

PARTNERS

Newsletter of the Patient and Family Advisory Program at Moffitt Cancer Center | Spring 2020

Tapping into Telemedicine

During the pandemic, virtual visits are up 5,000% at Moffitt

By Sara Bondell

Timothy Haifley was due to begin another round of chemotherapy for testicular cancer at Moffitt Cancer Center when a high fever landed the 45-year-old in a Tallahassee hospital.

Haifley needed to see his medical oncologist, but



he didn't have to travel from his Tallahassee home to Moffitt. Thanks to telemedicine, he and his wife had the appointment from home.

"Sitting in front of a computer was just like we were talking to him in person," Haifley said of his oncology visit. "I said everything I wanted to say and asked anything I wanted to ask. It was just like we were sitting across the table from him, just without the four-hour drive."

It not only saved time, but also stress. Haifley is severely immunocompromised because of his treatment, so a virtual visit got him the care he needed without the long trip and face-to-face appointment that may have increased his risk of contracting COVID-19.

The visit also allowed Haifley's wife to be at the appointment, which would have been impossible since Moffitt has instituted a no-visitor policy to cut down on foot traffic during the pandemic.

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MESSAGE FROM THE CO-CHAIR



*Shani Parkin, Co-Chair
Patient and Family
Advisory Council*

While reading a journal article entitled, “How to Control Medical Debt After a Cancer Diagnosis,” it brought to mind a conversation that I had with a colleague recently diagnosed with stage 4 cancer. They were extremely concerned that even with health insurance, their out-of-pocket expenses would still be in the range of \$12,000+ with absolutely no guarantee that it wouldn’t exceed this amount.

This is a real concern for many patients and one that Moffitt openly embraced, resulting in a search to find a company that cares about the patient’s need as much as we do. In 2019, a relationship was established with AccessOne, a leading provider of patient payment options.

AccessOne offers several affordable flexible payment options tailored to meet each patient’s financial need regardless of balance, and all patients are accepted regardless of credit history. They will review your payment options with you before you attend your appointment. If you have an idea of how much the service will cost, they can work with you to determine your monthly payment. Some of the benefits of choosing AccessOne:

- There is no application process in order to qualify. AccessOne can get you signed up during your first call.
- When you have an active AccessOne account, all your Moffitt bills will automatically be sent to AccessOne so that you can include them on your existing plan.
- Further information can be obtained from the Moffitt Business Office or contact AccessOne directly at:
 - 1-888-458-6272
 - **AccessOneMedCard.com**

*Patients can also request cost estimates for procedures and testing. For any information about estimates, please contact our **Business Office** at 813-745-8422 or **click here** to email us.*

Team Vicki: Soldiers on for a Cure

Moffitt Cancer Center Foundation

Vicki calls them her “soldiers” – the family and friends who rallied around her during not one, but two battles with breast cancer. “We had meals on our doorstep nightly,” recalls Vicki’s husband, Ted. “Friends took Vic to her treatments so that I could maintain my office schedule, and they made sure our family had everything covered so that Vic could focus on staying strong.”

And in recent years, she has called on those soldiers to fight the larger battle – finding cures for cancer. Team Vicki Peters/Carrie Kukuda/Get a Grip Fitness is a powerful force in the annual Miles for Moffitt fundraising event. The team, made up of an impressive 93 members and led by co-captains Vicki and Carrie, owner of Get a Grip Fitness raised more than \$19,000 for cancer research this year.

Rachel, one of Vicki’s four daughters, explains why participating in Miles for Moffitt means so much to the whole family. “It’s really important for us to support Moffitt Cancer Center and the research they’re doing. We got lucky that our mom had good outcomes twice, but we know that hasn’t been the same kind of outcome for a lot of our family and friends. When we donate, we believe we are helping to prevent cancer for others in the future.”

Supporting Miles for Moffitt is just one way patients and families can support the cancer center. This annual family friendly event is a community-wide movement of inspiration, courage, and hope that raises critical funds for cancer research. Miles for Moffitt is a community that is here for you and we can’t wait to come together on October 24. Registration opens this summer!

*To learn more about how you can make an impact at Moffitt, call the Moffitt Foundation at 813-745-1403 or visit **Moffitt.org/Give**.*

Tapping into Telemedicine

Virtual cancer care

Telemedicine isn't a new concept. Hospitals began experimenting with it in the 1950s using the telephone. As times changed, so did the technology; two-way interactive television sets and eventually the Internet and video chat applications made delivering virtual health care even easier.

