

PARTNERS

Newsletter of the Patient and Family Advisory Program at Moffitt Cancer Center | FALL 2023

PATIENT'S PERSPECTIVE

Love in Action

*Kerrijo Ellis, Patient Advisor,
Patient and Family Advisory Council*

“Love is an action, never simply a feeling.” - bell hooks

Love is a powerful emotion that can be expressed in many ways. The impact of love can be profound and life changing. Through my cancer journey I have experienced the transformative power of love.

As I reflect on my 28th year, I am overwhelmed with emotion and a sense of nostalgia for the things that could have been. The cards held so much promise - the thrill of adventure, the satisfaction of academic success, and the joy of discovering new passions. Little did I know that the year would be a turning point in my life. In December 2021, my world was turned upside down when I received the devastating news that I had stage 3 non-Hodgkin lymphoma. Suddenly, all my plans, hopes, and dreams were put on hold as I began to navigate this new reality. My heart was heavy with confusion

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Kerrijo Ellis

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Patti Halula

CO-CHAIR COLUMN COURAGE

*Patti Halula,
Patient Advisor and Co-Chair,
Patient and Family Advisory Council*

Lately, the word courage has been on my mind. Perhaps it's because I have recently been a part of someone else's courage and celebration. There are many definitions of courage but the one that resonates with me the most is: "bravery and strength in the face of pain or grief."

There was a young woman feeling challenged by her treatment for breast cancer. She was challenged so much so that she didn't want to continue her treatment. The pain and discomfort of side effects had become too much for her to manage mentally and physically.

After a chance encounter with her, I shared my journey with cancer and all the challenges that chemotherapy can bring. After sharing my own experiences and telling her about the mental challenges that can stretch your emotions from one end of the spectrum to the other, she chose to finish treatment.

Over the next several weeks, we texted after each of her treatments and spoke about how it went and how she felt mentally and physically. After listening to her, I came

to really appreciate what it took for her to show up for treatment. Knowing how she would feed afterwards while also having to care for her family, that took courage.

And what a day her last treatment was. I was honored when she asked me to be a part of her bell ringing in the infusion center, signifying the end of her treatment. There were laughs, tears, hugs, and many kind words of, "You did it!" Her joy was so wonderful to watch.

Her family, other patients waiting for treatment, nurses, myself, her medical team – together, we all celebrated her courage. That moment was nice reminder that simply walking into Moffitt Cancer Center is courageous. Making the choice to seek treatment when you have no idea what treatment may bring into your life is courage. And when you courageously step out into the unknown, you might be surprised to learn that is where hope lives.

Visit [Moffitt.org/Courage](https://www.moffitt.org/Courage) to read inspiring stories of hope and encouragement.



Did you know?

Did you know the Courage Bell is for everyone? All patients are welcome to ring the bell to celebrate victories, like treatment completion and birthdays. Patients can also ring the bell to get through a hard day and rally support. Ask your care team about the Courage Bell at your next visit.

Love in Action

Continued from page 1

and uncertainty as I found myself at a loss for what steps to take next.

Growing up, my family was my rock. No matter what challenges came our way, we always stuck together and supported each other. It was a comforting feeling to know that I could always depend on them, no matter what. As I was rushed to the hospital, I couldn't help but feel scared and alone. However, my family was there every step of the way. And for the three weeks that followed, as I was in the hospital enduring experiences I never thought possible, my family never left my side. They were there through every test and every setback.

My heart swells with gratitude when I think of the unwavering support and love that my family has shown. They came to the hospital every day, even when I was barely conscious and in pain. They slept in my hospital room with me, providing comfort and support during the darkest moments of my illness. When it was time for my first appointment at Moffitt, they were right by my side, holding my hand and offering words of encouragement.

Throughout my chemotherapy treatments, they never left my side. Their actions spoke volumes about their love for me. My heart overflows with appreciation for the unconditional support and affection. Whether it is a small gesture or a



grand display, expressing love and support can make a world of difference to those who receive it.

During challenging times, like a cancer diagnosis, a family's love and support can be especially meaningful. A beacon of hope and strength. It is a blessing to have such a strong and reliable support system, and I am grateful for them every day. The love and support I received motivated me to become a volunteer. I have made it my purpose to give back to the cancer community as my journey continues through remission.

*Moffitt offers support groups where you can talk with people who have experienced cancer. Please call the department of Social Work at **813-745-8407** or visit [Moffitt.org/SupportGroups](https://www.moffitt.org/SupportGroups) to learn about the support groups that are available.*



We want to hear from you!

