Strategies for Overcoming “Chemobrain”

The most common symptoms reported by cancer survivors include being forgetful, easily distracted, or disorganized. Although commonly called “chemobrain” or “chemofog,” chemotherapy may not be the sole cause of mild cognitive impairments in the aftermath of cancer treatment. Even as they are feeling better physically, some cancer survivors find themselves having issues with short-term memory, information-processing speed, and the ability to organize information.

“In our clinical care, the most common problem we hear is difficulty finding words or names—the tip-of-the-tongue experiences,” said Karen Syrjala, PhD, co-director of the SCCa Survivorship Clinic. “You see a good friend in the grocery store, and you know her name as well as you know your own but your brain can’t seem to make the right connections to retrieve the name. Some people feel easily distracted or unable to calculate in their heads as easily as before. People also frequently report short-term memory issues and difficulties with hand-eye coordination.”

Getting Assessed

Since numerous health and behavioral factors can affect optimal cognitive functioning, Dr. Syrjala recommends that cancer survivors who have concerns start with an evaluation. It should include an assessment of the type and degree of any medical problems, medications, nutrition, sleep patterns, stress level, and any mood disorders such as depression or anxiety, which often reduce cognitive functioning.

Depending on the severity of the problem, treatment may include intervention by an occupational therapist, who can help with on-the-job accommodations and cognitive training. You may get help with at-home strategies such as using a notebook, smart phone calendar, or other aids to track appointments and reminders. Research is making it clear that one of the best ways to improve “chemobrain” is regular exercise. Survivorship Clinic staff can help you find cognitive rehabilitation and fitness programs. For information or to schedule an appointment, call (206) 288-1024 and ask for the Survivorship Clinic.

Steps to Clear the Mental Fog

Many survivors find that their memory problems improve over time. Until then, try these strategies to cope with post-cancer cognitive difficulties.

Get Organized

» Use a notebook or electronic aid such as a smart phone to keep track of appointments and to-do lists. Put all appointments, notes, and reminders in one place.

» Use sticky notes or a dry-erase board in a visible place to remind yourself of things you need to do. Put a sticky note by something you never forget (perhaps your toothbrush) to remind yourself of something you tend to forget such as morning medication. If you find yourself overwhelmed by scattered notes, put reminders or checklists in a single spot, like a notebook.
Myth Busters

Myth: “Chemobrain” Is All in Your Head
Even though patients have been talking about these problems since the 1970s, only in the last decade has systematic research been conducted. As science does a better job defining the difficulties stemming from “chemobrain,” many in the medical community who were once skeptical have come to accept its existence.

The prevalence of “chemobrain” is hard to pin down. Estimates of cancer patients affected range from about 14 percent to as high as 85 percent. It depends on the type of treatment, whether testing is done during or after treatment, and individual vulnerability to the effects of cancer and treatment.

Cognitive deficits are largely temporary and most patients can expect a return to normal executive function, including high-level, multi-tasking abilities, within five years, based on a study of bone marrow and stem cell transplant patients led by Dr. Syrjala. However, the study, published May 2, 2011 in the *Journal of Clinical Oncology*, also found that memory and motor coordination remained lower in five-year survivors than the regular population that had not received cancer treatment. “About 20 to 30 percent of cancer survivors have long-term cognitive effects that may impair their ability to manage the demanding world we live in,” said Dr. Syrjala, who is also director of Biobehavioral Sciences at Fred Hutch.

Myth: Chemotherapy Causes “Chemobrain”
“Blaming cognitive problems solely on chemotherapy is too limiting,” Dr. Syrjala said. One of the central puzzles of “chemobrain” is that many of the symptoms can occur for reasons other than cancer treatment. Baseline studies of cancer patients after diagnosis but before treatment have found a higher percentage than expected scored below average on tests for verbal fluency and memory. Coexisting factors like increased age, fatigue, stress, and non-chemo medications make it difficult to determine the main causes.

