classes to manage anxiety. You can reach mental health services at: <https://healthy.kaiserpermanente.org/northern-california/health-wellness/mental-health/services>

Kaiser Permanente offers their members free access to Ginger, an app that gives you access to 24/7 text-based emotional support coaching where you



can discuss goals, share challenges, and create an action plan with your coach.

As a Kaiser member you also can get the My Strength app, which builds a personalized plan

to strengthen your emotional health whenever and wherever you need it. ☒

PATHWAYS FORUM – Thriving After Breast Cancer

We had our first Pathways Forum webinar in February 2023, hosted by our community partner Zero Breast Cancer. There were about 140 attendees, and the recording has been viewed more than 100 times on YouTube. <https://www.zerobreastcancer.org/zbc-does/speaker-series/pathways-breast-cancer-webinar-series>

The polls taken during the webinar showed that about half who attended were people living with breast cancer, survivors or thrivers; around 25% were researchers; and the remaining were family and/or friends of people with cancer, patient navigators and breast care coordinators, and health care providers.



Most people were interested in hearing about the Pathways Study findings (52%), nutrition (50%), breast cancer (47%) or Vitamin D (38%). The forum content was well received. Those responding said they left the forum with an increased understanding of Vitamin D (70%), diet & nutrition (59%), and the Pathways Study (74%).



We are especially grateful for participants' feedback as we start preparing the next Forum. Your comments are helping to improve the next event in the following ways:

1. The presentations will use less scientific and technical language. We will still base presentations on science evidence, including from the Pathways Study to explain the 'why', and ensure that we bring it back to what it means to our participants.
2. We will have more Q&A time, so that we can answer as many of your questions as possible during the Forum.

If you attended the Forum and would like to give us feedback, you can reach out to us with your comments by calling our toll-free number: 1-866-206-2979 or emailing us at DOR-pathways@kp.org. ☒

NEXT PATHWAYS FORUM

We are excited to announce the **2nd Pathways Forum: People, Places, and Breast Cancer: The Pathways Study and how our communities impact survival and quality of life.**

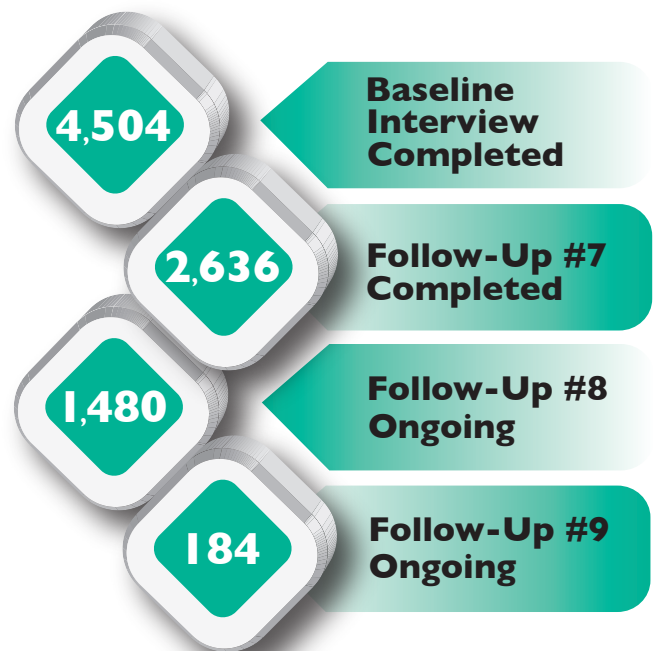
Mark your calendar for this online Zoom webinar on September 21st, 2023 at 11:30 a.m., featuring Dr. Salma Shariff-Marco, PhD from UCSF and Dr.

Candyce Kroenke, ScD from Kaiser Permanente Division of Research who will present highlights of their Pathways and other research on how our surroundings impact survivorship after breast cancer

You will need to register online to attend. Pre-register now using the link or the QR code: or this link: zbclink.org/PathwaysForum2



PATHWAYS UPDATE – Who Is Participating



We are grateful for your role in the Pathways Study. All of you add meaning and diversity to our team and contribute your unique perspectives to the information we are gathering. Thank you for participating! ☒

New Contact Information?

To keep in touch with you we must have your latest contact information. Please let us know if your phone number or home address has changed. You can reach us by calling our toll-free number: 1-866-206-2979. ☒



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