PATIENT’S PERSPECTIVE

Running Scared and the Wake-Up Call

James Ridley, Prostate Cancer Survivor

Albert Einstein once said, “We cannot get to where we dream of being tomorrow unless we change our thinking today.” Little did I know that statement was going to change my life. It all started in the fall of 2018 during a routine physical. Everything checked out well until I heard, “Your Prostate Specific Antigen (PSA) score is 50!” At that point, I felt like someone had knocked the wind out of me. The physician began to explain to me that for someone my age, my PSA score should be around 3.5, and 50 was very high! He immediately contacted a urologist and scheduled an appointment for me that day. In one visit to the doctor’s office, I went from being a vibrant, healthy male in excellent physical condition to a prostate cancer patient.

I met with the urologist who recommended a biopsy. When he described this procedure, I was very hesitant and delayed three weeks before scheduling the procedure. I didn’t have any symptoms or signs. After the biopsy, my pathology report indicated a high Gleason score which confirmed prostate cancer. He suggested that I should act very quickly before the disease spread. I flew to Ohio shortly after to discuss my health plan options with my family. I said, “Pray for me.”

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It certainly isn’t unusual for a patient or their family to look for ways to thank an individual team member or their entire clinic after a hospital stay or upon completion of treatment. The most popular way, by far, is to say thank you with a gift of candy, cakes or other sweet treats. However, there are other ways to show your appreciation that don’t cost you a dime, but simply a moment of your time!

While working and volunteering at Moffitt’s front desks, we frequently are asked by a patient or family member for suggestions on how to thank an individual team member, as they were at a loss on the best way to recognize them. My question was always the same, “How do you personally like to be recognized for an act of kindness or a job well done?” Invariably their reply would be, “Oh, a simple thank you or a handwritten note means more to me than a bunch of flowers or a box of candy any day!”

Did you know that a single thank you can really make the recipient feel special? Saying thank you is the simplest and most elegant way of telling people that they are appreciated for who they are and what they do. We can never repay all the good things that people do for us, but we can surely express our heartfelt gratitude with our words.

If you would like to recognize a Moffitt team member or a volunteer, there is an easy way to do it. You can stop by our front desks or the Patient Library & Welcome Center to ask for a “Gratitude Card” to say thank you – those two little words mean so much.

Another way to express your gratitude is by sharing a note on the online Gratitude Wall. You can leave notes of thanks, encouragement and celebration, but please make sure to include the team member’s name. Your comment is sent to the team member mentioned, as well as their manager and director. Comments are also posted on a public forum in various places across Moffitt Cancer Center and will be viewed by our team members, patients, families and caregivers. Come back and leave as many messages as you’d like!

You can access the Gratitude Wall by visiting Moffitt.org/GratitudeWall or by scanning the QR code on the right using your phone's camera. When you get there, hit the plus sign (+) located at the top of the Gratitude Wall and add your comment! It’s that easy but it makes a world of difference to all those who work tirelessly and selflessly to care for our patients, their families and caregivers, and one another.

To leave a note of gratitude to any Moffitt team member, please visit Moffitt.org/GratitudeWall.
Caring for COVID-19 Positive Patients During the Pandemic

Angel Johnson, BSN, RN, CMSRN®

Since the start of the pandemic, I have cared for patients with COVID-19 at Moffitt. It was scary for my peers and scary for our patients. Patients were fighting cancer and now they had a new, possibly deadly, virus to deal with. There was so much that was unknown in the early days of the pandemic. We really didn't know what we were fighting — no one did. Every day, doctors and nurses were learning new ways to treat the virus, what would help ease the symptoms and what was not helpful. We now know more about what symptoms to look for, what to expect and when to worry. It now feels a little less scary.

For a long time, we had to limit families, visitors and caregivers from coming with the patient to their appointments. This left people separated from their families and support systems. To fill this gap, we stepped in as nurses. We strengthened the emotional support system for our patients even more so than we normally did every day. Trying to fill the role of support was difficult as our faces were covered and our voices were difficult to hear, muffled by two masks.

Our normal method of showing care using facial expressions and touch was gone. We had to make our care known through our deeds and our eyes. The caring touch that so many nurses possess became different after COVID-19.

It became important to find ways of dealing with the stress of the pandemic. I know some of my peers took up new hobbies such as baking and some redecorated their homes. I started a type of meditation called transcendental meditation. Twice a day, I take quiet time for me. It lets me drown out the noise and chaos of the world. It has proven to be a great tool for dealing with the stress.

As difficult as the pandemic has been, being the sole caregiver of my patients due to COVID-19 restrictions has made a more personal and caring bond between us.

