



PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

WINTER 2020-2021

How Pathways Members are Taking Care of Themselves during Covid-19

For most of us, cancer changed our lives. The Covid-19 pandemic is changing our lives again. In much of Northern California, we went through a time of wildfire smoke and now the days are shorter due to the winter season. Members of the Pathways Study Community Advisory Board (CAB) decided self-care is an important and timely topic for us to address.

Am I at higher risk for Covid-19?

Cancer and cancer treatment can affect our immune systems, the parts of our body that find and fight infections, including the virus that causes Covid. People who have immune problems are likely at higher risk of having worse Covid symptoms. Chemotherapy is hard on the body's defenses, but after treatment ends, it usually goes back to normal over time. Studies haven't shown that endocrine therapies, like Tamoxifen, raise the risk for getting Covid or having a more serious illness.

In the early days of the pandemic, it was harder to get follow-up cancer care, including mammograms and other screening. For the safety of our members, community, doctors, and staff, KP temporarily closed some facilities, limited services or hours at others, and expanded virtual and phone care options. To protect yourself and others, they ask that you not come into a facility without an appointment. You have many other ways to get quality care, including phone appointments and email. Clinicians will determine if you need an in-person appointment. If you do need to come in, rest assured that KP is taking every precaution to help keep our facilities safe.



Laura, a Pathways CAB member, said that the pandemic has raised her fear that her cancer could return. Fear of recurrence is common in people who have had cancer. And it can cause more stress and make anxiety worse. Many of us are also worried about other things. Mia, another CAB member, said, "as everything has piled on top of the next thing (health, economy, climate, politics) staying positive takes much more effort."

Our health is about much more than seeing a doctor or taking medicine. Along with KP, Zero Breast Cancer (a Pathways partner), focuses on things we can do to take care of ourselves, as individuals and as a community. Self-care means prioritizing your health and well-being, being kind to yourself, and supporting your mind, body, and spirit. This is especially important during difficult times.

So, what were five breast cancer survivors on the Pathways CAB doing to care for themselves before the pandemic and how has that changed? What has helped and what gets in the way of self-care? Read on for what Sara, Mary, Mia, Irene and Pam are doing and ideas for you. As Irene said, "Somehow, we all need to cope with the reality we are living with!"

**Note the names have been changed to protect privacy.*

Continued inside

Taking Care During Covid-19 *continued*

Move your body

Being physically active is not only good for our bodies, it also helps our minds and our moods. It even helps our immune system! Studies show that breast cancer survivors with even low and moderate activity have better mental and physical health. Every little bit helps, too. Being physically active also reduces cancer risk, including a recurrence.



The aim is to get our heart rate up for 30 minutes a day, all at once or broken into 5- or 10-minute bursts. Several CAB members used to take exercise classes, at a senior center

or a gym (some are free or have discounts). Mia told us her gym closed and stayed that way. Mary's classes shut down, too. "After 3 weeks, people started thinking outside the box," she said, and her classes moved online. "I am able to do everything I did before, but differently." She is still taking yoga, Zumba, and Feldenkrais Method classes.

Taking a class online doesn't always work. Sara's water aerobics classes have been canceled. Irene told us, "Trying to get my exercise is difficult and so very necessary. The exercise class I loved does not work for me anymore," she said. "Recently I started learning exercises from a physical therapist at KP. This helps to do effective exercises at home."

Sara is still able to go for walks. Her group is smaller than before, and they wear masks and keep distance between them. Mia walks after work. "I love walking and commit to 10,000 steps each weekday; I try for 20,000 on weekend days. The city I live in is beautiful, so walking is pleasant."

Having someone else to move with can be very helpful. Mary said, "My husband and I spend a lot of time walking our dog in the neighborhood and on the beach. Funny, we were able to meet

'new' neighbors that had been here for years, but with everyone's busy lives prior to Covid we never met." She also gets together with friends to walk with masks and at a distance. Pam and her husband "started exercising inside the house and riding a stationary bicycle." Before long, Pam reported, "I bought a new bicycle and we've been riding outside."

If you haven't been moving much lately or have health problems that limit your ability to move, you can start low and build slowly. KP has coaching and offers free, on-demand videos to help get and keep you moving (see Resources on page 5).

