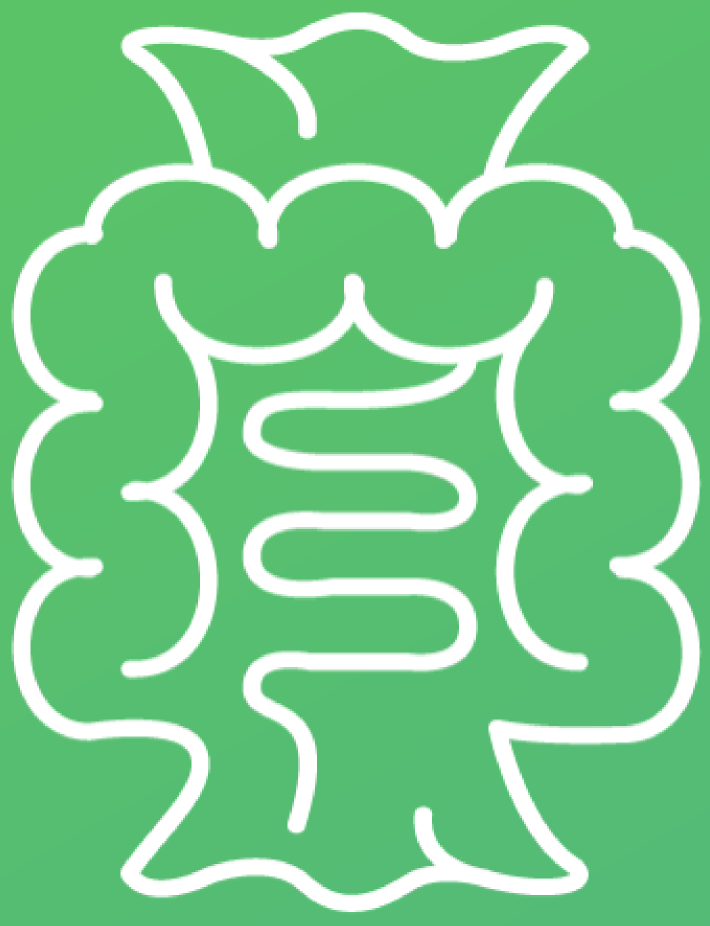


CAREGIVERS HANDBOOK TO INTESTINAL TRANSPLANT

A Guide For Caregivers of Intestinal Transplant Patients

Transplant
UNWRAPPED

TABLE OF CONTENTS

The purpose of this material is to help caregivers with the basic tasks and responsibilities that come with taking care of an intestinal transplant patient.

The material covered is not all inclusive and is simplified for ease of reading. Information about the actual transplant and the intestinal transplant process can be found on our website and reputable medical journals.

Introduction

Your loved one has most likely been ill for a very long time, has seen multiple specialists, had loads of different medications, tests, treatments, and a host of surgeries. They have likely had many diagnoses or been told numerous times that nothing can be done to help them.

This journey has been exhausting and painful for your loved one and you. You have now been told that there may be hope in the form of a **rare procedure** called an isolated small bowel transplant, a modified multi-visceral transplant, or a multi-visceral transplant.

You are now on a **new path** full of many **unknowns**. Here are a few **helpful insights** and practical solutions to help you manage this experience for yourself and your loved one.

Basic Roles of the Caregiver

Medical

Gathering information as an active part of the healthcare team, talking to doctors, and helping care for your loved one.

Financial

Talking to the insurance company, managing transplant costs, and daily household finances.

