

# What I Wish I Had Known

## NorthShore University HealthSystem Kellogg Cancer Center

### What I Wish I Had Known When I Discovered I Had Cancer

Navigating your cancer journey as a patient, or as a caregiver helping a patient, can be easier if you are mentally and emotionally prepared. Members of NorthShore University HealthSystem's Kellogg Cancer Center Oncology Patient Advisory Board have assessed their own experiences to try to help you prepare. We understand that everyone's journey is different and that every point discussed here may not resonate with you specifically, but we hope that sharing our experiences will help others as they begin a cancer journey of their own.

It's important that both patients and caregivers understand that each person's journey is uniquely theirs. We hope to help you understand what your loved one is experiencing.

Best Wishes,  
Kellogg Oncology Patient Advisory Board

### As a Patient, What I Wish I Had Known When I Discovered I Had Cancer

The physicians, physician assistants, nurse practitioners, nurses and the entire medical team at Kellogg Cancer Center are your advocates and partners in this journey. They will treat you as a person and not just as a medical diagnosis. A multidisciplinary care team will support you throughout your journey and can include oncology social workers, integrative medicine specialists, nutritionists, nurse navigators, and a multitude of others. There continues to be advancements in cancer care and there are many new treatment options, as well as personalized care plans. Abundant, and often times, free resources are also available including support groups and complimentary classes which are available at both Kellogg Cancer Center and many outside organizations. There is life during and after cancer. It may be a new normal, but it can be a very good normal.

### Be Your Own Patient Advocate

You can and should be a strong patient advocate for yourself and ask every question you feel needs to be addressed. It might be helpful to write down the questions you have for your doctor in advance so that you don't leave an appointment disappointed that you forgot to ask something. Have a friend or family member accompany you (in person or by phone/video) to take notes because in the moment, it's easy to feel pressure and to forget important elements of the conversation. If you are uncomfortable with something, discuss it with your doctor. If you feel that additional testing or a referral to a sub-specialty department may be beneficial, inquire about it. If you have side effects, reach out to your care team immediately because there are usually medical protocols that can help you feel better. There are many ways to reach your care team and get questions and needs addressed quickly. NorthShoreConnect for less urgent issues, the 24 hour answering service for urgent issues (don't wait until the morning if you are sick), and the Kellogg Immediate Care can often save you a trip to the emergency room. The emergency room, however, may be necessary when appropriate.

## Supporting Your Well-Being

Think about ways to support your well-being, such as emotional support groups, meditation, mindfulness stress relief classes, professional counseling, massage, exercise as appropriate and helping others.

## Explore All Treatment Options to Find What Works for You

If the standard treatment tends to have less than desirable results or more risks than you are comfortable with, find out from your doctor whether other treatments are available including a clinical trial or non-standard treatment, even if it requires special approval from the FDA and your insurer.

## Welcome Different Emotions

Every patient's journey is different and some more difficult than others. Regardless of your particular journey, you can still experience love, laughter, joy and fulfillment in life. Whether you wind up running a marathon, are able to play with children or grandchildren, enjoy a hobby, or simply finish a book, look to incorporate what makes you happy, even when treatment and fears may interrupt.

You can put yourself first as needed while still being considerate of others. Speak up for yourself. Do things that may make you feel better and help maintain a positive attitude so you can deal with the obstacles and then come out on the other side. Lead your life as normally as possible, including exercise, socializing, and participating in activities that you like.

Cancer can trigger many fears about your personal and work life both during and after treatment. You may feel overwhelmed. Even with all the love, support, kindness, well wishes, offers to help, and commiserating with fellow patients, you may feel acutely alone at times. Your fears are completely normal. Even while living with cancer every day, remember humor, hydrate, and find the courage within you to persevere. Start your morning with a positive thought that helps you get through the day. Consider wearing a bracelet daily during treatment with an inspirational message, such as "never let your fear decide your fate."

## Reach out to Others

Reach out to others and learn to lean on others when needed. Finding strength, love, and support of family and friends can be crucial in your journey. Find someone close to you who you are able to confide in: spouse, relative, friend, or whomever. Talking with cancer survivors can also help you cope, as well as counseling and support groups, which are widely available

Think about how to explain to people close to you how you want to be treated. For example, you may not want people either asking you questions or treating you as the "sick one" all the time, or you may prefer total openness. There may be times when you feel very sharp and other times you do not. Be educated about your disease and treatments. Consider information from patient and caregiver groups with your same disease. If necessary, ask your doctor to check with the leading researchers to see if there is important, newer unpublished information. Be careful of information on the internet from unreliable sources or those that have a financial interest in getting you to believe their information. Be sure to discuss information you gain from outside sources with your medical experts to ensure it is a reliable resource.

## As a Caregiver, What I Wish I Had Known Before My Loved One Got Cancer

**Help your friend, relative, or loved one research physicians who specialize in their specific disease.**

At times, “active surveillance” or “watch and wait” may be the optimal approach. This may last for a short or long time. Try to prepare for being told that your loved one’s condition has changed and treatment decisions are needed. Although new treatments, trials, and research continue to be available, do not always assume that treating sooner than later is the best approach. It is important to remember that treatment effectiveness can vary with each individual patient based on many factors.

Take care of yourself so you have the strength to be an effective caregiver and still be yourself. In order to be there as support for someone else it is equally important to take care of yourself. Try to find time to do things you like, even if only for a short time.

You may be disappointed that family and friends are not as supportive as hoped or needed. Consider discussing this with them since they may not know the best way to provide support or if their help is wanted.

Your loved one/patient may have difficulty effectively processing important treatment information and may need your help digesting certain information. This may cause an overwhelming sense of responsibility as the caregiver which can ebb and flow as both of you move through this journey together. Consider support services for yourself such as counseling, support groups, and integrative medicine as ways to support yourself as you support your loved one.

Responses to treatment, including side-effects, are very individualized. Prepare for, but do not obsess over potential side-effects reported by others. Your loved one/patient’s condition also can change for the better. Cancer can change your lives, creating limitations and constraints, but does not always have to be the primary focus.

Clinical trials may be the best and possibly the only way to receive the newest treatment. New treatment developments continue, and it is important to remain current about developments, even after initial treatment is completed. It is also very important to discuss these with your treatment team.



**Kellogg Cancer Center**