

The Shepard Lantern

Cancer Center News

Summer 2008

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Marion L. Shepard Cancer Center
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Cancer Survivor's Day



The Marion L. Shepard Cancer Center and the Shepard Cancer Foundation hosted its 2nd annual Survivor's Day event on Sunday, June 8th at First Church of Christ in Washington. Nearly 40 local cancer survivors along with their family members and caregivers attended the event.

The featured speaker Amy Harwell is a cancer survivor and the author of several books related to dealing with cancer. She provided an inspirational message about her own journey with cancer. Cancer Center Medical Director, Dr. Jennie Crews recognized each survivor in attendance and each

were given a round of applause in honor of their battle with cancer. "This was a great opportunity for our staff to honor and recognize our patients and other survivors for their strength and courage during their battle with cancer," said Dr. Crews. It also gave our patients and their family members an opportunity to socialize with each other and to be able to share some of their own challenges and successes in the cancer journey. National Cancer Survivors Day, which is held each year in many communities around the world, is a symbolic event to demonstrate that life after a cancer diagnosis can be a reality.

Mark your calendars! Shaggin for a Cause Oct. 10th

See page 7 for more details

Food For Thought

To soy or not to soy

Laurel McKenzie, RD, LDN

Many women diagnosed with breast cancer are concerned about whether they should include soy foods in their diet. After all, we hear about the benefits of soy but we also hear that estrogen-like effects of the soy may make estrogen-sensitive cancers grow. So what's the explanation? Should we look at the ingredient list of every food and scrutinize the list of unintelligible words in the search for every speck of anything that sounds like soy, or glycine soja? The idea that soy foods are dangerous for women with breast cancer (or other hormone related cancers such as ovarian or endometrial cancer) causes much anxiety. Let's take a practical look at the topic and science behind the soy connection.

Soy, a member of the legume family, is a source of low fat protein which can replace the use of meats to reduce cardiovascular and cancer risk. Soy foods contain dozens of nutrients that appear to have many important functions in our bodies. They protect cells from damage, encourage damaged cells to die rather than keep multiplying, provide necessary nutrients that control normal cell growth, and help cell to cell communication; all being protective properties. Research connects 25 grams of soy a day to reduced cholesterol levels and for some women, less menopause-associated hot flashes.

Soy foods also contain a group of nutrients called isoflavones that are known as phytoestrogens. Since "phyto" means "plant" this translates to "plant estrogens." These phytoestrogens are not the same as human estrogens and they don't cause the body to produce excess estrogen. They are about 1000 times weaker than human estrogen. However, because of the similarities in the structures, scientists are very interested in how they impact our body. Researchers believe the isoflavones may have protective properties against some cancers like breast, prostate, colon and lung cancers. Large studies that looked at groups of women with a high soy intake

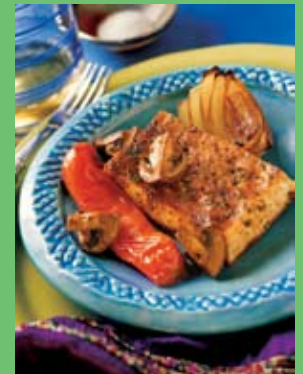
showed a lower risk of breast cancer and endometrial cancer, but there are many possible explanations other than the soy. Further human studies are needed and are on-going. Some studies suggest that the good effect of soy on breast cancer prevention is associated with consuming it at a young age when the breast tissue is developing in the teen years with less benefit as an adult. Some research shows that eating soy foods increases proteins that bind human estrogen in the blood, causing lower body estrogen levels.

