Celebrating Our Caregivers

Sean T. Powell, MSW, LCSW, CCM, OSW-C, Director of Social Work and Patient and Family Services

Caregivers are the unsung heroes in the cancer journey. They are thrust into their role with no formal training and often little time to prepare. Their love and concern for the patient drives them to take on new and foreign responsibilities and tap into strength and determination they didn’t know they had. They wear multiple hats: appointment coordinator, decision maker, informal counselor, spokesperson and taxi driver. They focus much of their attention on their loved one, often neglecting their own needs during the caregiving journey.

As a former caregiver myself, I can truly empathize with the enormity of the task. My sister and I cared for our father after he was diagnosed with colon cancer. At that point, I had been an oncology social worker for over fifteen years, so I had a bit of a leg up on most other caregivers. But it didn’t...
Celebrating Our Caregivers

remove the stress of caring for another person during a difficult time and absorbing additional responsibility. It provided me with insight into the experience of the caregivers I worked with daily and an increased appreciation of their role. It also helped me to be better prepared to address their needs to support them during their journey.

This edition of PARTNERS celebrates our cancer caregivers and the numerous contributions they make to the success of their loved ones’ treatment as well as their quality of life. We have some articles from both caregivers and professionals about the shock of a new diagnosis, ways to find tangible help, and recommendations on how to cope and take care of yourself. The job you are doing is invaluable and Moffitt appreciates the care, concern and selflessness you demonstrate every day. It’s not just the patient’s courage that inspires us, it is yours too.

MESSAGE FROM THE CO-CHAIR

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

My name is Patti and I have been a metastatic breast cancer patient at Moffitt since 2002. I have been a breast cancer patient since 1994. I share this because that is how long my parents, siblings, husband and 15-year-old daughter have been by my side through every emergency, every hospitalization, every procedure, every doctor appointment and every relapse.

I never really understood what being by my side did to them emotionally and mentally. I never really understood all the worry over tests, scans, new medications, checkups and progression of disease. That is until I became someone else’s caregiver.

Being a caregiver can take up a large part of your life. It can take up all your thoughts and consume you with worry. The thing about that is how quickly you can become anxious and exhausted with test results, medication, appointments and decisions needing to be made. As a caregiver, it is very easy to become overwhelmed with everything your loved one needs. Some days may be filled with appointments and some days there may be none. If I have learned anything about being a caregiver, it is the importance of taking care of myself to be there and take care of my loved one. On the days that there are no appointments, that means having a place to go and share my emotions, my fears, my worries and my tears. Perhaps it is in a support group, perhaps it is with another caregiver or friend. Perhaps it is a day off just to sit and recharge my mind and emotions because being a caregiver sometimes means you need to be stronger than you feel. One thing is true — caregivers need support just as much as the patient.

To learn more about the Patient and Family Advisory Program, including how to become a Patient Advisor, please email PatientAdvisors@Moffitt.org.
Lucky and Grateful

*Megan Wing, Patient Advisor,*
*Patient and Family Advisory Program*

I am an Ewing's sarcoma survivor. I was diagnosed when I was 32. I had no experience with cancer except for what I had seen on television or movies. Those were a poor window into what really happens, but that is for another time. I am here to give thanks to my caregivers. I was lucky enough to have two caregivers. My husband, who was still the new guy at his work, took the ball and balanced our life on one finger while making sure I had everything I needed and did everything I was supposed to do. I remember before we got into the thick of it, we sat on the couch and cried in each other's arms. Then we stopped and got to work. He is my rock and I drew strength from his strength. We made it through this together. He handled the doctors and nurses when I couldn't process anymore. He stayed up late with me at the hospital while I received chemotherapy. He shaved my head when the stubble started to fall out. But he did so much more than that. When I think back on just how much he did and how much he gave, I am in awe and I am grateful. There never was any doubt about us, but had there been, our experiences in 2013 squashed it. I am beyond lucky.