Eat well

It can be hard to eat healthy, especially in times of stress. On the other hand, being at home so much, some people are taking more time to think about and cook food. Pam said that since Covid, "We have been eating healthier and lost weight." Mary noted that she "was cooking more the first 3 or 4 months and maintaining weight. Now I don't know what happened. I got tired of cooking and I've been eating a lot of comfort food and eating out. I've gained 10 pounds, which now I have to work off ... not happy about that!"

The risk of getting cancer again is lower if we eat mostly food from plants. Irene said, "Last week, I was told to work toward learning to live on a plant-based diet, because there is concern about my kidneys. I will take a class on this issue and clearly, anything I used to do needs to be evaluated and probably changed."



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Stress can also cause changes in appetite—Sara has been eating less—or emotional eating. Ask family and friends to practice healthy eating with you, and share healthy, delicious recipes and cooking tips. If you need more help, talk to your doctor or a registered dietitian.

Look online for groups that support healthy eating and share success stories. Find delicious, healthy recipes on the KP Food for Health blog or check out healthy cookbooks at your local library. You can find the blog in the Total Health section of the kp.org website.

Connect with people

It's so important for us to be with others and not alone all the time. Mia, like some other CAB members, lives alone. She said, "Staying connected to people (beyond work zoom calls) has been difficult."



Spending time with family and friends was a big part of Pam's life. Many of us are finding new ways to get together, through video calls, online gatherings on Zoom, or meeting in parks and other outdoor spaces at a distance. For Pam, camping is her happy place. While she can't hang out with family and friends like she did before Covid, she said, "we did start to camp again at some point and it has made a big difference. It's different, but since it's outside it provides a way to see some of our family and friends."

Mary is enjoying "prayer sessions and book club geared to self-help, both are on zoom." And she's met more people online. "I wouldn't have met these people if I hadn't participated in the online activities," she noted.

Still, many of us miss being able to touch others. "The biggest change," said Mary, "is the physical contact. I miss the hugging." Pam has been looking for a safe way to hug her grandson. We each need to decide for ourselves about what risks we are willing to take.

In June, Mary and her husband found out that we are going to be first time grandparents! "I was excited, but sad at the same time because my daughter lives in the Los Angeles area. We got a trailer to keep our distance from strangers while we headed down to see my daughter. I am grateful and thankful that I am able to go visit, especially when the baby is due."

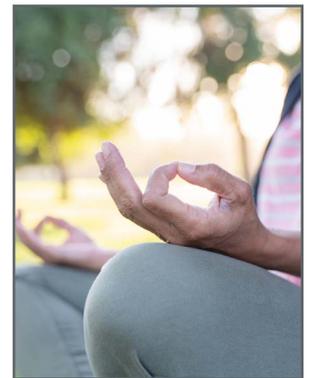
Take a Break

Many of us are feeling stress. Some of us are now spending all our time at home with many other people. Some of us are trying to work and help our kids keep up with their schoolwork. Listening to music, watching a comedy, and reading or listening to a book can take us away from our daily stress. Mia said, "I listen to books while walking and it is a time when I can just get away from it all. The exercise is good for my body and getting taken away into a plot is great for my mental health."

Mary likes to read the Bible, "it calms me down," she says. Sara told us that when she feels depression is pulling at her, she tries "to help other people with their problems to keep busy and my mind occupied."

Breathe deep, meditate or pray

Meditation and deep breathing can calm us immediately. In only one minute we can reduce stress and anxiety! If you have a smartphone or tablet, check out these apps to get you started:



- Insight Timer is a free app that leads you through breathing and meditation in many languages;
- Calm is a similar app that is available for free to KP members;
- KP's myStrength has a variety of guided meditations free for KP members.
- UCSF has free online meditation classes for cancer survivors, including in Spanish.

Walking alone can be a moving meditation, a chance to look at trees, flowers, water, birds or other homes



and breathe deeply. Just being in a park, in a garden or on a street with trees can lower stress. Being in green spaces, or near water, has been shown to improve mood and mental health. Mary says she is “fortunate to live in a green area with lots of trees and trails near the ocean.”

Ask for support

We all need help from time to time and it is okay to ask for support. Talking to someone in a safe space can help us figure out what we’re feeling. Sharing those feelings can help ease the burden of keeping whatever it is that’s bothering us a secret. And, by talking to someone and sharing our experience, we form closer connections with the people we trust.



