

HOPE & HEALING

CANCER INSTITUTE

BUILT TO BEAT CANCER

A guide to helping survivors navigate through their journey

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Northside Hospital Cancer Institute Call Center: 404.531.4444



ASK AN EXPERT

What Records Should I Keep During and **After My Cancer Treatment?**

By: Dawn M. Hayes, PT, PhD, GCS Manager Oncology Quality & Accreditation

Health care systems in the United States continue to be challenging and overwhelming, especially when you have a cancer diagnosis. Treatment of cancer may occur over a long period of time, require more than one type of treatment and include numerous medical office visits, often with multiple providers. While navigating your cancer care journey, one important activity to do during and at the end of your care is keep and organize all of your personal medical records.

Why is it important to keep copies of your medical care?

Maintaining your personal medical history and details about your care helps to prevent unnecessary tests being repeated, improves your care by informing the next provider about what has been done and helps you better advocate for yourself. Collecting and organizing your medical information helps you play an active role in your care and prepares you for discussions with your provider.

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How do I get copies of my information if needed?

One way is to ask for copies each time you visit a provider or receive care. If the practice has a patient portal, take the time to sign up and learn how to use the portal. This can be a very valuable source of updated information and dates for your event tracking. Both hospital systems and practices will have information about how to request copies of your medical records.

Collecting and organizing your medical information requires patience and persistence. If needed, ask for help from your family, friends or caregiver. Remember that collecting information on an ongoing basis can be less overwhelming.

What are some ways to organize the information?

Use a method you are most comfortable with, as you will often be the one who is using the information.

Below are two suggestions:

- Keep paper copies and organize in folders, a file box or three-ring notebook
- Keep the information electronically on a computer or USB drive

Adopt whatever method works for you and your caregivers. Most importantly, keep your information secure and protected. There are tools and services *(continued on page 2)*

Helpful Resources:

- 1. American Cancer Society, Keeping Copies of Important **Medical Records**
- 2. Mesothelioma Aid Organization, Personal Record-Keeping for Cancer Patients
- 3. Cancer.Net, American Society of Clinical Oncology. 3 Steps to Building a Personal Medical Record, 2018
- 4. Breastcancer.org, Managing Your Medical Records



What Records Should I Keep During and After My Cancer Treatment? (continued from page 1)

available to help manage your personal health information. Some are internet-based that can be accessed by a computer, while some may be printed or downloaded. A web-search may also provide ideas to create your own tool.

It is never too late to start collecting and managing your personal medical information. Your success in keeping records of your cancer care improves your knowledge of the medical care you have received, empowers you to advocate for yourself and helps you cope with the overwhelming nature of any medical illness, especially cancer. When navigating your cancer care journey, many aspects are out of your control, but keeping good records can help you regain some control and lead to better participation in your care.

What should be included in your personal medical records?

DIAGNOSIS INFORMATION

Specific information about your cancer, such as the type of cancer, staging and area of your body affected

DIAGNOSTIC TEST RESULTS

Diagnostic tests, follow-up tests (like biopsy results/pathology report), imaging results (MRI, CT) or PET reports (radiology) and lab results

FOLLOW-UP TESTS

List of recommended follow-up tests and appointments you completed or need to schedule

GENETIC TESTING RESULTS

Copies of any genetic testing results and recommendations

TREATMENT SUMMARIES

Copies of treatment summaries provided by your doctors that include information on the treatment you received such as surgery, radiation, chemotherapy, immunotherapy and other medications. Specifically:

- Surgery surgeon name, date, operative report or summary, any implants
- Radiation doctor name, dates, area of your body treated and amount of radiation you received
- Chemotherapy doctor name, dates, drug names, protocol or regimen, number of cycles and any negative reactions
- Immunotherapy dates, drug names, doses, any side effects

SIDE EFFECTS EXPERIENCED

Information on any side effects or symptoms you experienced during any treatment you may have received

CONTACT INFORMATION

Contact information for your providers, support services such as nurse navigator, social worker, dietitian, financial assistance