I also want to give thanks to my mother. She lives in Michigan and is retired. When we asked her, she flew down immediately to stay with us for a few months. We had no idea what to expect. Having her there from the start gave us the greatest peace of mind. I can't imagine what she went through while watching her baby girl endure treatment because my mother's face never wavered. It felt like we were just on vacation together, enjoying each other's company. We built puzzles and watched shows. We went out to eat when the numbers said I could and she brought me food when the numbers said no. I was lucky to be able to do almost everything for myself but I knew she was there when I needed her, and for that, I am grateful.

*To learn more about Moffitt's Adolescent and Young Adult (AYA) program, please call 813-745-4736 or email AYA@Moffitt.org.*

**Did you know...**

*Moffitt offers cancer screenings at several of our locations!*

To detect certain types of cancer early, Moffitt recommends that adults receive screenings on a regular basis as determined by established guidelines. You do not need a referral or a cancer diagnosis to come to Moffitt for a screening. These screenings are available for our community at Moffitt:

- Colonoscopy
- CT Lung Screening
- Breast Screening (Mammography, MRI, Ultrasound)

*To learn more about the specific screenings recommended, visit Moffitt.org/Screenings.*
Certain times of the year, like special holidays or birthdays, present us with another challenge: taking care of those who are feeling sad because of the death of their loved one. They feel the pain more during these special times. Although grieving is by its very nature a lonely task, it requires the help of other people. The social distance caused by COVID-19 makes it hard, yet there are ways in which those who are grieving, their families and friends can overcome this difficulty.

If it is not possible to be physically present, do it virtually through video calls, phone calls, emails or send cards with words of love and affection. Plan to watch movies or have meals together even if you are in different places. For religious people, family prayers and virtual religious services can help. It is important to understand that feelings such as sadness and anger are normal after the death of a loved one, and it is not necessary to add guilt to these feelings. Welcoming such feelings is an act of kindness and compassion.

Providing time and space for the person to grieve can be done by making yourself available to listen and offering to help with daily tasks that the person finds to be more difficult. Shopping, doing the laundry or helping with cleaning are some ideas. Using delivery services to send them their favorite food is also a loving gesture.

Meeting virtually to remember the person who died and sharing laughter and tears can help make a person’s life into a cherished memory. If a funeral was not possible because of COVID-19, organizing a virtual memorial service may also be a good idea.

If you would like to talk with a Chaplain, please call 813-745-2856.
MOFFITT RESOURCES to Help Patients and Caregivers

UPCOMING EVENTS April-May

Virtual Relaxation/Meditation for Stress Relief  
813-745-6052  
Virtual/Zoom only, RSVP only, please email PatientWellness@Moffitt.org

Open Art Studio  
Arts in Medicine Studio  
MCB – 3rd floor, Mon.–Fri., 9:30 a.m.–4:00 p.m

New Patient Chemotherapy Class  
Bichoy.Gabra@Moffitt.org  
MCC – Owl’s Den – Every Mon., 12-1 p.m., 1st floor  
MCC – Owl’s Den – Every Thurs., 1-2 p.m., 1st floor

Virtual Meet the Experts  •  813-745-1690  
Virtual/Zoom only, Tuesdays and Wednesdays, 10-10:30 a.m., RSVP only, please email PatientLibrary@Moffitt.org

PATIENT AND FAMILY SUPPORT GROUPS

Due to social distancing, we are offering virtual support groups via Zoom. To learn more about any of the support groups offered, including times, please call the Social Work office at 813-745-8407 or visit Moffitt.org.

**General Cancer Support Group**
Weekly meeting for patients diagnosed with any cancer type to connect with others and share mutual support. Meets every Tuesday, 1-2 p.m. via Zoom Meeting. To register, please call 813-745-8407.

**Family and Friends Support Group**
Weekly meeting for families and caregivers of patients with any cancer type to connect with others and share mutual support. Meets every Wednesday, 1-2 p.m. via Zoom Meeting. To register, please call 813-745-8407.

**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 Meeting. To register, please call 813-745-8407.

**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 Meeting. To register, please call 813-745-8407.

**Families First: Parenting During Cancer**
A support group for parents raising young children and teens while living with cancer. Please contact the Social Work Office for dates and times at 813-745-8407.

