



PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

WINTER 2019

MEMORY & THINKING PROBLEMS AFTER BREAST CANCER

Have you heard the term Chemo Brain? For years, women treated for breast cancer reported memory and thinking problems, and unfortunately they were mostly ignored. Finally, beginning about 15 years ago, an increasing number of researchers and doctors have come



to accept that cancer and cancer treatment can cause such problems. They are working to understand what is happening and how to help people who have had cancer deal with Chemo Brain, also known as Cancer-related Cognitive Impairment

(CRCI). We can take heart, that most of us will recover our brain function and that there are things we can do to deal with memory/thinking problems.

One breast cancer survivor named Karen shared her story of CRCI with our Community Advisory Board (CAB) member, Paula Coombs. Karen lives in Contra Costa County and was diagnosed when she was 39 years old, and her 3 children were all under 9 years old.

It is real and you are not alone

Perhaps the most important thing for some of us to know is that real, physical changes have taken place and that others have gone and are going through the same thing. We are not losing our minds! For Karen, memory issues started a couple of months after chemotherapy.

One day I was going somewhere in the car and suddenly was not sure if my one-year old son was in the car; I did not remember buckling him into the car seat. This was frightening for a Mom. Another time I was at the grocery store and couldn't remember my debit card PIN and had to switch to a credit transaction.

CRCI is a dreaded side effect of cancer. It affects memory, decision-making, attention, and processing speed. Research shows that some breast cancer patients report these cognitive problems beginning at diagnosis. Early CRCI appears to be linked to more severe physical symptoms, fatigue and emotional distress or worry. One study using

functional Magnetic Resonance Imaging (fMRI) to view brain activity during a memory test found that women who received chemotherapy performed worse than other breast cancer patients and healthy controls, and that their brains were working much harder.¹

Imaging studies suggest that the brain's structure is changed temporarily by chemotherapy, disrupting the organization in several areas and reducing the ability to process information.² Hormone and targeted therapies can also cause cognitive problems.³ Work is continuing to determine who may be affected, with age and genetics identified as likely risk factors.

Knowing the cause of our CRCI can be a relief, but how do we deal with these changes?

Managing memory/thinking problems

Scientists have studied many ways to improve memory and cognition after cancer. Some interventions help by managing fatigue, including healthy eating, good sleep, aerobic exercise, and meditation/deep breathing. (Check out KaiserPermanente.org's Health Encyclopedia for "Cancer: Home Treatment for Fatigue" or the video "Cancer: Help for Fatigue.")

For ongoing CRCI, there are things we can do to cope. Karen told us that she was and is frustrated with her memory changes. "I'm not the same Mom I used to be; I have to step back to a new normal," she said. "I have slowed down and simplified." This is in line with other CRCI advice:

1. Allow more time to do things than you did in the past
2. Avoid multi-tasking
3. Reduce clutter and keep important things in a designated place (like your phone)
4. Follow a routine
5. Find ways to organize yourself – a checklist, notes, a calendar, smart phone apps or alarms, etc.

For Karen, an online calendar was invaluable. "I found that using Google calendar for every little thing helped... I use reminders on the calendar for the day before and then the hour before. Alarms and reminders are really useful for remembering medical appointments and when to take

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medications. They can also help to establish healthy habits, like setting a time for exercise and for getting together with friends.

The people in our lives are also critical for providing support and keeping our brains working. Cognitive changes are not something that others can see. It is important to share your memory or thinking problems with key people to encourage them to be patient and not expect you to be the same person you were before cancer.

For Karen's young family, it wasn't easy to deal with her memory deficits. "I would say it left them confused at times, shocked at times, but they accepted that it was due to the cancer treatment and didn't dwell on it too much." When her daughters see that she has lost her cool, they say "it's okay, you had cancer; it's not your fault!" And she has a husband who has taken up the slack so that she can rest. It isn't always so easy for our families to accept our forgetfulness or step up when we can't do or keep track of things. The American Society of Clinical Oncology's Cancer.net has lots of tips for talking about these things with spouses/partners and with kids.

For those of us who were working when diagnosed with cancer, it may have been tough to decide when to go back to work and how much to share about cognitive and other problems with our boss and colleagues. The workplace can be a source of socializing and self-esteem. One survivor was supported by her employer and co-



workers as she built back up to full-time. Some of the moms in Karen's support group said that going back to work helped to improve their memory. Another

survivor said she could no longer handle two different computer systems and luckily was able to retire.

Time with friends can be an important social connection. Karen recalled a time when she was out with a friend and in the middle of telling a story she suddenly couldn't remember what she was talking about. She told her friend she lost track of the thought and it wouldn't come back. "Friends don't realize that memory loss is actually a thing," Letting friends know that this is normal after cancer treatment and that it should get better can make both of you feel better!

We can also meet new people while we challenge our minds. One benefit is that they don't have any expectations about our thinking abilities and all of our stories will be new to them. Some possibilities for building social time include:



1. Taking a class at a community or senior center
2. Volunteering time and talents to help a cause
3. Traveling, whether a local walking tour or an international adventure
4. Connecting with old friends and new on social media

Fortunately, more research is ongoing on how to help people who have had cancer cope with cognitive difficulties and improve our quality of life during and after cancer. As of 2014, however, only one type of program was found likely to be effective: cognitive training.⁴ Cognitive training in these studies involved repeating sets of structured problems or mental challenges and led to significant improvements in executive functions (thinking flexibility and speed) and some improvement in memory. Until they can tell us more about the type or amount of training needed, we can try new hobbies, play games, and solve puzzles as a fun way to engage and stimulate our brains!