Moffitt patients can receive top-notch, Moffitt-quality care without leaving the comfort of home. New and established patients can interact with clinical care teams through face-to-face video appointments by using a computer or a mobile device.

While primary care medicine has been using telemedicine for years, consultation with cancer patients has lagged behind.

“What we do is highly specialized,” said Dr. Philippe Spiess, medical director of Virtual Health at Moffitt. “There may be unique aspects to caring for cancer patients that may be only captured through a face-to-face interaction.”

Then came the COVID-19 pandemic, sending health providers scrambling to find ways to deliver care while reducing the risk of infection. And cancer patients were no exception.

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Virtual Visits FAQs

A new way to connect with your providers

Key benefits include:

- Access to your care team at your convenience
- Reduced travel costs and office wait times
- One-on-one treatment and services
- Increased efficiency

Q: Who can use Virtual Visits?

A: New and established patients accessing care and in relatively stable condition can use Virtual Visits. Moffitt offers telemedicine services for patients who are determined eligible by their care team.

Q: Will I be charged for my Virtual Visit?

A: Depending on your insurance benefits, you may have out-of-pocket costs for Moffitt's Virtual Visits option. Not all health plans provide coverage for virtual doctor appointments, so you should check with your plan to determine the specific coverage. *If you have questions or need financial assistance, please contact 800-456-3434 ext. 8422.*

Q: Can I get a prescription through Virtual Visits?

A: Yes. Virtual Visits allow for appropriate prescribing based on the provider's evaluation.

Q: Which providers offer this option?

A: This service is offered by Moffitt medical oncologists, surgeons, advanced practice professionals

(APPs), nurses and clinicians such as genetic counselors and dietitians.

Q: Are Virtual Visits available outside the state of Florida?

A: Due to COVID-19, state restrictions have been lifted and we are able to offer care to patients in the following states: AZ, CO, CT, DC, DE, FL, HI, ID, IN, IA, MI, MS, NH, NM, NY, NC, ND, OR, PA, TN, WV.

Q: Am I eligible to use this service?

A: Moffitt knows each patient has unique needs for their care. Ask your providers and clinical team to determine if you are eligible for services to be delivered from an alternate location.

Q: Does Moffitt offer translation services during Virtual Visits?

A: Yes, video translation services are available in different languages. Please ask your scheduler or medical team to connect you with an interpreter at the time of the appointment.

Q: What equipment do I need?

A: You will need a computer with Google Chrome or a mobile device with an internet connection. If your device doesn't have a built-in microphone and webcam, you will need those as well.

For instructions on how to get started, visit [Moffitt.org/VirtualVisit](https://www.moffitt.org/VirtualVisit).

Keeping Patients And Loved Ones Connected

Moffitt Cancer Center is committed to the health and safety of our patients, their families and our team members.

We are taking all necessary precautions on COVID-19 from the Centers for Disease Control and Prevention. In order to protect our immunocompromised patients and team members from the risks of COVID-19, we will no longer allow visitors on campus.



We encourage you to use your smartphone or mobile device to stay in touch with your loved ones while at Moffitt through Facetime, Skype, Duo, or Zoom. We have team members on site at all of our locations to provide support. Please call 813-745-4710 Monday-Friday from 8am-5pm or email PXCaregiverVirtualSupport@Moffitt.org. After 5pm on weekdays and weekends, please call our IT Help Desk at 813-745-4357.

Moffitt Caregiver Virtual Visits. A way for patients and caregivers to stay connected. Virtual Visits for caregivers are available for both Inpatient Visits and Outpatient appointments. If you have a mobile device, our team can help to set up a Zoom video conferencing for your loved ones to join you on virtual appointments or visit with you during an inpatient admission.

If you don't have a mobile device to use for a Virtual Visits appointment, we can lend you an iPad. For support, please call 813-745-4710 Monday-Friday from 8am-5pm or email PXCaregiverVirtualSupport@Moffitt.org. After 5pm on weekdays and weekends, please call 813-745-4357.



Guest Wireless Access. To connect to Wi-Fi at Moffitt, go to "Settings" on your device. Look for Wi-Fi connections. Click on "Moffitt Guest" and wait for it to connect. If you see an icon prompting you to sign into the Wi-Fi network, click on it. If not, open a web browser and type: guest.moffitt.org to open the User Policy page. Select "Accept" User Policy at the bottom of the page. Need help? Visit an information desk at any location or call 813-745-4357.