Hormone changes and immune fluctuations common with cancer treatment contribute to cognitive problems. Stress hormones as well as reproduction-related hormones can change thinking. These stress hormones also affect sleep. “So it’s easy to see how sleep, stress, and thinking are related and how much these can all be thrown off by a cancer diagnosis and treatment, and why exercise and stress management can help to regulate the body’s healthy cycles and help thinking,” Dr. Syrjala said.

Practice New Habits
- Use the alarm on your phone, watch, or clock to remind you of important scheduled events like appointments or needing to take medication.
- Adjust your schedule so you do your most intensive brain work when you are most alert.

Take Care of Yourself
- Get a good night’s sleep to boost memory and concentration.
- Exercise regularly to help steady your thinking, stabilize emotions, increase confidence, and decrease fatigue. Moderate physical exercise has been shown to improve memory and decision-making abilities. Exercise also can reduce levels of inflammatory cytokines, which can impair thinking.
- Learn to meditate and practice it 15 minutes a day. This quiets the “noise” in your head and helps with concentration and thinking. Mediation tapes can be found online or check with the SCCA Patient and Family Resource Center or Survivorship Clinic.
- Try yoga and relaxation classes to help you develop your ability to focus.
- Take steps to manage your mood. Frustration, depression, and worry worsen memory and attention.

Get Help if You Need It
- Ask for help on the job or at school. Special accommodations (such as having more time to finish tests or tasks) might be the help you need.
- Seek help with depression or anxiety if it’s more than you can manage on your own.
Women Who Exercise After Breast Cancer Live Longer

October is Breast Cancer Awareness Month and as good a time as any for breast cancer survivors to take up exercising. Research shows that exercise after diagnosis is linked to longer survival and higher quality of life, but many breast cancer patients and survivors are not meeting national guidelines for weekly physical activity. The recommendation calls for 2.5 hours of moderate-intensity exercise per week, such as brisk walking or vacuuming, or 1.25 hours of vigorous-intensity activity per week, such as running or heavy yard work.

“Women with breast cancer significantly decrease their levels of physical activity after diagnosis and, as a result, few are meeting even the minimum standards set by the surgeon general,” said Anne McTiernan, MD, PhD, who studies the relationship between exercise, weight, cancer prevention, and survivorship at Fred Hutch.

Even small steps can make a difference. If you have a job that requires sitting for much of the day, Dr. McTiernan suggests trying to incorporate some activity. “Try to get up and walk around a little at work or during your lunch breaks,” she said. She also encourages exercise programs tailored to cancer patients and survivors such as:

• Exercise and Thrive
  www.fhcrc.org/exerciseandthrive
• Team Survivor Northwest
  www.teamsurvivornw.org

Physical activity can improve your emotional health, help you manage stress, improve “chemobrain,” maintain a healthy weight, and reduce your risk of heart disease.

For women who have completed cancer treatment, the Women’s Wellness Clinic can help you shift your focus to recovery. You will receive a Wellness Plan that includes nutrition tips, fitness recommendations, and emotional support. For more information, call (206) 288-7222.

Ashley Walker, Nearly Two Years Cancer-Free

Two years ago, Ashley Walker noticed a flattening on her breast. She felt a lump. At 29, she figured it was nothing, but she called the Breast Health Clinic at SCCA’s Women’s Center just to be sure.

The very next day she saw Laila Mansoori, ARNP, who ordered an ultrasound. The findings led to a mammogram and then a biopsy. That afternoon, Laila referred Ashley to SCCA’s Breast Cancer Specialty Center with a suspicion of breast cancer, which was confirmed as stage IIIA invasive ductal carcinoma in situ.

Ashley met with her team, which included Sara Javid, MD, surgeon; Julie Gralow, MD, medical oncologist; and Janice Kim, MD, radiation oncologist. Ashley decided to have a bilateral mastectomy. “I wanted to get rid of it!” she said.