If you have a loved one who is unable to attend your outpatient appointment or visit you during your hospitalization, there are options to connect virtually. The Caregiver Virtual Support team can assist you with setting up a video call and making sure that you have technology to connect with your loved ones. For more information, contact 813-745-4710, then select option 1 or email PXCaregiverVirtualSupport@Moffitt.org.

Acupuncture Eases Cancer Side Effects

Used as complementary therapy, research shows acupuncture may help patients feel more like themselves by reducing:

**PAIN | NAUSEA | FATIGUE | STRESS**

And other treatment side effects and symptoms.

Services are available to Moffitt patients through an independent contractor. For more information, call **760-710-7836** or email Liem@RevitalizeAcupuncture.com.
Trust in Transition: Reflections of a BMT Caregiver

Laura Barber, Family Advisor, Patient and Family Advisory Council

My husband, Steve, received a life-saving stem cell transplant from a very generous, unrelated donor almost ten years ago at Moffitt. As his full-time caregiver during those 100 critical days post-transplant – and making the transition from being inpatient at 3 West back into our home – I understand how other caregivers might be feeling at this crucial moment: probably nervous, maybe even frightened.

As a caregiver for a Bone Marrow Transplant (BMT) patient, Moffitt has provided you with the best training and tools possible. Yet when it’s just you and your loved one exiting the safe refuge of the hospital, it is definitely overwhelming. This is true whether the patient is receiving a transplant from a donor or transplant from their own body. This is also true whether you are entering the Hope Lodge, residing in temporary housing or living close enough to return to your home. Leaving the hospital under any circumstances can feel overwhelming for caregivers.

As I wheeled Steve to the valet that crisp November afternoon, tears quietly ran down my cheeks. They were tears of gratitude for the exceptional BMT professionals and providers. Tears for all those we encountered in the clinic, treatment center and while Steve was inpatient. They were tears of anxiety, but also tears of trust. We believed in our BMT team, which included both of us. I faced this new chapter of our journey prepared, and I knew I could always reach the clinic anytime if I had any questions or doubts about something. I had to trust that the transition of the patient to me as a caregiver had been made, and I was ready.

To prepare as a caregiver – especially for a patient in a compromised state – you must find ways to build trust within your environment. Here are some tips that helped our experience:

- **Review your notes, book(s) or classes** when needed. A lot of information is given to a caregiver at one time. Look back on these notes to refresh your memory.
- **Watch out for shoes, hands and faces.**
  - Shoes meet the dirtiest surfaces like floors in public spaces – keep shoes in a separate area of the house.
  - Hands touch everything – wash them frequently.
  - Faces – we never noticed prior to transplant how much we fingered eyeglasses, rested our heads in our hands, etc. It’s worth the effort to avoid touching your face.
- **Be gentle on yourself as a caregiver** – you will be very busy during this transitional time. Find any helpful shortcuts to your normal routine, like using disposable plates instead of washing dishes.
- **Don’t hesitate to call your medical team** if you are unsure about something or if there are changes in the patient. This is a critical time and continued communication with your team is of the utmost importance.
- **Finally, take a deep breath** – you’ve got this!

Moffitt hosts weekly virtual support groups for families and caregivers of patients with any cancer type to connect with others and share mutual support. To register for the Family and Friends Support Group please call 813-745-8407 for log in information.
MOFFITT RESOURCES

MOFFITT RESOURCES to Help Patients and Caregivers

UPCOMING EVENTS

June – August

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

Virtual/Zoom only, RSVP only
Weds. at 12:15 p.m.
PatientWellness@Moffitt.org

Virtual Gentle Restorative Yoga Class
813-745-6052

Virtual/Zoom, RSVP only
Tues. at 11 a.m. and Thurs. at 2 p.m.
PatientWellness@Moffitt.org

Magnolia Open Art Studio

In person, Moffitt’s Magnolia campus
3rd floor – Arts in Medicine Studio
Mon.-Fri., 9:30 a.m.-4 p.m.

McKinley Open Art Studio

In person, Moffitt’s McKinley campus
1st floor – Arts in Medicine Studio
Mon.-Fri., 9:30 a.m.-4 p.m.

Patient and Family Orientation
813-745-1690

Virtual/Zoom only, RSVP only,
Mon.-Fri., 2 p.m.
PatientLibrary@Moffitt.org

Virtual Meet the Experts
813-745-1690

Virtual/Zoom only, 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 any of the support groups offered, including times, please call the Social Work office at 813-745-8407 or visit Moffitt.org/SupportGroups.

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. Meets via Zoom meeting. For dates and times and to register, please call 813-745-8407.