**Support Group for Caregivers of Brain Cancer Patients**
Monthly meeting for caregivers of patients with brain tumors, brain metastasis and CNS. Meets first Tuesday of each month, 5-6 p.m. via Zoom Meeting. To register, please call 813-745-8407.
Support to Caregivers

**Donna DiClementi, LCSW, Manager for Outpatient Social Work**

To support someone is to help bear the load, to uplift and to help build a foundation. And that is exactly what our support groups at Moffitt Cancer Center are designed to do for people living with cancer and their loved ones. Two of our many support groups that focus primarily on loved ones and caregivers are the Family and Friends Support Group and the Support Group for Caregivers of Brain Cancer Patients. Both virtual support groups are led by qualified social workers with advanced training.

Megan Yoder, LCSW, OSW-C, and Liz Brown, MSSA, LCSW, co-lead the Family and Friends Support Group every Wednesday from 1:00-2:00 p.m. **Megan and Liz share that this group provides a comfortable space for our patients’ loved ones to talk about the impact of cancer in their lives.** The group members have been able to connect through Zoom from the comfort of their homes at a time when many are isolated and need support. The group allows for caregivers to meet others who may have similar thoughts and learn healthy ways to manage their emotions. Oftentimes, just talking about one’s experiences with others who are going through something similar is helpful.

The Support Group for Caregivers of Brain Cancer Patients focuses on a specific group of caregivers. Christina Macnamara, LCSW, OSW-C, facilitates this Zoom group on the first Friday of every month at 1:00 p.m. Macnamara says, “Caregivers of brain cancer patients can feel alone in their experience. Being a part of this group lets them share their thoughts and reactions. They finally feel understood.”

Support groups for loved ones are an essential part of care offered at Moffitt. We know that a diagnosis of cancer doesn’t only impact the patient. Encouraging loved ones to participate in these free groups can help increase their knowledge and resilience.

*If you would like to know more about these support groups or any others, please call the main Social Work Office at 813-745-8407.*

**“The Moffitt Cancer Support Group for spouses and caregivers is a great opportunity to give yourself a reprieve from daily caregiving. Being a caregiver does not provide much opportunity for taking time for yourself. This group is facilitated by licensed clinical social workers. Liz and Meghan, the leaders of the group, are knowledgeable, supportive and caring. You can talk or just listen to others. Attendees have spoken about their experiences while others attending have offered support, advice and shared their own. It is an opportunity to learn, to see that you’re not alone and that others are experiencing similar feelings. In my case, I have seen that others are dealing with much bigger problems than me. Whatever stage of cancer your loved one is at – it is not easy! The support group gives me the strength I need to help my husband with a difficult and life changing diagnosis. It also gives me hope that everything will be okay. I am very grateful that Moffitt offers this service and I am grateful to Liz and Meghan for helping me get through each week.”**

— Moffitt Caregiver
A Perfect Love Story
Bruce Mackey, Family Advisor, Patient and Family Advisory Council

My wife, Loyce, and I had 55 wonderful years together! We felt that our marriage was something special and we thoroughly enjoyed our life together. Cancer entered our lives when Loyce was diagnosed with stage III melanoma in the late 1970’s, but she also faced breast cancer and metastatic sacral breast cancer over the years. Throughout her cancer journey, Loyce was resolute in her fight against each occurrence. As the years passed, I continually learned how to become a very supportive and loving caregiver for her.

After recovering from her last radiation treatment, Loyce returned to her active social life and vigorous exercise program: playing tennis and walking 3 1/2 miles daily, rain or shine. For the next 8 years, life was wonderful! Alas, our world came crashing down when she fell down our second floor steps. Severe trauma resulted in shattered sacral bones and nerves.