After the mastectomy, Ashley received five months of chemotherapy and six weeks of radiation. In between her treatments, she got engaged to her fiancé, Shawn, and they bought a house together.

“I had two lives—my normal life and my cancer life,” Ashley said. “I had my work and friends; I went out on the weekends. When I needed to, I went to my cancer appointments.”

Getting cancer when she was young and healthy angers Ashley, and she does have a fear of it coming back. But she doesn’t let it stop her.

In August 2014, she and Shawn, got married. She plans to get a tattoo of a cherry blossom branch with a pink ribbon. And for the next few years, she’ll take tamoxifen and make regular follow-up visits to the Women’s Wellness Clinic.

“Some say, ‘why me?’” Ashley said. “But, cancer made me stronger. It made the best of me come out—that’s why Shawn proposed. I prefer to feed on the positive. It perpetuates and attracts more positive.”

This October, you may see Ashley’s picture in Safeway stores in honor of Breast Cancer Awareness Month.
By Kim Jordan, Registered Dietician

Does sugar cause cancer or feed cancer cells? While there is no direct link between sugar consumption and cancer risk, the sugar in our diet and in our blood can play a part in increasing cancer risk. For the average American, sugar plays a role in excess calorie consumption; the resulting weight gain and metabolic changes can promote cancer.

Sugar in Our Diet

For most Americans, added sugar in sweets and processed foods far outweighs the sugar we consume from natural sources. This is partly because we are unaware of the sugar added to processed foods that do not taste sweet, such as pizza sauce, canned vegetables, and fast foods.

The average American eats more than twice the sugar suggested by the American Heart Association—an average of 22 teaspoons per day versus the recommended six teaspoons for women and nine teaspoons for men. Most nutrition labels list sugar in grams and there are about four grams of sugar in one teaspoon. Excess added sugar plays a role in weight gain and seems to promote fat gain around the middle, technically known as visceral adipose tissue (VAT). So it’s really what sugar can do to your waistline that sets the stage for cancer.

Sugar in Our Blood

One of the main ways fat promotes cancer is by changing the way we respond to carbohydrates. Overweight and obese people often have a condition called insulin resistance. This means blood sugar has a harder time getting into cells; it remains in the blood, and the body must produce more insulin to try to normalize blood sugar levels. This condition is caused by numerous factors but excess abdominal fat is a main driver. And the process spirals: Instead of being used for energy, extra sugar in the blood is often converted to fat and stored. As more fat is gained, insulin resistance worsens, and so the pattern repeats itself. Insulin resistance leads to higher blood levels of insulin and insulin-like growth factor, which promote low level, chronic inflammation, that supports a pro-cancer microenvironment within the body.

Fat cells impact cancer risk through other mechanisms as well.

» They produce leptin, a hormone that promotes cell proliferation; and is significantly higher in overweight or obese people.

» They reduce adiponectin, which inhibits cell growth.

» VAT cells, especially, can produce cell proteins called inflammatory cytokines that prevent other cells from responding to insulin as they should.

» They influence tumor growth regulators.

» They produce estrogen, high levels of which may increase the risk of breast, endometrial, and other cancers.

The connection between sugar and cancer is indirect but potentially powerful. The best approach is to avoid processed and convenience foods that have added sugars. To satisfy your sweet tooth, eat fruits and vegetables, which package natural sugar, numerous phytonutrients, and fiber that help protect against cancer.
Remember Your Caregivers in November

November is National Family Caregivers Month, a great time to thank your caregivers for their support. Consider giving them a break by doing chores for them or making them a special meal. Family and friends who provide emotional, financial, nursing, social, and other support play an important role in helping patients thrive after cancer treatment.

Apple-Almond Tart

This great fruit-based dessert has the added bonus of fiber and phyttonutrients from the almond crust. This might look a little complicated, but it's not. In less than 30 minutes you can be baking a delicious treat.