If you would like to share your story, provide feedback or subscribe to our newsletter, email

PatientAdvisors@Moffitt.org

or call **813-745-2963**.

Learn About Upcoming Moffitt Events

Moffitt offers a variety of virtual and in person events. These events are here to help you learn and connect with other patients and caregivers. You can find a full list of upcoming events by visiting **[Moffitt.org/Calendar](https://www.moffitt.org/Calendar)**.

Mom, I've Got Cancer: A Family's Journey

Susan Brill, Family Advisor, Patient and Family Advisory Council and Volunteer of the Year

I have twice heard those terrible words, “You have cancer.” What is even worse is to hear your son say “Mom, I've got cancer.” Our 44-year-old son was enjoying a busy life with a wonderful wife and two very active teenage sons. Unfortunately, he suffered from gastroesophageal reflux disease (GERD), which later turned into Barrett’s esophagus, a condition where the esophagus becomes damaged due to prolonged exposure to stomach acid.

I nervously waited while the doctor performed a biopsy. I was hoping for good news but then I was called into his room. I saw my son and his wife in tears and then they spoke that word, cancer. I needed to be strong for them, so they did not see my own tears at that time. My tears were saved for when I was alone at night.

Because of COVID restrictions, my son had to be dropped off alone at Moffitt Cancer center at 5:30 a.m. to have a section of his esophagus removed by Dr. Pimiento, a wonderful surgeon. That morning, I felt empty and anxious. His surgery was followed by months of chemotherapy and then immunotherapy. I stayed busy helping as much as I could by driving him to chemo and picking up his meds and whatever else was needed to lighten the load of his burden.

I kept my phone on my pillow waiting for that late-night call from him. To hear the fear and anxiety in his voice broke this mother’s heart. His strength slowly returned during those COVID days as his sons did their e-learning

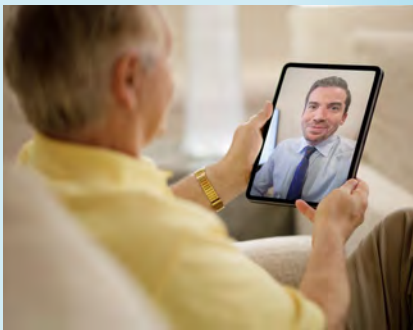


Susan and her son Jonathan.

while his wife performed her work from the kitchen table. The safety bubble to protect my son from COVID included only his immediate family, my husband and myself.

I am happy to say his scans look great! To say that I am proud of my survivor son would be an understatement. It was only through love, prayers and the hope that Moffitt gave us that got our family through this difficult time.

At Moffitt, we offer many services to help caregivers, including the Family and Friends Support Group. To learn more, visit [Moffitt.org/SupportGroups](https://www.moffitt.org/SupportGroups) or call 813-745-8407.



MEET THE EXPERTS

Connect with Moffitt experts and learn helpful information for patients and caregivers. Sessions held via Zoom on Tuesdays and Wednesdays at 10-10:30 a.m.

To register please visit [Moffitt.org/MeettheExperts](https://www.moffitt.org/MeettheExperts) or call 813-745-1690.

MOFFITT RESOURCES

to Help Patients and Caregivers

UPCOMING EVENTS

September - November

Virtual Relaxation/Meditation for Stress Relief **813-745-6052**

Virtual/Zoom, RSVP only
Weds. at 12:15 p.m.
[Moffitt.org/Meditation](https://moffitt.org/meditation)

Virtual Gentle Restorative Yoga Class **813-745-6052**

Virtual/Zoom, RSVP only
Tues. at 11 a.m. and Thurs. at 2 p.m.
[Moffitt.org/Yoga](https://moffitt.org/yoga)

Magnolia Open Art Studio | 813-745-8407

In person at Magnolia Campus, No RSVP
3rd floor – Arts in Medicine Studio
Mon.-Fri., 9:30 a.m.-4 p.m.
ArtsinMedicine@Moffitt.org

McKinley Open Art Studio | 813-745-8407

In person at McKinley Campus, No RSVP
1st floor – Patient and Family Center
Mon.-Fri., 8:30 a.m.-5 p.m.
ArtsinMedicine@Moffitt.org

Patient and Family Orientation **813-745-1690**

Virtual and in person, RSVP only
Mon.-Fri., 2 p.m. or by appointment
PatientLibrary@Moffitt.org

Virtual Meet the Experts | 813-745-1690

Virtual/Zoom, RSVP only
Tues. and Weds., 10-10:30 a.m.
PatientLibrary@Moffitt.org

PATIENT AND FAMILY SUPPORT GROUPS

For your convenience, we offer support groups via Zoom. To learn more about support groups or to register, visit [Moffitt.org/SupportGroups](https://moffitt.org/supportgroups) or call the Social Work office at **813-745-8407**.