For 14 months, we consulted medical specialists in Daytona, but none of them could control Loyce’s excruciating pain. Finally, her local oncologist recommended Moffitt’s neuro-oncology clinic. Within a week, she met her Moffitt neurosurgeon, who scheduled surgery the following week. Right away, we experienced the special caring Moffitt spirit! Unfortunately, the surgery was unsuccessful, but by working with the Interventional Pain Clinic and Supportive Care Medicine program, we were able to address our emotional and spiritual needs before going home to hospice care.

A few days before Loyce passed away, we talked about how I should spend the rest of my life. She asked that I concentrate my efforts on helping others and becoming a Moffitt volunteer, as her Moffitt care was so far superior to her previous cancer center experiences. Now, eight years later, I am a Tampa resident enjoying my very rewarding life as a dedicated Moffitt Family Advisor volunteer.

To learn more about how to become a patient or family advisor, please call 813-745-2963 or email PatientAdvisors@Moffitt.org.

In 2020, Moffitt’s Patient and Family Advisory Council established the Patient and Family Advisory Program Bruce and Loyce Mackey Volunteer of the Year Award in honor of Bruce and Loyce Mackey. Bruce was the inaugural recipient of the award due to his passion, dedication and commitment to collaboration since 2014.
Nutrition for Caregivers

Diane Riccardi, MPH, RD, LDN, Clinical Dietitian

Caring for someone with cancer is a true act of selfless love, but when this responsibility stretches over months or years, it can result in neglecting your own health.

Eating a healthy diet is an important part of self-care. Good nutrition keeps your immune system strong and increases your energy level. How can you think about nutrition when you have so much to do in your caregiving role? Try these strategies:

1. Prepare meals for yourself and the person you are caring for at the same time. Planning your own meals can seem like a luxury but cooking healthy meals won’t be as difficult if you combine the effort with your caregiving role. No time to eat with your loved one? Pack your food in a cooler to warm up later.

2. Plan ahead for easier food prep when you’re pressed for time. Use a slow cooker while you’re at doctor appointments or try the alternative and speed up cooking at home with a pressure cooker.

3. Keep an ongoing shopping list in the kitchen or simply ask Google to create a list on your mobile device. To save time and social distance during the pandemic, grocery shop during off-peak times or use a grocery delivery service.

4. Ask for help and accept it. Consider asking family and friends to make dinner one night a week, pick up items at the grocery store or help clean up the kitchen after dinner.

5. Still skipping meals and snacking on high calorie, salty food? Keep on hand pre-cut, fresh fruits and vegetables, or whole grain crackers and pair with low-fat cheese or hummus.

Choosing nutritious food is one of the most beneficial things you can do to keep yourself healthy. When you take care of yourself, you’ll feel better and can take better care of your loved one.

For more information about Nutrition, click here or call 813-745-3609.
Moffitt recently opened a satellite facility in Wesley Chapel and brought access to nationally ranked cancer care to Pasco County. This new location is located on the campus of AdventHealth Wesley Chapel Hospital. Moffitt will occupy nearly 28,000 square feet of the new building that features 20 exam rooms, 22 infusion chairs, three blood draw stations, two linear accelerators and a CT simulator. Patients will be able to access infusion (medical oncology), radiation oncology and surgical oncology consultations at this new location.

In effect, the new building off Bruce B. Downs near the Shops at Wiregrass will showcase a multi-specialty model in cancer care. Moffitt at Wesley Chapel's services include malignant and benign hematology, the breadth of solid tumor oncology, gynecologic oncology, endocrinology and more. Future growth of multi-specialty services offered at the site will be based on the needs of the community.

The new facility is staffed with Moffitt team members and physicians who will work closely with on-site radiology and lab processing services provided by AdventHealth. Clinical trials are scheduled to begin approximately six to nine months after opening. Phase 3 trials will be conducted, eventually moving toward more complex trials in the future.

Moffitt will employ all team members involved in the delivery of cancer care consistent with Moffitt standards. The facility has been designed to provide Moffitt patients the same experience as they would at any of the other campuses. The aesthetics of the facility have been created to provide a calming spa-like atmosphere for a softer ambiance rather than a typical hospital environment.