Crust ingredients:
- 1 ½ cups almond meal or flour
- 1 pinch sea salt
- ¼ teaspoon baking soda
- ½ teaspoon ground cinnamon
- 1 teaspoon pure almond extract
- 3 tablespoons walnut or extra virgin olive oil
- 1 tablespoon real maple syrup
- 1 tablespoon water

Steps:
1. Preheat the oven to 350°F.
2. Place a rack in the middle of the oven.
3. In a mixing bowl, stir together the almond flour, sea salt, baking soda, and cinnamon. Break apart any lumps with your fingertips.
4. In a small bowl, stir together the vanilla, oil, maple syrup, and water. Add the oil mix to the flour and stir the dough together with a rubber spatula until thoroughly combined.
5. Turn the dough onto a 9-inch pie plate or tart pan. Use your fingertips to press the dough, making sure to press it all the way up the sides of the pan.
6. Place the tart on a sheet pan and bake 15 minutes, or until the crust is a light golden brown.
7. Remove the tart shell from the oven and let it cool.

Filling ingredients:
- ¼ cup butter, at room temperature
- ½ cup powdered sugar
- ¾ cup almond meal/flour
- 1 tablespoon whole grain pastry flour
- 1 large egg
- 1/8 teaspoon almond extract
- 3 medium apples, cored and sliced thin
- ¼ cup granulated evaporated cane juice sugar (may substitute regular granulated sugar)
- ½ tsp ground cinnamon
- 4 tsp butter, melted

Steps:
1. Line baking sheet with parchment paper; set aside.
3. Place apples on top of almond mixture in a spiral. Mix together sugar and cinnamon; sprinkle evenly on top of apple slices. Drizzle melted butter on top.
4. Refrigerate tart on baking sheet for 15 minutes.
5. Bake at 350°F for 18 to 20 minutes or until golden brown. Serve immediately.

Makes approximately 8 servings.
Two survivors who climbed Mt. Adams will talk alongside Dr. Julie Gralow about setting goals and sticking to them at this year’s “Healthy for the Holidays” event on Saturday, Nov. 8. This free event will also include a healthy cooking demonstration and presentations on exercise benefits for survivors and preventing late effects from cancer treatment. The event will take place in the Thomas Building on the Fred Hutch campus.

Healthy for the Holidays is sponsored by the Fred Hutch Survivorship Program and the Women’s Wellness Clinic.

Continental breakfast and registration start at 8 a.m. Presentations begin at 8:30 a.m. and end at 12:30 p.m.

Space is limited. RSVP by Oct. 31 to survivor@fhcrc.org or (206) 667-2013, or register online at www.fhcrc.org/en/treatment/survivorship/events-education/holidays/healthy-for-the-holidays-2014.html. The website includes a map and directions. Free parking is available that day in any surface parking lot.
Spiritual Struggles after Transplant

Spiritual and religious struggle is common among people who have received bone marrow or stem cell transplants, even years after the procedure, according to a survey conducted by the Fred Hutch Bone Marrow Transplant Program at SCCA from July 2011 through June 2012. Such struggles were reported by 27 percent of the people who responded.

The survey included questions such as “Are you at peace?” and “How much strength/comfort do you get from your religion/spirituality right now?”

Survey takers were asked if certain statements accurately described them, including “I wonder whether God/Higher Power has abandoned me” and “I have doubts about my faith.”

Spirituality Research Focuses on Health and Healing

“A growing body of literature indicates spiritual struggle is strongly associated with bad outcomes like poor coping, longer hospitalizations, longer rehab, depression, anxiety, poor quality of life, and even mortality, but little is known specifically about survivors of stem cell transplantation,” said Reverend Stephen King, PhD, manager of chaplaincy at SCCA.