With breast cancer, you are usually told whether your tumor is estrogen-positive or estrogen-negative. The estrogen-like quality of the isoflavones of soy worries experts that by adding soy to the diet of a person who

Oven Roasted Tofu

Ingredients:

- 16 oz Extra firm tofu, drained
- 3 tbsp Balsamic vinegar
- 2 tsp Soybean oil (vegetable oil)
- 2 tbsp Sugar
- 1 Clove garlic, minced
- ½ tsp Dried, crushed oregano
- ½ tsp Salt
- 1 Sweet red pepper, quartered
- 1 Medium onion, quartered
- 4 Medium mushrooms, quartered
- Chopped parsley for garnish



Instructions:

Cut tofu in half vertically then horizontally. Drain on several layers of paper towels to remove as much liquid as possible. Score surfaces to allow more marinade to penetrate tofu. Combine vinegar, oil, sugar, garlic, oregano and salt; mix well. Place tofu and vegetables in a shallow baking pan leaving enough space between the pieces for even roasting; brush with vinegar mixture. Let stand 30 minutes, brush again and let stand 30 minutes longer.

Bake tofu, pepper and onion at 500°F 30 to 35 minutes. Turn once halfway through baking time. Add mushrooms during last half of roasting time. Transfer to platter and sprinkle with parsley. Makes 4 servings.

had an estrogen-positive tumor may increase the chance of the cancer returning. Due to some of the studies, experts are not sure if soy isoflavones fight with estrogen in the body to lower the chance of the cancer returning or increase that chance by working with the body's estrogen.

After review of hundreds of studies on soy by experts, it is believed that *whole* soy foods like tofu, tempeh, miso, soy milk, edamame (green baby soy beans), and soy nuts, can be included in the diet without worry. Some say one to two servings per day is probably safe for a breast cancer survivor and others are more cautious and recommend only three to four serving per week.

There is most concern for use of soy isoflavone powder or pill supplements that are more concentrated forms and used on a daily basis. They are not adequately researched. It is best to tell your doctor if you plan to use these and be prepared for words of caution against it. If you use protein powders for added protein, use those made with whey or egg white proteins.

The American Institute for Cancer Research reminds people that, "current recommendations advise women taking tamoxifen or aromatase inhibitor medicines to avoid or strongly limit soy foods until treatment is concluded. Women who have had estrogen-positive (ER+) breast cancer may want to be somewhat restrictive in their soy intake (perhaps no more than a few servings of soy per week) until research provides clearer answers."

For cancer prevention, I propose that soy should be viewed in the context of the total diet. Adding highly processed soy foods like soy chips, soy supplements, and soy dogs to the "Americanized" high fat, low fiber, low plant-food diet would probably not be beneficial. But if you are focusing on healthy diet that is plant-food rich, high fiber and moderate in healthy fats, then *whole* soy foods fits well into this picture. A good website for recipes or to learn more about soy is www.soyconnection.com.

Rest assured, the decision to soy or not to soy is up to you. If the concept creates too much anxiety, it's perfectly acceptable to avoid; but if a little speck gets by you on that ingredient list, stay calm...it's safe not to worry.

Patient Perspective:

YOU have cancer ...OK, now what?

Jeff Tubaugh
Stage 4 Melanoma
Survivor

I have read many books on this subject and one that I have found to be very helpful is *Happiness In a Storm* by Wendy Schlessel Harpham. She is a survivor as well as a physician. Her book and several others have led me to the conclusion that it is healthy to be your own advocate. Throughout my journey with cancer I have had the opportunity to consult with many, many excellent doctors. I have also had the opportunity to visit and sometimes stay at some great hospitals and cancer centers. However, these institutions do not always do a great job of communicating with their patients or each other. There are many reasons for this and they are way beyond the scope of this little article.

The bottom line is you need to be **YOUR OWN ADVOCATE**. Don't assume anything! Always carry a hard copy of all of your records with you when you go for consultations and appointments at places other than with your own doctor. Always ask questions. Always write down the answers to these questions. If at all possible take someone with you to make sure you interpret the discussions correctly and are taking accurate notes. If you're not feeling good have that person take the notes for you then review them **BEFORE YOU LEAVE**.