Tapping into Telemedicine

5,000% increase

Moffitt launched telemedicine about two years ago, with 30 providers offering virtual visits to select cancer patients as part of a pilot program. The pandemic spurred Moffitt to ramp up its efforts to help reduce risk of exposure to the virus, and the virtual health team quickly trained staff and identified which appointments would be appropriate to convert to virtual visits.

At the end of February, 76 Moffitt providers were performing virtual visits. A month later, there were almost 200. Telemedicine visits grew more than 5,000% in three weeks.

Relaxed state and federal telemedicine regulations have allowed providers to extend virtual care to patients outside of Florida for the first time, and insurance companies have acted quickly to make telemedicine a covered service.

Virtual visitors

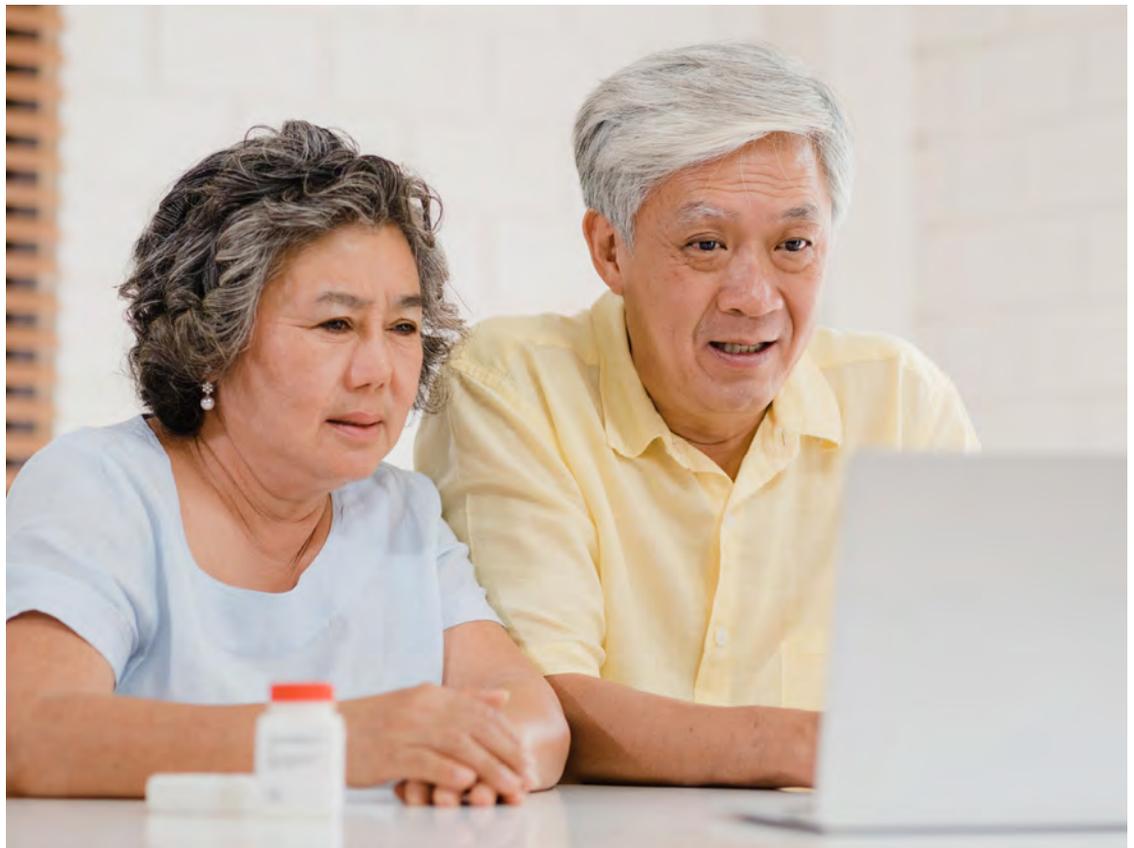
To reduce the risk of infections, Moffitt has had to prohibit visitors to the cancer center, except in special cases. Going to appointments alone can be difficult for patients who have to digest large amounts of information about their disease.

“It’s so important to have someone with a patient who is undergoing treatment or receiving a diagnosis because patients are so anxious and overwhelmed about what is going to happen,” said Dr. Margarita Bobonis, a psychiatrist in Moffitt’s Supportive Care

Relaxed state and federal telemedicine regulations have allowed providers to extend virtual care to patients outside of Florida for the first time, and insurance companies have acted quickly to make telemedicine a covered service.