MEDICAL HISTORY

Information on your general medical health such as other diseases, medications and allergies

CURRENT MEDICATIONS

Updated list of your current medications - name and dose

EMERGENCY CONTACT INFO

Emergency contact information (name, phone number) and/or a list of people in your life who are helping with your care

LEGAL DOCUMENTS

Copies of your living will, advance directives and medical power of attorney

UPCOMING CANCER AWARENESS MONTHS

January - Cervical Cancer

February - Gallbladder/Bile Duct Cancer

March – Colorectal Cancer, Kidney Cancer and Multiple Myeloma





BOOST YOUR HEALTH & WELLNESS



Tips for Managing Mental Fatigue

By: Nicole Kong, MEd, CCC-SLP

Undergoing and surviving cancer treatment can result in mental fatigue and/or impact the ability to stay organized. Cancer patients may experience changes in their ability to remember, focus, concentrate and/or multitask. Many factors can contribute to this including the nature of the cancer

diagnosis, the course of treatment, stress/anxiety/emotions, lack of sleep, nutrition deficiency, pain, altered blood levels and the natural aging of the brain.

Experiencing these deficits can be frustrating, but there are many strategies and tips that can be utilized to keep life on track:



Use external memory aids/reminders

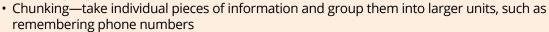
Write/create lists

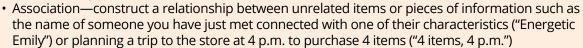
Use internal memory reminders

- Use alarms or timers on your phone
- Use a calendar or planner
- Organize medicine pill boxes
- Keep a journal of events or important information



 Repeat/rehearse—say what you want to remember over and over again by verbalizing it out loud or silently in your mind





- Visualization—create pictures of the information in your mind
- Clarification—ask others to repeat the information
- Acronyms—form an abbreviation from the initial letters of other words and pronounce as a word such as ROYGBIV (red, orange, yellow, green, blue, indigo, violet)



- Use routines, such as paying bills the same day every month
- Assign a place for everything and keep everything in its place
- · Take your time and perform one task at a time



- Get a good night's rest
- Eat a variety of healthy foods
- · Drink plenty of water

Reduce distractions

Stay physically fit and active



- Reduce stress and anxiety
- Seek out relaxing and pleasurable activities
- Play brain games (i.e. crossword puzzles, Sudoku, word-finding puzzles)
- Take mental breaks during the day
- · Ask family and friends for support

A speech pathologist with expertise in oncology can also provide therapy for patients who experience mental fatigue or difficulty staying organized.

<u>Click here</u> to learn more about Oncology Rehabilitation Services (including virtual visits) offered at Northside Hospital. A physician referral is required for therapy services. If you have a question or want to schedule an in-person or virtual appointment, please contact our scheduling team at **404.236.8030**.





Do I Need to Take A Dietary Supplement?

Many people with cancer take dietary supplements such as vitamins, minerals and herbs with the hope of halting or even reversing the course of their disease. In fact, it has been reported that

20-85% of individuals use dietary supplements after being diagnosed with cancer. For cancer prevention, the evidence is clear: vitamins, minerals and other supplements alone do not work.

In many instances, family members or friends encourage people with cancer to try different dietary supplements. In one recent study, up to 77% of people with a cancer diagnosis reported taking a multivitamin or mineral supplement daily. Dietary supplements are most often used by breast cancer survivors, followed by patients with prostate, colorectal and lung cancers.

If you do choose to buy a dietary supplement, make sure to read the label very carefully and understand the claims made by the manufacturers. It is easy to misunderstand the claims made about a product. The manufacturers of dietary supplements can make four kinds of claims on the labels of their products: nutritional claims, claims of well-being, health claims and structure or function claims.