As Karen noted, we need to remind ourselves that this is our new normal and move forward with our memory or whatever other changes we are experiencing. If you are concerned about your memory or thinking ability, talk to your health care provider for ideas about what to do.

The Pathways CAB hopes that this article is useful, and we encourage you to share it with others. Our next article will cover pain as a side effect of breast cancer treatment.

Do you have an idea or a story to share about how your cancer or treatment still caused you pain at least 2 years later? Please send a brief summary via email to DOR-pathways@kp.org and we may contact you for an interview in early 2020. Thank you!

1. Jung, M.S., Zhang, M., Askren, M.K. et al. Brain Imaging and Behavior (2017) 11:86.
2. Bruno, J., Hosseini, S. M. & Kesler, S. Altered resting state functional brain network topology in chemotherapy-treated breast cancer survivors. Neurobiology of disease 48, 329–338, doi: 10.1016/j.nbd.2012.07.009 (2012).
3. M Lange, F Joly, J Vardy, T Ahles, M Dubois, L Tron, G Winocur, M B De Ruiter, H Castel, Cancer-Related Cognitive Impairment: An update on state of the art, detection, and management strategies in cancer survivors, Annals of Oncology, mdz410
4. Ah, Diane Von et al. "Evidence-based interventions for cancer-and treatment-related cognitive impairment." Clinical Journal of Oncology Nursing, 18 Suppl (2014): 17-25.



New Annual Health Update Survey

We have started to call those of you who have completed the 96-month Follow-Up Survey to now complete the new Annual Health Update Survey.

What to expect? This new survey takes about 20 minutes to complete and is divided into four main sections. The first section is an update about your breast care and health conditions, the second part asks about your quality of life after the breast cancer diagnosis, the third section has questions about the quality of your sleep and the last section focuses on memory and concentration.

Our interviewers will reach out to you to schedule a time that is convenient to complete this survey. We try to be flexible and will work with your schedule. Our goal is to be able to complete as many surveys as possible since the results are more valuable when more people participate.

If you were not able to complete this survey when you were contacted by our interviewers but would like to complete it now, please call our toll free number (1-866-206-2979) and we will schedule an appointment with you.

We are grateful for your participation in Pathways. All of you add meaning and diversity to our team and contribute your unique perspective to the information we are gathering. Thank you for participating! ❖



Brain Fitness

In our new Annual Health Survey we have included a new section on memory and concentration. We've heard from our Community Advisory Board and many of you that brain fitness is an area of concern. We wanted to share with all of you that Kaiser Permanente offers a free Brain Fitness class for both members and nonmembers, you do not need a referral to attend but you need to register. In this one session class, you will learn the basics of brain function, things that negatively impact memory, and ways to improve brain health.

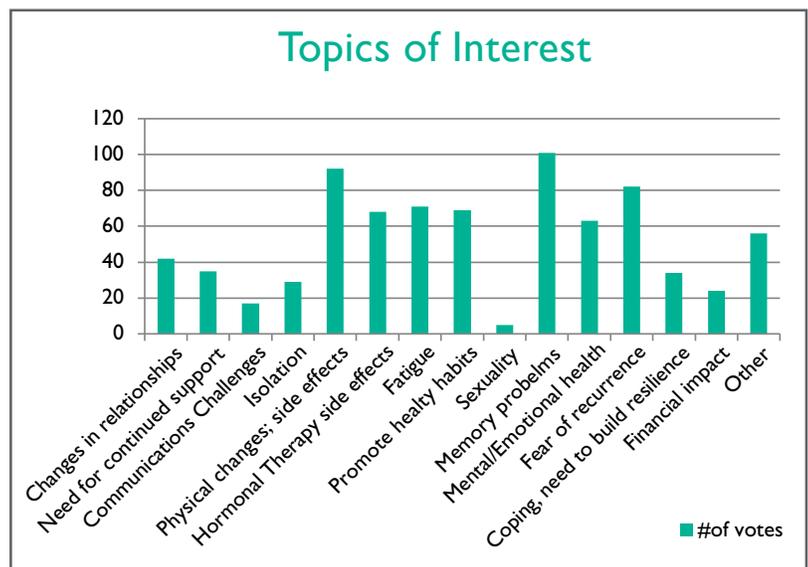
This class is being offered every three months at KP South San Francisco. The new class schedule will be out in December. You can call: (650)742-2439 for more information. ❖

Results of the Postcard on Pathways Study Topics of Interest

You might remember receiving in the mail a light purple postcard asking about what topics would be of interest to you for our researchers to focus on and to highlight in the future.

In the chart to the right, you can see the results of the 235 postcards we have received so far. Your answers were taken into consideration by our researchers when deciding the new questions to add to our new Annual Health Update Phone survey.

It's not too late to mail your postcard. You can mail your postcard or you can leave your reply on our toll free number: 1-866-206-2979. ❖



New Contact Information?

In order 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** or email us: **DOR-pathways@kp.org** ❖

For the most up to date information on the Pathways study, please visit our website:

<http://pathways.kaiser.org> ❖