Program. “Bringing a family member to an appointment is like having a peripheral memory.”

Moffitt is now applying the virtual visit concept to connect patients and family members. A video call



application or phone call can bring a caretaker into a room virtually, providing support and an opportunity to hear all the information, ultimately making for a more successful appointment.

To learn more about Moffitt Virtual Visits, click [here](#).

Young Adults: Making Our Voices Heard

Joel Santos González and Jacqueline Beaushaw, Adolescent and Young Adult Program (AYA) Ambassadors

As a young adult, advocating for yourself can be intimidating and confusing at times. Talking to your doctor about personal issues like sexuality and fertility can be embarrassing. These days we have so many options for communicating, whether it's in person, by phone or electronically. How do you as a patient communicate your concerns? I'm a believer in using everything. I find that to be the most effective way to ensure that the message is delivered. If you



need to reach someone on your team at Moffitt, I recommend both calling and leaving a message via your patient portal. Inevitably, the message reaches the right place and the concern is addressed. Put your message out there in every format possible and someone will respond.

And don't stop advocating for yourself in the doctor's office! Moffitt has an Adolescent and Young Adult Program centered on improving the experience for young adults with cancer. Moffitt's AYA program recently started a committee with a group of young adult patients called AYA Ambassadors. What do we

do? In 2020, we will be starting an online newsletter that we will be writing ourselves. It will be focused on young adult issues and will feature information about resources, program updates and our stories.

We are also focused on creating opportunities for young adults to meet. Being diagnosed with cancer at a young age may be isolating and it can be refreshing to meet other young adults who understand. The AYA Ambassadors will have some exciting new events coming up in 2020 as well as the currently recurring events, such as our weekly Lounge Night and our monthly AYA dinners.

For more information about the AYA program or the AYA Ambassadors Committee please [click here](#), call 813-745-4736 or email AYA@Moffitt.org.

Young Adults Living with Cancer AYA Initiatives

Amber Skinner, Coordinator for the Adolescent and Young Adult Program (AYA) and Latte Program

Join the Adolescent and Young Adult (AYA) Program at our upcoming virtual AYA lounge night event! Connect with other fellow young adult patients, caregivers and survivors:

When: May 14, 2020

Time: 5:00pm – 6:15pm

RSVP: Aya@Moffitt.org by 5/12

Details: Grab a few pieces of paper and your favorite drawing essentials (pens/pencils) and join us for a virtual AYA Pictionary game night event for cancer patients and survivors between the ages of 18-39.

Zoom link: <https://moffitt.zoom.us/j/91950709909>

Call in number: 1-646-876-9923

Meeting ID: 91950709909#

New Book by Scott Hamilton, Brad Paisley to Help Parents Talk with Children About Cancer

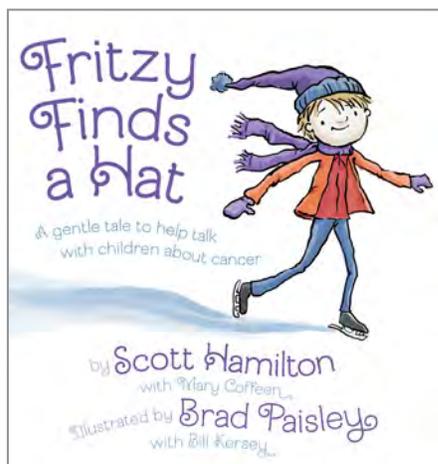
Mary Coffeen, Foundation Special Projects Administrator

Moffitt Cancer Center has partnered with Scott Hamilton and Brad Paisley to produce a book that will help parents talk with young children about cancer.

Hamilton is a member of Moffitt's national Board of Advisors. An Olympic gold medal-winning figure skater and bestselling author, he teamed up with country music superstar Brad Paisley to share the story, which is aimed at children ages 5-8. Mary Coffeen, Foundation Special Projects Administrator, helped with the development of the book and turned to Moffitt's oncology social workers for input.

Fritzy Finds a Hat tells the story of an ice-skating little boy who learns his mom has cancer. Each new page has him searching for a different hat for his mom to wear as she undergoes cancer treatments. The delightful illustrations by Brad Paisley lend an air of whimsy and thoughtfulness, while the gentle storyline by cancer survivor Scott Hamilton teaches children a powerful message of how their love and support can sometimes be the best medicine. Fritzy Finds a Hat can be read to younger children or given to older children to read themselves.