Type of Claim	Description
Nutritional	Nutritional claims are statements about the effect dietary supplements, vitamins and minerals have on diseases known to be caused by the nutrient deficiency. For example, "Vitamin C prevents scurvy." These claims do not need to be pre-approved by the FDA (U.S. Food and Drug Administration). However, the label must also make clear how prevalent the disease is in the United States to help consumers weigh the risk of contracting the disease against the potential risks of the supplements itself.
Well-being	Claims of well-being are claims that relate to overall well-being. Unevaluated statements such as "makes you feel better." Claims of well-being do not need to be pre-approved by the FDA or other government agencies.
Health	Health claims can state the specific effects of a dietary factor on the body. For example, "Whole grain products reduce cholesterol levels." The FDA must pre-approve all the health claims and requires that they be supported by evidence from scientific studies.
Structure or Function	Structure or function claims are claims about the effect of the dietary supplement on the structure or function of the body. For example, "Antioxidant rich beverages improve overall health" or "Calcium builds strong bones." These structure claims are confusing to consumers. They are not reviewed by the FDA and must be accompanied by the disclaimer, "This statement has not been evaluated by the FDA. This product is not intended to diagnose, treat, cure or prevent any disease."

No matter your cancer treatment regimen, it is best to consult with your doctor or registered dietitian regarding the potential benefits and risks of each dietary supplement before adding any to your regimen. If you are already taking dietary supplements, bring the products with you to your provider's office for approval of the dose and to ensure that the ingredients do not negatively interact with your cancer treatment.

The American Cancer Society recommends that when using a multivitamin or mineral supplement, consumers should choose one that provides less than 100% of the daily value of any nutrient. At this time,

there is no proof that taking a dietary supplement will reduce the risk of cancer, recurrence or improve the likelihood of survival. **American Institute of Cancer research does not recommend dietary supplements for cancer prevention.**

Survivors are advised to get their needed antiinflammatory, anti-carcinogenic nutrients from a healthy diet rich in colorful vegetables, fruits, nuts, seeds and whole grains rather than through dietary supplements. Living a healthy lifestyle has also been associated with a reduced risk for developing cancer or other chronic diseases.



Recipe Corner: Scrambled Turmeric Tofu with Greens

- 1 14-ounce package extra-firm tofu
- 2 tablespoons nutritional yeast
- 2 teaspoons turmeric
- 1/4 teaspoon smoked paprika
- 1/4 teaspoon black pepper
- Pinch sea salt (optional)
- 2 tablespoons plain, unsweetened soymilk
- 1 tablespoon extra-virgin olive oil
- 2 green onions, sliced
- 2 cloves garlic, minced
- 6 ounces (about 2 1/4 cups) sliced mushrooms
- 2 cups loosely packed chopped greens
- (e.g., mustard, collard, spinach, kale)
- 1/4 cup sun-dried tomatoes, chopped

Preparation:

- 1. Remove tofu from package and press it by wrapping it in paper towels and placing it between two plates with something heavy on top for five minutes, to allow extra liquid to drain off tofu.
- 2. Place tofu in a bowl and break apart with your hands to achieve a crumbly texture. Mix in nutritional yeast, turmeric, smoked paprika, black pepper, salt (optional) and soymilk. Set aside.
- 3. Heat olive oil in a skillet and sauté green onions, garlic and mushrooms for about five minutes.
- 4. Add crumbled tofu, chopped greens and sun-dried tomatoes and sauté just until greens start to wilt (about two minutes).
- 5. Serve immediately.

Makes 6 servings (about 3/4 cup each). Per serving: 152 calories, 9 grams total fat (1 gram saturated fat, 0 grams trans-fat), 0 milligrams cholesterol, 8 grams carbohydrates, 14 grams protein, 3 grams dietary fiber, 71 milligrams sodium, 0 grams sugar, 0 grams added sugar

References:

- Recipe found at <u>aicr.org/cancer-prevention/recipes/scrambled-turmeric-tofu-with-greens/</u>
- Dietary supplements commonly used by cancer survivors: Are There Any Benefits? Nutrition in Clinical Practice ASPEN Journal, October 2017, 607-627
- U.S. Food and Drug Administration. Label Claims for Conventional Foods and Dietary Supplements fda.gov/food/food-labeling-nutrition/label-claims-conventional-foods-and-dietary-supplements



STORIES OF HOPE & HEALING

Survivor Story: Meet Ed

What are the events that led up to your cancer diagnosis?