Survivorship Program Support Group
Monthly meeting for people who attend the Survivorship Program to connect with others and share mutual support. Meets the last Tuesday of every month, 1-2 p.m. via Zoom meeting. To register, please call 813-745-8407.
PSA had climbed even higher. The good news was the cancer was still localized or encapsulated. He also recommended that a collaborative option for treatment would be Moffitt Cancer Center since I live in Tampa. My health insurer considered Moffitt as a “center of excellence,” so I was all for it.

This was my wake-up call. I lost a friend to prostate cancer and I knew I needed to find a medical team that I trusted. I met with Dr. Levine at Moffitt who had a wonderful bedside manner. He talked to me like a friend and got to know me. He noticed that it had taken a long time for me to make a decision and said that he would help me execute a plan. I had complete trust and confidence in his advice. I felt very comfortable with his plan of action. He shared that my prognosis was good. He ordered scans to make sure the cancer hadn’t spread, and they came back stable. He offered to partner with the providers at UC Health to create a plan so I could get my treatment with my family’s support. With this dream team in place, I was ready. That gave me the unflinching courage to follow through.

I received 28 treatments of proton therapy in Ohio with no concerns about serious side effects. As I write this, I am happy and grateful to report that I am cancer-free. My PSA score 0.6!

If you’re reading this and you are in denial about a cancer diagnosis, like I was, here’s what I want you to know: Every great athlete has a coach. That coach can see things that you can’t see. But if you follow the instructions, you will be met with success. Prostate cancer is not something to play
around with because you never know when it will metastasize. Black Americans are more likely to die from prostate cancer. Don’t wait to get treatment. Even if you don’t have symptoms, do something about it. Don’t keep the diagnosis to yourself. You’ll feel better and so will your family. Now, I am excited to go to my quarterly visits with Dr. Levine, who I trusted to save my life.

James Ridley sharing his story on New Years Eve 2021 at Bible Base Church.

On New Year's Eve of 2021, I was able to share my testimony on the stage of Bible Based Church. The worst thing you can do is stay in denial. When in doubt, find empowerment by picturing yourself sharing your testimony on a stage, like I did!

If you’re concerned about your prostate cancer risk, if you already had a PSA elevation or abnormal DRE, or both, please contact our oncologists to discuss next steps. We don’t require a physician’s referral to make an appointment with our Genitourinary Oncology Program. Call 1-888-663-3488 or complete a new patient appointment request.

“**African American men are more likely to get prostate cancer at a younger age and to die from the disease. Additionally, African American men are also more likely to have their prostate cancer metastasized at the time of diagnosed. Although the reasons for this is complex and multifactorial, the good news is that if the disease is diagnosed in a timely manner, and the appropriate treatment is received, then the outcomes in African American men are no different from other groups. This means that measures aimed at ensuring timely diagnosis and staging, coupled with adequate and equitable management strategies will help to decrease deaths from prostate cancer in African American men.**”

— Kosj Yamoah, MD, PhD, Chairman, Department of Radiation Oncology, and Director of Radiation Oncology Cancer Health Disparities Research at Moffit Cancer Center
Moffitt Team Members Help Patients...

Amazing Team.
I want to thank Dr. Chatwal and her amazing nurse Alyssa, Dr. Montejo and his radiation team, and Dr. Liu and his team for the amazing care they provided to my husband. He fought the fight with everything he had in him and his team of doctors and nurses were there to support him and provide the best care. Thank you so much. Even though he lost his battle, I will forever be grateful.

Nancy Schaer – You are a ray of sunshine in the MKC Breast Clinic dressing room. When I got into your room, I was nervous and anxious, but you put me at ease with your concern and conversations. Your ability to talk and listen with everyone in your room is amazing. Great job. Keep up the good work. You’re fantastic.

Sandy Capps – Sandy went above and beyond to help me get a COVID test before my surgery and prevented me from having to reschedule. She was kind and solution-oriented the entire time!

Thank you to our social worker! Huge thank you to Christine Dortenzio, our social worker who helped connect my parents to lodging nearby while my dad is going through radiation. I’m so thankful that they won’t need to travel 80 miles each trip – twice a day – for the week they need to be here. It was such short notice so we weren’t sure it would work out, but thanks to your coordination, it did. We are so very grateful!

Thank you – Nurse Kim Lievre with the McKinley Cutaneous Clinic has found her calling. Not only is she informative and responsive to all of my inquiries, but she’s compassionate and truly shows her care and concern for her patients. I’m thankful for her and all of the staff at the McKinley Campus.
One of the more impactful things that has been echoed by dozens of patients is to let your loved ones know often how much you care. I take this advice to heart, and always let my loved ones know – even if it might embarrass some of them!