Proceeds from the sale of the book will benefit the Families First program at Moffitt, which helps families talk with their children about cancer as they navigate this difficult disease. Proceeds also will benefit cancer research at Moffitt and research funded through the Scott Hamilton CARES Foundation.



Books are available at several online sites, including Amazon.com, Target.com, Barnesandnoble.com and wherever books are sold.

Information Overload

*Regina White, RN, MS, OCN,
Patient Education Specialist*

You had an appointment with your doctor and were given a large amount of information. You were asked if you had any questions. You felt like you should have some, but you were overwhelmed with all the new information. So, you said no, you didn't have any questions.

At home, you attempt to remember and make sense of all you heard. You look over the printed materials you were given. You now come up with several questions you wish you had thought of earlier.

If this situation sounds familiar to you, you are not alone. There are some steps you can take to feel more informed at your next visit. You may know about some of them already, such as writing a list of questions or bringing someone with you to listen and take notes. You may also be able to record your visit, but never do this without asking permission first.

Another way is to summarize for the doctor or nurse what you were just told. You might say something like, "I want to make sure I understand you correctly. Once I get home, I need to..." or, "To summarize, I will..."

You could also ask pointed questions like, "Can you review with me again what I need to know about this medication?"

Many health care providers are using a technique called "Teach-Back" to ensure you understood what they just explained. They may ask you open ended questions rather than just expecting a yes or no response. This is an opportunity for you to recap what you just heard which helps to reinforce the information.

Sexuality, Intimacy & Cancer

The Importance of Communicating as a Form of Intimacy

*Kristine Donovan, PhD, MBA,
Supportive Care Medicine*

A sustained, committed relationship is not just about physical intimacy; it is about emotional intimacy too. In fact, emotional intimacy is often the bedrock on which physical intimacy rests.

The key to building and deepening emotional intimacy in a relationship is good communication.



Simply defined, communication is a process of giving and receiving information between individuals. When we communicate with our intimate partner, we use more than words; we use body language, facial expressions, tone of voice, eye contact and physical

contact. We also generally have a goal (or two or three) in mind. So, not so simple!

Good communication requires an honest appreciation of your goal. Is it to express yourself, get your partner to do something, or to feel connected to your partner? If your goal is to feel more emotionally connected, consider the following:

How are you feeling physically? Fatigue, sleeplessness and pain are just a few symptoms that can undermine efforts to connect. Make symptom management a priority for both patient and caregiver.

Is there time spent together away from the cancer center? Set aside time and space at home to focus on each other.

Touch while you are together and while you talk. If watching television is something you do together – and maybe it is all you can do right now – be physically close to one another.

Remind yourself of what made you fall in love with your partner. When all else fails, commit to treating each other with compassion, respect and dignity.

If you are interested in brief counseling for concerns related to sexuality, intimacy and cancer, please contact Kristine Donovan PhD, MBA, in the Department of Supportive Care Medicine at 813-745-4630.



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.

Families First: Helping Families to Cope

Jolene Rowe, LCSW, Manager of Social Work Inpatient

Kids are always listening

Your child may be deeply engrossed in their computer game, but they are listening.

Your child may be glued to the television set watching their favorite movie for the 5th time, but they are listening.



You may find that it is harder than you realize to keep the news of your cancer diagnosis from your children. As a parent, it is normal to want to protect your children from any distress or worry. That parental instinct is strong. However, children often overhear conversations, phone calls and comments made by others. Without accurate information, children will draw their own conclusions about what they are hearing. For these reasons, sharing the news of your diagnosis and treatment with your children early on can be very helpful. Early communication about your cancer allows you to be in control of what is communicated and how.

First of all, be honest. It is okay that kids know you are upset about the diagnosis, but share your hopefulness at the same time. If that dreaded question of death comes up, reassure them that you are seeking treatment for your cancer and doing everything possible to get well. You don't have to share a lot of details. Keep it simple and use language that they can understand based on their age. Younger children may only need information about the physical changes they see, such as hair loss, or changes in their routine, such as having to ride home from school with a friend because you're not able to pick them up due to your treatment schedule. Older children may need more details. It can be helpful to ask kids what they know about cancer so that you can dispel any myths or wrong ideas about cancer, such as their fear that your cancer may be contagious.

Check in with them regularly and better yet, set up a weekly time to connect as a family to see how they are doing and ask if they have any questions or concerns. Engage others in your support system as well to be available to them, such as close family members, friends or trusted teachers. All of these steps will help kids to know that they are included, they can ask questions, and they can express their concerns about what is happening to you and the family.