I was feeling completely fine leading up to my cancer diagnosis. I went to the doctor for my annual physical in early 2015, and it was routine bloodwork that led to my diagnosis of multiple myeloma. I was then referred to Dr. Dan Dubovsky at Atlanta Cancer Care.

What treatment did you receive?

Following my diagnosis, I received a stem cell transplant (an outpatient procedure) in August of 2015. The process as a whole took about three months. The Blood and Marrow Transplant (BMT) Program team at Northside Hospital was extremely efficient, so there were no medical or administrative issues. Fortunately, I did not suffer from most of the side effects that I was warned about. However, I did feel fatigued for several weeks, and I also experienced an altered taste (everything tasted metallic) for about a week or two. Both were side effects of the high-dose chemotherapy infusion given on the first day of the process. My current treatment consists of a short

infusion once every three weeks, routine lab work every month as well as an oral maintenance drug.

Did you utilize patient support resources at NHCI? If so, which would you recommend?

Due to my diagnosis, most of my recovery was spent in isolation at home, with support from my husband. Network of Hope (NoH) had not yet started at the time of my diagnosis and treatment. Once the program was founded, I felt compelled to give back and currently volunteer as a mentor. In my role as a BMT NoH mentor, I have had lengthy phone conversations with at least five people who were considering a stem cell transplant. During these conversations, we discussed their concerns, which were primarily administrative and logistical.

What advice do you have for someone navigating their treatment and recovery journey?

The most important piece of advice I can give is to avoid feeling sorry for yourself and instead feel fortunate that cancer treatment has advanced to the state it is in *(continued on page 6)*



Survivor Story: Meet Ed (continued from page 5)

today. It is also imperative to take one thing at a time, one day at a time. I recommend using the time in and around treatment to catch up on reading, television and home-related tasks. Also, be sure to make plans for things you want to do post-treatment.

How far out are you from treatment or is treatment ongoing?

I am almost six years out, although the cancer returned (as predicted) after four years. I was told early on in my initial treatment that this would happen, but the disease would continue to be treatable, allowing me to live a normal lifestyle. As planned,

I am currently undergoing maintenance treatment with immunotherapy drugs, and things are going well.

Closing Thoughts

As I have said consistently over the past five-plus years, I would not have ever volunteered for a cancer diagnosis, but everything that has followed from it has been a blessing. I feel extremely fortunate to have been provided with advanced treatment and care from an entire platoon of superb medical and support personnel. I am also immensely grateful for family and friends who have helped me through this journey.



COMMUNITY SUPPORT & RESOURCES

Cancer Support Community Atlanta Has Moved!



Cancer Support Community (CSC) Atlanta, Northside Hospital's partner in providing psychosocial oncology programs for cancer patients and caregivers, has a new

home! As of January 1, CSC Atlanta is in a beautiful new space in Center Pointe, located just around the corner from their previous address. It has been updated with a beautiful new look and streamlined with a much more efficient layout for members. While they are still only offering digital programs, they will be ready for each of you when their doors finally swing open for in-person programs.

In the meantime, online program offerings have increased. In addition to offering live events, their website is now home to a vast library of recorded programs. One of the most popular programs focuses on nutrition. The online monthly cooking demonstrations are being filmed in the new demonstration kitchen, so be sure to RSVP to this month's program for a sneak peak into the kitchen.

Another ongoing nutrition program is the monthly nutrition seminar, which is always a favorite. This program is hosted by Kristin Cuculovski, clinical oncology nutrition coordinator with Northside Hospital Cancer Institute, and each month a different nutrition topic is presented. Kristin's immense knowledge of nutrition for oncology patients ensures that her seminars are rich with information that is geared both to the oncology community and to anyone interested in improving their health through healthy eating habits. Topics include nutrition and heart health, things to consider when starting a plant-based diet and foods that may help boost your immune system.