We may need support from someone outside our circle. Women sometimes feel that we can’t ask for help because we are supposed to care for others. People in some cultures may not be used to talking about emotions or mental health. Sara shared that she has always suffered with depression and other health issues. Since the pandemic, she said, “I started to reach out to my doctor for some kind of therapy.” If you have depression, anxiety, addiction, or other mental or emotional issues, check out KP resources. You don’t need a referral for mental health services, but your primary care doctor can connect you with support and help you access care. If you don’t know where to start, KP has online self-assessments you can take, and you can share the results with your doctor.

Get your sleep

Sleep has a big impact on our physical health and our emotions. Stress can affect our sleep and lack of sleep can make stress worse. It is also important for our immune systems. Prioritize sleep by setting a



bedtime for yourself, keeping devices and screens out of the bedroom, and creating a relaxing bedtime routine. Experts also say to turn off screens at least 30 minutes before going to bed. The article “Insomnia: Improving Your Sleep” has helpful tips on the subject, you can find it the Health & Wellness section of the kp.org website.

Gratitude

Did you know that seeing the good in our lives can help us feel better? Mia is committed to practicing gratitude every day. What does this mean? Just take a moment every day to think about 3 things that you are grateful for in your life. It helps to keep things in perspective and increase our positivity. You can learn more about the practice of gratitude by going to the KP Health Encyclopedia and typing in the word gratitude.

Moving Forward

Mary says that we may have “the thought that you can’t do this, that you can’t do that. But you can actually do many things with caution and mindfulness. You can do it but you do it differently. The mentality has to shift.” For Pam, the pandemic has made her think about what is important and remember what she wanted in life. She is planning a big change!



We want to hear from you! What are you doing to cope and take care of yourself during this pandemic? Please share your stories and ideas, so we can include some in a future newsletter.

Resources

If you are looking to make a lifestyle change, KP can partner you with a wellness coach to create a customized plan that outlines small, easy steps that you can take to manage your weight, quit tobacco, reduce stress, increase activity or eat healthier. You can schedule convenient phone sessions at times that work for you. Coaching is available at no cost to Kaiser Permanente members, in English and Spanish. No referral is needed, call **(866) 862-4295** for more information. ☒

THRIVE LOCAL CONNECTIONS

Staying healthy is not only a result of high-quality medical care alone. A person's total health depends on important social factors, such as access to basic nutrition, a safe place to live, economic opportunities, and reliable transportation.



Many of our members are struggling with needs they never anticipated — safe housing and food, utilities and transportation costs, and even meeting the cost of their medical care.

In response, Kaiser Permanente launched Thrive Local Connections (TLC), a national member call center that aims to connect members to social services to help them stay healthy.

TLC is not intended to replace any existing programs within the KP care delivery system, but rather to add a new resource for members coping with unforeseen pandemic-related needs.

The service is free to KP members, please call **800-443-6328** to access this service. ☒

PATHWAYS UPDATE

We continue to contact participants to complete our surveys.

Some of you still need to complete the 96-month follow-up survey, it is a very short questionnaire that you can answer in about 5 minutes.

Everyone else is now doing annual follow-up surveys. This questionnaire takes about 15 minutes to complete. Starting this winter 2020, we are incorporating a new section to collect information about how the COVID-19 pandemic is affecting the participants of the Pathways Study. This part of the survey takes an additional 20 minutes. We hope you can find the time to share your experiences with us.

It is critical to the quality of the study to have as many participants as possible complete each survey to help us learn more about the different aspects of breast cancer. We will work with your schedule to make your participation possible.

As always, we greatly appreciate your continued dedication to the Pathways Study. If you missed our call and would like to complete your survey, please call or email us. In addition, to keep in touch with you, we must have your latest contact information. Please let us know if your phone number or home address have changed. You can reach us by calling our toll-free number: **1-866-206-2979** or email **DOR-pathways@kp.org** ☒

UPCOMING NEWSLETTER

We had planned to share, in this newsletter, an article on heart health issues as a side effect of breast cancer treatment but because of the ongoing COVID-19 pandemic, we decided to postpone our Cardiovascular Disease issue to share information that might be of more immediate use during these difficult times.

You can still contribute to the upcoming cardiovascular disease issue. If your cancer or treatment caused heart health problems, then feel free to send us an email or leave us a voice mail message. Thank you!

We want to thank those of you who reached out with your comments and feedback about our newsletters. We want you to know that we read and listen to all your messages and use this information to improve the content we decide to share with all of you. We want the information we share in the newsletters to be useful to our participants.

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

For the most up to date information on the Pathways study, please visit our website:
<http://pathways.kaiser.org> ☒



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