While the Wesley Chapel location will be most convenient for residents living in Pasco County and areas north of Tampa, anyone is welcome to use the new facility.

Providers moving to the Wesley Chapel location will notify their patients before their next appointment. For more information about Moffitt at Wesley Chapel, please call 813-745-8000, option 6.
Many of us can recall a time sitting next to a loved one when the doctor delivered news of a medical diagnosis. Imagine your loved one looking to you for guidance on what they should do next. A sense of uncertainty may overcome you as you think about what is best for your loved one’s care or what decision you might make if the shoe was on the other foot.

Some of us must be creative when bringing up health care directives. Some of us may have to plan a long road trip just to keep our loved one from running away. A person living with cancer may not want to think about decisions they had hoped never to make. Although, by encouraging conversation about health care directives, all who are involved can find comfort in knowing that the most significant decisions have already been decided.

Early on, think about how you can best support your loved one’s decisions and promote their voice to be heard by the members of the medical team. It is common and appropriate for a loved one to ask you for an opinion on a decision, and it is important to remind them of your constant support for their health care decisions. When guiding your loved ones to make health care decisions, consider the following suggestions:

- Allow time for your loved one to think about how they would like to make decisions regarding their care.
- Provide your loved one with resources, such as an Advance Directive, to help guide their health care decision making.
- Support your loved one’s decisions knowing you have done your best as their advocate and caregiver.
- Advanced care is not a one-time conversation; you should re-visit it each time your healthcare condition changes.

Want to include your family and friends in your visit?

If you have a mobile device, our team can help to set up a video conferencing call to connect you with loved ones. If you don’t have a mobile device, we can lend patients on site an iPad to use during the appointment.

This service available for both inpatient and outpatient care. For support, please call 813-745-4710, then select option 1.
Curbside Clinic Service at Moffitt’s McKinley Campus

Heather C. Morgan, Director of Infusion Services & Blood Draw Services

Moffitt has always been patient focused, striving to consistently provide the highest in quality care for all patients. Throughout this pandemic, Moffitt has sought innovative ways to continue to safely administer treatments while addressing the safety concerns of our patients. We focused on how to best maintain social distancing and adhere to CDC guidelines without compromising best practices. The concept of the Curbside Clinic was first introduced to us by Johns Hopkins, Baltimore.

The goal of the Curbside Clinic is to provide an alternate location where treatments can be safely administered in order to reduce the potential risk of exposure to COVID-19 individuals some of who we know may exhibit no symptoms. Curbside offers a select number of treatments. Patients must meet certain eligibility criteria to be scheduled at the Curbside Clinic for their treatment. They are contacted the day prior by a member of the Curbside Clinic team to ensure that there are no recent events that would make them a better candidate for an internal clinic visit.

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Present Curbside Clinic offerings:
- Continuous infusion chemotherapy pump disconnects
- Select non-chemo injections
- Select vaccines for splenectomy/asplenia

The Curbside Clinic launched on October 15, 2020 at Moffitt’s McKinley campus. The patient never needs to get out of their vehicle to receive the same level of safe, quality service they would have received inside. The appointment times are 15 minutes or less. Thus far, the Curbside Clinic has received high patient satisfaction ratings. 100% of those surveyed that have used the service say that they would “definitely” use the service again. We are keeping our finger on the pulse of patient care.

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 or call 813-745-1690.

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VIRTUAL Patient and Family Orientation

Learn how to:
CONNECT WITH PROGRAMS AND SERVICES
PARTNER WITH YOUR CARE TEAM
FIND YOUR WAY AROUND MOFFITT

• Presented in English and Spanish
• View online at MOFFITT.org/Orientation

813-745-1690 | Orientation@Moffitt.org.

CHANGING THE ODDS TOGETHER

Florida has the second-highest cancer burden in America and now, more than ever, we are called upon to make a difference. Your investment in a Moffitt specialty license plate helps researchers pioneer innovative medicines and treatment protocols, which empowers our physicians to transform lives, one patient at a time.

To learn more about the Moffitt license plate program visit MoffittPlate.org.

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.

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