Please visit the CSC <u>website</u> to participate in recorded stress management classes, gentle exercise programs, education forums and a variety of other free programs. We look forward to being together again soon and welcoming you into the new CSC home at 1100 Johnson Ferry Road NE, Suite LL90 near the Northside Hospital Atlanta campus.



For more information on upcoming CSC Atlanta classes or to access the calendar visit <u>cscatlanta.org</u>.





GET INVOLVED



Spotlight on the Network of Hope Phone Mentoring Program: Interview with Pat

How long have you been volunteering with Network of Hope (NoH) and more specifically, the phone mentoring program?

I began volunteering with NoH in April of 2008 and from that time on, I have been involved with phone mentoring in some form. In fact, one of my first assignments with NoH was follow-up phone calls to patients after hospital visits.

Please describe the history of the phone mentoring program.

The program has been in place for over 20 years and was started by Susan Casella, RN, who recently retired from her role as breast health education coordinator, at the inception of NoH in 1998. In the early years, the phone mentoring part of the program was mainly handled by Susan and Barbara Harn, RN. Yet, throughout the years, phone calls for patients evolved. Currently, as phone mentoring volunteers, we make two types of phone calls: patient follow-up calls and patient mentor calls (see Table).

Patient Follow-up Calls

- · Lasts 15-20 minutes on average
- Takes place 10-14 days after surgery by the individual who visited the patient in the hospital (NoH volunteer requests permission to call the patient during the initial hospital visit)
- Involves a recap of the hospital visit
- Inquires about the patient's well-being after the hospital stay and answering questions
- Concludes with the mentor providing a recap of the conversation to help the patient understand what has been shared

Patient Mentor Calls

- · Lasts 30-60 minutes on average
- Takes place before surgery, or post-surgery when a patient may need a little more help or support (NoH mentors do not visit the patient in the hospital)
- Addresses questions or concerns that have prompted the need for a phone mentor
- Involves answering any additional question(s) asked by the patient
- Concludes with the mentor providing a recap of the conversation to help the patient understand what has been shared

How many individuals volunteer with the program? How many calls are completed each week?

Currently, 24 volunteers complete an average of two and a half hours of calls each month, which can be anywhere from five to nine calls. Some calls take five minutes or less if someone has a question that can easily be answered, and other calls can take a little longer depending on the need or ask.

What qualities should an effective mentor possess and what type of training is involved?

An effective mentor understands that his or her role is to be dependable, engaged, authentic and attuned to the needs of the patient. The telephone mentor should also listen, encourage and work to build trust while maintaining a positive attitude. If there is a situation or request that is not in the realm of experience for the mentor, he or she can always consult with the rest of the NoH group and get back to the patient with additional information.

Becoming a phone mentor involves some formal training, usually conducted by an experienced phone mentor, covering what is recommended in the Network of Hope: Patient and Caregiver Support Team Training Manual, as well as some helpful tips. In addition, the new mentor works one-on-one with an experienced mentor, learning the specifics of how to conduct the phone call. In this individual session, the trainee can ask questions and discuss any concerns.

For more information about the Network of Hope phone mentoring program or to get involved, please contact Kymberly Duncan at **404.303.3676** or kymberly.duncan@northside.com.





EVENTS & CANCER CELEBRATIONS

CANCER SCREENING & PREVENTION

Built to Quit Smoking and Tobacco Cessation Course

Next 6-Week Session Start Date: March 2, 2021 Classes are currently web-based and meet weekly. They are conducted primarily in a group setting which encourages participants to learn from each other.



Prostate Cancer Screening

February 18, 2021 @ Northside Hospital Cancer Institute Radiation Oncology – Forsyth from 5:30-8 p.m.

Skin Cancer Screenings

March 18, 2021 @ Northside Hospital Cancer Institute Radiation Oncology – Midtown from 6-8 p.m. April 15, 2021 @ Northside Hospital Cancer Institute Radiation Oncology – Cherokee from 6-8 p.m.

Please visit our website for a full list of ongoing support and survivorship programs.