— Stuart Richards, Patient Flow Coordinator

There are two good quotes from patients. ’What was important in the past is not important anymore... What wasn’t important in the past is very important now,’ and ‘You will always be smarter tomorrow.’

— Dr. John Kiluk, Breast Oncology

I have learned so much since becoming a medical provider including learning a great deal from many patients whom I have worked with. One of the greatest lessons I have learned is the importance of living life to the fullest. It is easy to take things for granted in life. I have learned from others the importance of appreciating and valuing each day, and spending as much time as possible with family and friends.

— Dr. Meghan Haas, Supportive Care Medicine

As an oncology massage therapist at Moffitt, I spend my time focusing solely on the comfort of our cancer patients. It is an honor. One day, as part of our pre-massage protocol, I asked a recently operated-on patient how he would rate his quality of life on a scale of 0 (being the best) to 10 (being the worst). Lying there with a pain grimaced face he quickly responded, “0! My life is fantastic. Sure, I have cancer, but... I promise you, cancer does NOT have me.”

— Megan Marshall, Licensed Massage Therapist

One patient in particular comes to mind when I think about the many who have impacted me since starting here at Moffitt. One gentleman shared a bit of his story and it was incredibly clear how selfless he was and how very joyful. He told me his mission was to serve others as much as he can and, in doing so, he was then filled with joy. I think about him often and hope he continues to inspire me to always be willing to help and lift others up!

— Kaley Ransbottom, Artist in Residence
Talking Often Helps

Tony Winter, MDiv, Board Certified Chaplain

Being told that you have cancer is one of the things no one wants to hear. It will make you look deeper and maybe differently at much of what you know and believe about your life. I have listened to hundreds if not thousands of patients tell their stories.

Patients may have questions like:

Where is God? What did I do to deserve this?
Will life ever get back to normal?

As a chaplain, they usually will tell me about what has happened most recently. Then their story will journey back in time to important moments that brought them to the present time. Eventually, they will explore where they may be going next. I will help them connect with what has helped them find meaning in the past. Together, we will see if it still does now or if it may again in the future.

Patients may have questions like: Where is God? What did I do to deserve this? Will life ever get back to normal? I have said to many of my patients that if I ever wrote a book, it would be titled, “How Cancer Hijacks Your Life.” I say this because many things like career goals, time with family, vacations or retirement were all put on hold, changed or cancelled after their health challenges and cancer treatments took over so much of their energy.

If you can identify in some way with what you have just read, know that Moffitt Cancer Center has Board Certified Chaplains available to talk with you.

If you would like to talk with a Chaplain, please call 813-745-2856.

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 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.
Mind and Body Connection After Cancer Diagnosis

Dr. Liem Le, DAOM, Licensed Acupuncturist

Whether you are a cancer survivor or someone living with cancer, you might feel no longer in-tune with your body due to effects of the cancer treatments. Maybe you feel that your body isn’t functioning like it used to and that you are entering a “new normal.” However, having helped many patients thrive through their cancer treatments into survivorship, I can tell you that this is not always the case. The many therapeutic modalities available at Moffitt Cancer Center, such as physical therapy, massage, acupuncture, yoga and mindful meditation, can often help to mitigate the side effects you might experience.

The mind and body is connected: our bodies respond to the way we think, feel and act, and vice versa. For this reason, self-care is not a luxury – it is a necessity – to relax, reduce stress, and to promote healing and recovery. Taking time to treat yourself is essential, whether taking a quiet walk, taking a nap, having a nice meal or a massage.

As a survivor or as someone living with cancer, there are times when you might feel alone. There may be times when others around you do not perceive your emotional pain or hardship, as you might not “look like” you are experiencing the more overt physical effects of cancer. I always encourage my patients to express how they feel to their family, friends or support group.

Do not diminish your experience and feelings – they are valid. Physical and emotional scars might last long after treatment and may reopen every time you have follow-up visits and scans. Focus on the things you can control: diet, exercise, sleep and socialization. If and when you are ready, I suggest volunteering or supporting others who are going through their cancer journey – this can be an empowering and healing experience.

Most importantly, remember to take quiet time to listen to yourself, your body, your needs, and reflect on how resilient, courageous, and strong you are despite what you have gone or are going through.

Moffitt Cancer Center’s Integrative Medicine Service offers several supportive care options for reducing the side effects and symptoms associated with many cancer treatments. Services they offer include massage therapy, acupuncture, yoga, and meditation. For more information about the Integrative Medicine Service, please call 813-745-6052, email PatientWellness@Moffitt.org or visit Moffitt.org/HealingAndWellness.

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

To register please visit Moffitt.org/MeetTheExperts or call 813-745-1690.

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

• Virtual sessions are presented at 2pm on weekdays
• 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