General Cancer Support Group

Weekly meeting for patients diagnosed with any cancer type to connect and share mutual support. Meets every Tuesday, 1-2 p.m. via Zoom.

Family and Friends Support Group

Weekly meeting for families and caregivers of patients with any cancer type to connect and share mutual support. Meets every Wednesday, 1-2 p.m. via Zoom.

Metastatic Breast Cancer Support Group

Meet with people who have been diagnosed with stage IV metastatic breast cancer to share mutual support. Meets every Tuesday, 11 a.m.-12 p.m. via Zoom.

Breast Cancer Connection

Monthly support group for anyone who has been diagnosed with breast cancer. Meets the first Tuesday of every month, 6-7 p.m. via Zoom. .

Families First: Parenting During Cancer

A support group for parents raising young children and teens while living with cancer. Meets every third Wednesday of every month, 4-5 p.m. via Zoom.

Survivorship Program Support Group

Monthly meeting for Survivorship Program participants to connect and share mutual support. Meets the last Tuesday of every month, 1-2 p.m. via Zoom.

Finding Our Way Through Loss and Grief

This is an 8-week support group for family and caregivers who have lost a loved one to cancer while under treatment at Moffitt.

Coping With the Fear of Recurrence

Sean Powell, MSW, LCSW, CCM, OSW-C, Senior Director of Care Management

Early in my career as an oncology social worker I worked with a woman who was newly diagnosed with a genitourinary cancer. Her words describing her emotions at the time of diagnosis have remained with me to this day, “I was just going along and then life happened.” I think anyone who has been diagnosed with cancer can identify with her experience. Cancer comes out of nowhere and changes everything.

For many patients, they will undergo treatment and finally hear the words they have longed for, “You are in remission” or “We got it all.” It is a time of celebration, relief and gratitude. This scary experience is finally over.

However, the time before follow up or surveillance tests and scans or the anniversary date of diagnosis may be unsettling. What if the cancer has come back? The cancer came out of nowhere before, it can reasonably happen again. Patients may experience a range of emotions, including fear, anxiety or panic. You may notice you are irritable or have trouble sleeping or concentrating. This is completely normal. Humans love to be in control; however, this is one thing they can't control leading to the fears and uncertainty.



There are some things you can do to help manage these emotions and experiences. A recent study published in the journal of the American Society of Clinical Oncology found that patients with a fear of recurrence who attended a support group, talked with a counselor or chaplain, or sought support from trusted advisors reported less fear about follow-up appointments and tests. And the effects were long lasting, up to 7 or 8 months after using a support resource.



Moffitt has several resources that can help you with your fears of recurrence. Moffitt has oncology social workers and board-certified chaplains at all campuses who are available to talk to you on a one-on-one basis. We offer patient support groups that are open to all Moffitt patients and are available from the comfort of your home via Zoom. And we can refer you to community resources, such as Imerman Angels, who pairs you with volunteer cancer survivors who can relate to your experience.

To connect with any of these programs, please call 813-745-8407.

Are You a Young Adult With Cancer?

Amber Skinner, Adolescent and Young Adult Program Administrator

The Adolescent and Young Adult (AYA) Program at Moffitt Cancer Center was designed in 2011 to address the unique needs of AYA cancer patients (aged 15-39) and assist them in connecting with other AYA cancer patients their age. It is the AYA Program's mission to improve the cancer care experience and long-term outcomes for young adults with cancer by ensuring that all adolescent and young adult patients and survivors at Moffitt have access to resources, services and events specific to their age. This multidisciplinary program consists of medical oncologists, radiologists, pathologists, radiation oncologists, orthopedic and oncologic surgeons, nurse practitioners, registered nurses, social workers, researchers, other professionals and an AYA patient advocacy group (Ambassadors).

The AYA Program offers several programs to engage and support all Moffitt and catchment area AYA patients,

including the Swim Across America AYA Lounge, monthly social events in the Tampa Bay area, quarterly educational events, patient advocacy opportunities, and access to fertility preservation

education, financial assistance and resources. There are multiple subcommittees within the AYA Program, including subcommittees dedicated to patient education,

fertility, psychosocial topics, patient advocacy and nursing that are designed to address the specific and unique needs of this population.



To learn more about the AYA Program including the Magnolia campus lounge, resource packets, newsletters, and upcoming events, please email AYA@Moffitt.org or go to Moffitt.org/AYA.