Do **NOT** assume that every doctor will agree on your treatment. I'm a stage 4 melanoma survivor and the treatment suggested for me at Duke and UNC were completely different. After a lot of questions I decided on the treatment suggested by UNC. After some more questions and research I found that same treatment (a clinical trial) was offered at the Leo Jenkins Cancer Center only 20 miles from home.

ASK, ASK, ASK! Don't stop with just your doctor. There are a whole army of people that can help you. Another very important source of help is your social worker. This person, in many cases wears many hats and is connected to almost every professional you will want on your wellness team. They can put you in contact with mental health professionals,

Continued on page 4

Ask the Oncology Nurse

Myth busters: Chemo-Induced Nausea and Vomiting

Kristy Alligood, RN, OCN

I should expect to be nauseated and vomiting all the time when I start taking chemotherapy.

FALSE. Regardless of the stories you have heard from well-meaning friends and family, you should not have uncontrolled nausea and vomiting. The medical community has made numerous advances in understanding chemo-induced nausea/vomiting, including the development of several new drugs. Some of these new drugs are in IV form and will be given on the day of chemo. Some are in pill-form and will be given as needed by the doctor.

All people taking chemo will experience nausea and vomiting.

FALSE. Chemotherapy can react with the cells that line your stomach and intestinal tract, making you feel ill. This can also alter the way food tastes and can cause heartburn, both leading to nausea. Certain chemo regimens have a much higher risk than others for causing nausea and vomiting. People taking these chemotherapies often require additional instructions and medications to prevent these side effects. There are many options available to help you deal with this side effect. Your doctor and nurse will discuss these with you.

I should call my doctor if I start vomiting.

TRUE. All chemo patients are given a prescription for Compazine (a common anti-nausea drug). It is important for patients to take their Compazine at the first sign of nausea. If they continue to have nausea and vomiting, while taking Compazine every 6 hours as prescribed, then they should call the doctor. The nurse on-call will instruct you on other medications to take if needed. Again, it is important that you call the doctor if you have nausea/vomiting that is not controlled with Compazine. Uncontrolled vomiting can quickly dehydrate patients and potentially lead to hospitalization if not treated in time.

I should discuss my nausea with my doctor and nurse.

TRUE. Don't assume that your nausea/vomiting is "normal" and "to be expected". Talk with your doctor and nurse for additional ideas on how to manage these side effects. Some of these ideas may include: eating small, frequent meals, bland food, taking anti-nausea medicine 30 minutes prior to eating and drinking plenty of fluids to avoid dehydration. It also helps to wear loose fitting clothing, to rinse your mouth often to eliminate the bad taste in your mouth and minimize stimulation in the room you are in by reducing noise and turning off lights.

Patient Perspective Continued from page 3

dietitians, physical therapists and many many more people that you will want to have on your team

Always carry a notebook to write and organize your notes and ultimately your action plan. That's right your action plan! You are going to find that there is a lot more to getting well than just showing up for your treatments and appointments. Remember there will be times that you feel ROTTEN. Hey swallow your pride and ask for help. There are people all around you that WANT to help. BUT YOU HAVE TO ASK .

Remember your doctor next to you is the most important person on your team (at least that lives on earth). Always consult with them before you change anything about your treatment. They might agree or they might not. The decision is always yours. However, their opinion should always be valued and considered closely.

Jeff Tubaugh

A Stage 4 Melanoma Survivor and a board member of the Shepard Cancer Foundation.

Doctors Corner

Adherence to Oral Cancer Treatments

Jennie Crews, MD

The practice of prescribing pills to treat cancer is not new. For many years oncologists have used hormone therapy pills to treat breast cancer and chemotherapy pills to treat some types of blood cancers. Over the past five years, though, we have seen a surge in the number of new oral chemotherapy and biologic therapy medications for a variety of cancers. Oral therapies are more convenient for patients because they eliminate the need for frequent trips to the cancer center for infusions that can last for many hours. However, they pose new challenges for our patients. One such challenge is adherence. Adherence is defined as taking a medication, exactly as prescribed by a healthcare provider, on schedule, without any missed doses for the entire length of time that the medication is prescribed.