Information can be empowering for kids and help reduce their anxiety. It can be empowering for you as well. Take charge of that communication and remember that kids are always listening.

If you would like assistance in finding ways to best communicate the news with your children, please contact the Social Work office at 813-745-8407 and ask to speak with a social worker. We have numerous resources to assist patients in communicating about cancer in the family.

Making Decisions in Health Care and Ethics

Just Don't Tip Toe Around When It Comes to Your Health Care Decisions

Sean T. Powell, MSW, LCSW, Director of Social Work and Patient and Family Services

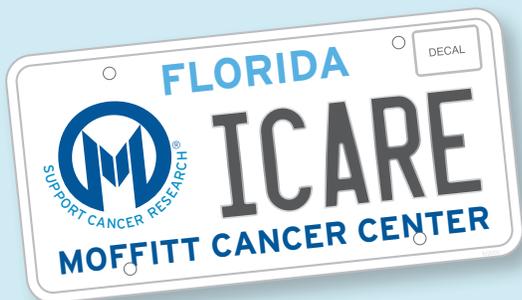
Spring is in full bloom and it is a time for renewal and rejuvenation. This is an excellent time as you move forward with spring cleaning to also do some housekeeping regarding your health care decisions.

An advance care plan is a document that speaks for you in the event you can't speak for yourself. An advance care plan can take many forms, including an advance directive, a living will, or a healthcare proxy. All of these documents allow you to spell out what kind of medical

care you want to receive if you can't speak for yourself. They also allow you to designate someone to speak on your behalf. We call this a health care surrogate. This can be anyone of your choosing, but most people select a family member, loved one or a close friend.



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While it isn't fun to think about what would happen if we were in an accident or diagnosed with a life-threatening medical condition, thinking ahead can allow you to take control of the decisions made and ensure you receive the care you want. Depending on your current health, you may choose to have CPR, medications, and other procedures to prolong your life. As you get older or are diagnosed with a medical condition, you can review your decisions and talk with your doctor about what is best for you.

It is also important to talk about your decisions with your loved ones. If you have completed an advance directive and designated someone to be your health care surrogate, make sure to discuss your decisions with them so they know how to guide your care in the event they are needed.

If you would like to discuss how these decisions are made or would like to talk to your social worker about your current situation, please call 813-745-8407.

I Want To Help... But, How?

Christine Healy, Licensed Clinical Social Worker

From the moment a person hears they have a diagnosis of cancer their lives are forever impacted. The initial blow is overwhelming and often affects all lines of communication. The intensity may change over time, but cancer has a way of blurring the senses and pushing us off balance. When this happens, friends and family have their own sets of reactions. Some want to jump in and takeover while others step back and wait for instruction. Neither one of these reactions may fit the bill, but both share a common goal of wanting to help. Patients often experience conflicting feelings about needing or asking for help. Being vulnerable or accepting that one can no longer function independently can cause even more stress. All of these emotions make it difficult to ask for help and challenging to understand how to offer assistance.

How well you know the patient and their particular situation is an important determinant of how to step in and help. If you know the patient will be traveling back and forth for treatments, offering rides might be helpful. If you are a neighbor, offering to mow a lawn, doing some grocery shopping, babysitting or pet care might be a perfect way to ease their burden. Dropping by with a meal is usually always appreciated and knowing not to linger too long is considerate. Visiting a patient often feels like the right thing to do, but patients, who may be in pain, sleep deprived or anxious, may feel obligated to entertain their “guests” which can cause added stress. Navigating life with a cancer diagnosis is a constant battle of what you want to do and what you feel you should be doing, whether you are a patient or caregiver. It is understandable

How well you know the patient and their particular situation is an important determinant of how to step in and help.



that under these circumstances, patients’ needs are not always clear.

Sometimes the direct approach works best. “I’d like to assist you through this. What would be most helpful?” or, “I know it’s hard to realize what you need at this time, may I make some suggestions about how I might help?” This approach takes the burden of “asking” away from the patient or caregiver, but also gives them the comfort and safety of feeling in control. Know that providing a sympathetic ear without advice or judgment is a great place to begin.

For more information about how to speak with a social worker, please call 813-745-8407.

Patient and Family Orientation



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

- 30-minute orientation
- Available in English and Spanish
- View online at **Moffitt.org/Orientation**
- Receive a free messenger bag with Moffitt resources and organizational tools.

813-745-4710 | Orientation@Moffitt.org.

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