DID YOU KNOW ?



Moffitt has partnered with three fertility preservation clinics in the Tampa Bay area to offer limited financial assistance for select preservation services for cancer patients in need. Please speak with your social worker about what resources may be available to you. Call the Social Work office at 813-745-8407 to find out more.



Talking to Your Provider About Sex

Dr. Kristine Donovan, Supportive Care Medicine Psychologist

A cancer diagnosis brings a flood of thoughts, emotions and questions. Am I going to live? Will I be able to have children?

What if I can't work while I undergo treatment? How will I tell my children? A very important question that isn't always top of mind but should be is how will cancer and treatment affect my sex life?

Sex may not have been top of mind after a diagnosis. And admittedly, some people may feel guilty thinking about sex when the priority is surviving. Sex and intimacy are important parts of the human experience and contribute significantly to quality of life. Understanding how these areas are impacted by cancer and what options are available to you allows you to be empowered to make the decisions possible and ensure a good quality of life. Admittedly, discussing sexual health can be challenging for patients and caregivers, especially if you are uncertain how your provider will respond.

Begin by knowing that cancer commonly affects an individual's sexual health and your provider is aware of this. Next, approach your provider with a specific concern at the start of your next visit. Tell your provider your sexual health is important to you and you have a concern you want to discuss.

Write down your concern and state that you would like to end the visit with specific suggestions about how to address it. This will help if you anticipate feeling anxious or uncomfortable. For example, you might say, "I have noticed that my level of sexual desire has decreased considerably since I started taking the medication that was prescribed. I'd like to understand why this is. And I'd like some suggestions on how to address this."

Having your spouse or partner with you will help you feel supported and they can help you remember what was said. If your provider seems dismissive or is not able to offer specific suggestions, ask them to send you to someone with sexual health expertise. This might be a medical or nursing professional or a counselor to help you address your relationship's sexual health.

Finally, ask for resources that deal specifically with cancer's effect on sexual health. Be persistent. In the meantime, know that sexual health is an important aspect of quality of life for many patients and that health care providers do want to talk with you about it.

Visit [Cancer.org/SideEffects](https://www.cancer.org/SideEffects) to learn more about how to manage cancer-related side effects including fertility and sexual concerns.

YOUR VOICE MATTERS

Learn How Sharing Your Voice Can Impact the Patient Experience

Ask about the Patient and Family Advisory Council at **PatientAdvisors@Moffitt.org**.



Advance Care Planning: The Best Gift You Can Give Your Family

Kristen Modesitt, Licensed Clinical Social Worker

Many people find that talking about end-of-life issues with family and friends can be emotional and difficult. Having this discussion and documenting your wishes helps to lessen stress and anxiety for the family in the event that someone needs to step in as the health care decision maker.

Advance care planning is a process of thinking about your wishes and desires should you experience a sudden illness or injury, or a chronic or life-limiting illness. Documenting your wishes and desires through advance directives provides the medical team and your health care decision makers with a roadmap as to what your wishes would be.

Anyone can be involved in discussing our advance care planning. However, it is important to review this document and express your wishes with the person that you will identify as your health care surrogate because they will be the one that will follow through with your wishes.

Within the document there are two sections: Health Care Surrogate and Living Will

A health care surrogate is a spokesperson, someone you trust, to represent your wishes to the medical team in the event that you are unable to communicate these wishes on your own. It is advised to have a dialogue with your appointed health care surrogate often so that they



stay up to date on your wishes as preferences and circumstances change.

A living will is where your wishes and preferences will indicate what type of life-sustaining treatment you would want and not want if you cannot be cured and getting better is not possible. You will want your health care surrogate and health care providers to follow these choices if you are unable to communicate your wishes.

It is always important that you select a health care surrogate that will be able to honor your choices and decisions because your treatment preferences may not be followed if your health care surrogate decides otherwise.

Advance care planning is a gift you can give to your family because they will know your wishes and will be honoring the choices you have made. At Moffitt, we encourage you to talk to your family and others involved in your health care and have certified facilitators for advance care planning to assist you with the process.

To reach one of the facilitators for assistance, please contact Patient Support Services at 813-745-8407.



Schedule an Advance Care Planning Session

Moffitt's certified advance care planning facilitators are available to help you and your family through the process. To schedule an advance care planning session or for more information, call the Social Work and Chaplaincy Care Office at **813-745-8407**.