It is easy to assume that patients with serious medical conditions, such as cancer, would be the most adherent patients of all. However, this is not necessarily true and there are many reasons why. Barriers to adherence include:

- 1. Financial.** Some patients may find it hard to pay for their prescriptions. This can be an issue even when patients have insurance. Our patients with Medicare Part D often spend many dollars on their medications when they hit the “doughnut hole”.
- 2. Remembering to take medication.** Taking a pill multiple times a day or even once a day can be difficult, even for patients on a limited number of medications. Up to 64% of patients report forgetting to take their medication regularly.
- 3. Side effects.** Patients may stop their medication if they are experiencing side effects that negatively impact the quality of their lives. In a recent study, 28% of patients stopped their medication due to side effects. Another 25% said they stopped their medication because it prevented them from doing other activities.
- 4. Access to care.** Patients may run out of medication and have difficulty going to the pharmacy or

contacting their doctor for refills. Patients may change insurance plans or insurance plans may change the brand of medications that they cover.

5. Lack of belief in the benefit of the medication.

Patients may not understand why a medication has been prescribed or how it will benefit them. Such misunderstanding can make patients reluctant to take medication. Some patients may find it hard to continue a medication when they feel fine or are no longer having symptoms related to their cancer.

6. Self-diagnosing or self-prescribing.

Some patients think that if a little is good, then more is better. Taking too much medication is being non-adherent and can be dangerous. Other patients may feel that they are very sensitive to medications and may cut down on the dose without consulting their doctor. This is equally dangerous.

The cost of non-adherence is potentially very high. Not taking a medication as prescribed, can lead to increased side effects, hospitalization, and recurrence or progression of disease. The good news is that there are ways to ensure adherence to your cancer medication. At the Marion L Shepard Cancer Center, we have financial counseling available for those who find it difficult to pay for their medications. Many pharmaceutical companies provide free medication through patient assistance programs for patients who qualify. Our social worker, can provide you more information about these programs. Our nursing staff can suggest ways to remember your medications. Sometimes a pillbox or a calendar is a useful tool to help you remember. The nurses, Dr. Inzerillo and I are available to answer questions you may have regarding side effects and benefits from the chemotherapy or hormonal therapy medications that you take. Many of the side effects from these drugs can be minimized and we are happy to tell you how. Please remember to discuss concerns with your provider and never stop a medication or change a dose without consulting us first.

Healing Journals, Helping Journals

Rachel Victoria Mills, Ph.D.

“How do you do it?” Many of us in difficult times find that question before us, often from well-meaning friends and relations. Some of us have ready answers - “Oh, a little faith, a little luck!” Some of us, more truthful, have to admit, “I don’t know. I just keep going, I guess - one foot in front of the other.” We’d like to know how, but when the world we once took for granted seems to be revolving in a different direction than we are, not much seems knowable.

A Place to Find Ourselves.

Journals - often called “expressive writing” - are saving places to bring muddled thoughts and emotions in hand, and enlighten us along the way. We keep journals for all kinds of reasons - to record our everyday thoughts, or our travels; to pass along family stories and history; to chart the plantings of each year’s garden and how they fared; to sketch in new visions for art; to keep ourselves fit; to allow grief its place in loss; to open ourselves to a new passage - school, marriage, children, job. A journal is different than a diary, which generally states the facts of existence: a journal expresses and creates meaning.

Privately, in our own voices, journals help:

- explore the strengths and resources we already have;
- make sense of the puzzles and contradictions which confuse us;
- compare new routines and needs with former ones;
- follow the course of our experiences and build an overall picture;
- imagine new ways of doing things;
- make decisions, one step at a time, and hold them firmly (or not) in words on a page;
- reveal the values and principles that form who we are, mind and body.

A journal, in other words, is a good way to take control of our experiences at turns which leave us spinning and in danger of losing who we are.