Analysis of 1,449 completed Long-Term Follow-Up (LTFU) surveys show that survivors are more likely to have difficulties in the spiritual or religious realms if they are younger (between 18 and 49 years of age) or report signs of depression or lower quality of life. There appears to be no correlation to a person’s religious preference or gender.

Screening Tools for Spiritual Help

Besides gathering information about survivors’ experiences, the survey is helping to identify the best tools to screen cancer patients for psychosocial distress, as required by guidelines that take effect next year from the American College of Surgeons’ Commission on Cancer.

Message from the Director

We’ve dedicated our fall issue to spirituality/religion because it is a big topic for many of you—as shown by your responses to the 2011-2012 special survey. We truly appreciate your participation in our annual questionnaire and topic-specific surveys. We use the information you provide to understand your experiences and perspectives.

We hope you enjoy receiving this newsletter. Thanks as always for staying in contact with us!

Best Regards,
Stephanie Lee, MD, MPH
Director of Research, Long-Term Follow-Up

“It’s very normal to have spiritual/religious struggles, even if you identify as agnostic or atheist,” Rev. King said. “That struggle can look very different in different peoples’ lives. For some, it means feeling punished by God. Others may feel in conflict about spiritual beliefs or practices with their family or religious or spiritual communities. Still, others may feel turmoil with the meaning of life or fear that they lack a strong enough faith.”

Rev. King advises talking to someone if you have these feelings, such as a faith representative, secular counselor with expertise in spiritual issues, or chaplain. For more information or to speak with a chaplain, contact:

phone: (206) 288-1099
e-mail: pastoral@seattlecca.org
For most people, one transplant is enough in a lifetime, but Debbie Bridge has had two—first to overcome non-Hodgkin’s lymphoma (NHL) and then to treat myelodysplastic syndrome (MDS).

Debbie recalls an extreme lack of energy as her main complaint before being diagnosed with NHL in 1997 at age 37. “I was a big-time walker,” she said. “I knew there was something wrong when I just didn’t have the energy for Bloomsday,” (an annual walk/run in Spokane).

Her doctor referred her to a Spokane oncologist for chemotherapy to treat her NHL, which put it into remission for seven years.

Recurrence Led to Transplant

In 2004, while being treated for appendicitis, Debbie’s doctors discovered that her cancer had returned. When it was clear she needed a transplant, “my doctor said, ‘You’re going to Seattle,’” Debbie said. “He insisted because he had worked often with (doctors at) Fred Hutch.”

Debbie received an autologous transplant using her own stem cells, which successfully treated her NHL.

Six years later, in 2010, Debbie developed MDS, a disorder in which the bone marrow does not make enough healthy blood cells. Her Spokane oncologist again referred her to SCCA. She was transplanted with stem cells from an unrelated donor in 2010, which cured the MDS.

A year later, she developed chronic graft-versus-host-disease (GVHD) and today receives care from her Spokane oncologist and SCCA’s LTFU Program.

Debbie attributes her strength to undergo so many years of treatment to her religious faith, and her parents, with whom she lives. “I couldn’t have made it through this without their love and support.”

Of course, Debbie has good days and bad days. “But I keep going,” she said. “God’s got plans for me. He’s not ready to take me home.”

In 1997, before she was diagnosed with cancer, she had prayed for a stronger relationship with God. “Going through this (cancer journey) is just part of that,” Debbie said. “God has guided me so far through everything.”

Transplant Support Group for Patients and Caregivers

Join us in person or by conference call.

What: A peer support group for patients and caregivers, facilitated by LTFU nurses. All transplant and returning follow-up patients are welcome.

When: Every Thursday, 11:30 a.m. -12:30 p.m.

Where: Seattle Cancer Care Alliance
825 Eastlake Ave. E.
Sixth Floor, Room 23

Conference Call Option:
1. Dial (641) 715-3300.
2. Enter 882679# at the prompt for a PIN number.

Long-distance charges apply. If you need financial help, we can provide a phone card.

Questions: Contact LTFU at (206) 667-4415.