One Size Does Not Fit All - The Senior Adult Oncology Program

Dr. Christine Sam, Senior Adult Oncologist

The golden years of a person's life should be exactly that - golden. We often dream big of travelling, exploring hobbies, and spending time with family and friends. A cancer diagnosis can shatter these plans and bring uncertainty. As an oncologist focusing on the senior adult population, I see the questions burning in my patients' eyes. Questions like, "How is this diagnosis going to impact my family and me? Am I going to be able to handle cancer treatment and maintain a good quality of life?"

At Moffitt, we recognize that older patients may have different health challenges, goals and life priorities that need to be accounted for when we plan cancer treatment. That is where the Senior Adult Oncology program comes in. We do not believe that age alone defines whether patients are able to get cancer treatment, and it is not a one-size-fits-all approach. Moffitt's Senior Adult Oncology Program is for patients 70 and above who need a medical oncologist specializing in the care of older adults, and patients can be referred by another provider or self-refer.



We use a proactive and evidence-based approach to evaluate patients and choose treatment plans that balance side effects with efficacy, as older patients can sometimes be at more risk for ill effects related to both cancer and cancer treatment. We do this using a multidisciplinary model, where physicians work closely with pharmacists, nurses, dieticians, social workers

and others to identify and address barriers to care, maximize physical function, and ultimately personalize treatment according to the unique goals and values of each patient. It is our privilege to care for our senior population, and we are continually working towards improving access to clinical trials and optimizing treatment protocols.



Visit [Moffitt.org/SeniorAdult](https://www.moffitt.org/SeniorAdult) for more information about Moffitt's Senior Adult Oncology Program.

Fall Prevention & Safety Tips

Vicki Vann, Patient Education Specialist

Falls can occur in any age group and anywhere. Unintentional falls are the leading cause of injury and death in Americans over the age of 65. The risk of falling is highest for older adults, but patients with cancer are also at high risk for a fall-related injury. Falls can cause serious health problems and lead to a loss of independence.



Did you know?

- More than half of all falls occur at home.
- Going to the bathroom by yourself is a frequent cause of falling.
- Chemotherapy can cause a drop in your platelet count. A person with low platelets may bleed more easily after a fall.
- Some chemotherapy and other drugs can damage the nerves in your feet, causing pain and numbness that hinders your ability to walk.

There are several things that put you at risk of falling:

- Difficulty walking, especially if you are experiencing numbness or tingling in your feet due to treatment side effects.
- Feeling over confident about getting out of bed by yourself when hospitalized.
- Having fallen before.
- Inactivity or spending a long time in bed.
- Feeling weak or dizzy.
- Certain medications. Please be aware of the potential side effects of all the medications you are taking.

What you can do to prevent a fall...

- Bring a family member or friend with you to your appointment or when you are out and about.
- Wear your glasses and hearing aids.
- Wear safe footwear. Avoid flip-flops and open-toed shoes.
- Ask for help if you are feeling weak, light-headed, sleepy or dizzy.
- Make carpets slip-proof.
- Do not use stools or step ladders.

If you do fall, remain calm and try not to panic. If you are in the hospital, stay put and call for help by using the call light or shouting. Do not try to move without assistance from a care team member. If you are home, use your cell phone or an alert device to call for help. Be sure and notify your doctor and your family that you have fallen. If you are here for a procedure which requires the use of medication that causes sedation, we may ask you to use a wheelchair throughout your visit at Moffitt and until you are safely in your car heading home.

Visit [NCOA.org/older-adults/health/prevention/falls-prevention](https://www.ncoa.org/older-adults/health/prevention/falls-prevention) to learn more about what you can do to prevent falls.



Are you a patient that has been prescribed a new chemotherapy to take home?

Great news! Moffitt Cancer Center's Specialty Pharmacy focuses on providing these medications with excellent customer service and expert support by our technicians. We can serve as an integral part of your treatment team.

To learn more:

PHONE **813-745-7354**
TOLL FREE **866-409-6670**

EMAIL **PharmSpecialty@Moffitt.org**
WEBSITE **Moffitt.org/Specialtypharmacy**



Patient and Family Orientation

Learn how to:

- CONNECT WITH PROGRAMS AND SERVICES
- PARTNER WITH YOUR CARE TEAM
- FIND YOUR WAY AROUND MOFFITT

- Virtual sessions presented at 2 p.m. on weekdays
- In-person sessions offered upon request
- Each session offers a 30-minute presentation with Q&A
- Presented in English and Spanish
- View online at MOFFITT.org/Orientation

813-745-1690
Orientation@Moffitt.org

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If you would like to be involved in making Moffitt the best it can be for all patients and families, contact the Patient and Family Advisory Program at PatientAdvisors@Moffitt.org or 813-745-2963.