A Place to Heal.

It sounds like complicated psychoanalysis, but it isn’t. Keeping a journal is something everyone can do. Lucky the talented artists and poets who can pour their souls into works of art and share them with the world! On the other hand, nearly everyone can put down simple thoughts, one word at a time, each word inspiring more and often surprising us with their discernment and insight. Some might be heartening or bring us relief; others overwhelm or bring us to tears. All of it, however, is beneficial. The journal is, after all, the hearth and home of our true reflections, the place where we look inside to heal.

Whatever jargon the outside world throws at us, especially in times of illness, journals help us invent a personal vocabulary for healing. In our own words, we can perceive and shape - and re-shape - our world to be more useful to us. Journals are excellent places to communicate not only with ourselves, but also with the professionals and relations who care for us.

Whatever disease is, it changes us, and change takes so much of our energy, spinning us off-balance for awhile. Whatever our role in caring, curing or surviving illness, we can address the stages of change we find physically and emotionally challenging:

- facing the loss of old ways
- working through pain
- minding emotions
- charting turns in the road
- gathering strengths and recognizing weaknesses
- adapting and re-inventing ourselves
- accepting difference and making it our own

Ah, but how to begin? Starting anything new always brings apprehension with it. But journaling has its own way of calming us:

Begin Here.

The **first** step is the easiest:

- Sit down in a quiet place, pen and paper or notebook in hand.

The **second** is just like it:

- Take a deep, deep breath - hold it, then let it go.

The **third** is almost instinctive:

- Ask yourself: "Where am I, right now?"

And then, the journal **begins**:

- Write down the words that come - from the inside, from the outside, from all around.

It's as simple as that. And **finally**:

- Keep going.

Accept what comes; think in no one's voice but your own, no one's ear listening but your own. Nothing is too insignificant; everything matters, even if at the moment you don't see how. Journal writers are after a much larger vista than the small present tense, an expanding, not diminishing, vision of possibility. The climb to it is worth a little patience with what we express a bit at a time.

Journals not only bring clarity, but also teach us what, essentially, we are as humans, rather than "patients" or "caregivers" or "relations". A journal, no matter how or why it is kept, is our Book of Life, a mirror in which we reflect, see and come to trust, understand, and know ourselves. That's the key to living through illness - or any of those unexpected turns that make a life story, if not always easy, always interesting.



Washington Civic Center
Friday, October 10, 2008
 6:30 – 11:00 p.m.

Beach Music Dance featuring the Craig Woolard Band
 Benefiting the Shepard Cancer Foundation

Tickets can be purchased at the following locations:

Marion L. Shepard Cancer Center
 Lifestyles Medical Fitness Center

Complementary Therapies

Restorative Yoga & Meditation

Free yoga classes are being offered on Mondays at 6:00 pm at Lifestyles Medical Fitness Center.

Conversations

A place for cancer patients to share their thoughts, concerns, fears and other feelings about the emotional and physical challenges of having cancer with other cancer patients. Offered the 2nd and 4th Tuesday of every month from 10:30 - 11:30am in the education room of the Marion L. Shepard Cancer Center.

Therapeutic Massage

FREE therapeutic foot, hand, and chair massage are available by appointment.

Journaling Class

Local teacher, poet and painter Rachel Victoria Mills will offer a workshop to help patients learn how to journal as a means of coping with the effects of having cancer. Thursdays 9:30 - 11:30am. October 9th through November 13th.

Knowledge is Power

Knowledge is Power is an educational forum for patients and caregivers who want to learn more about issues relevant to cancer. Programs are from 6:00-7:00pm. Dinner will be provided.

Registration is required.

September 9th – Guest Speaker, Allyson Daugherty, PT, CLT - Lymphedema

*All programs are for cancer patients, survivors and caregivers

For more information about any of these programs, or to register please call:

975-4308

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Cancer Center News

“We live for today, everyday”

-Cancer Survivor