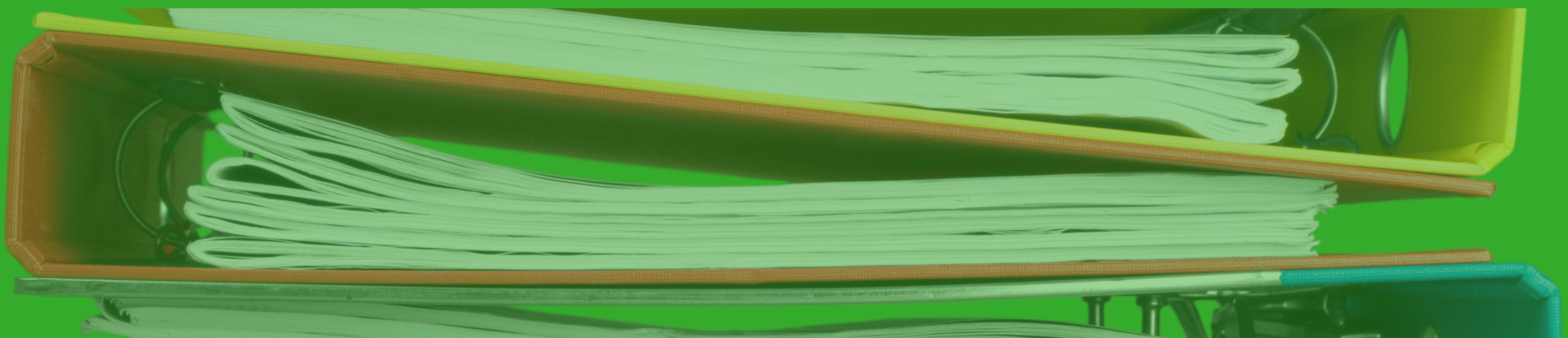
Emotional and Social

Being there to listen and support your loved one and keeping other family and friends informed and involved.

Getting Organized

When it comes to managing your loved one's healthcare, the more organized you are, the better. If you have access to accurate information regarding diagnoses, past medications, and surgeries, this will help prevent medical errors from occurring. The easiest way to do this is by keeping a **healthcare binder**:

- Obtain a large three-ring binder.
- Page dividers.
- Lined and hole-punched paper for keeping notes.
- Two to three storage pouches to keep in the binder for placing things like CDs or business cards from appointments.

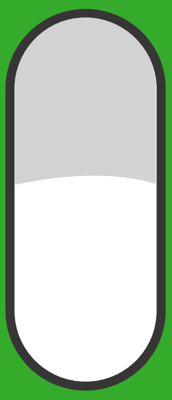


Suggested **Sections** for dividing your binder:

- Pathology reports, MRI, CT scans

- Lab reports and blood tests

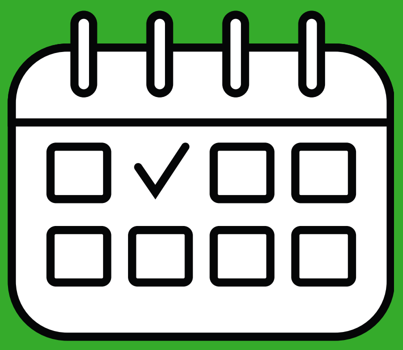
- Medication section



- Treatment log
- Health history

- Surgical history
- Notes and questions section

- Resources and Information: To keep track of all your doctor and appointment information.
- Calendar Pages: To keep track of all your past and future appointments.



Breaking Down the Sections

Medications

- Include both current and past medications.
- Indicate whether the medication was or was not helpful and if there were any adverse effects (allergic reaction and/or just any side effects your loved one experienced).
- Note who prescribed the medication and why it was prescribed.
- Dose of the medication.
- Dates medication was taken.
- Keep the most current medication list in a **digital form** on your phone so you have it with you all of the time, you never know when you might be asked their medication regimen.

Health History

- All current and past diagnoses.
- Helpful to create a timeline of the illness, ask the patient to fill in any gaps that you may have forgotten.
- Medication or food allergies.

Getting a Notebook

- Taking notes during medical appointments is an important role of a caregiver.
- Your loved one must focus on the doctor, and how they feel, so they will not be able to take notes on what is happening at the appointment.
- Having a separate notebook for notes can be very helpful.
- Write down as much information as possible in the notebook or the binder with blank sheets of paper so that it can be a 'go-to ' reference for the future.

Using the Binder and Notebook

- Carry the binder and notebook with you to all appointments and keep them both as up-to-date as possible.

- The binder is extremely helpful at the first visit to a new doctor. After that, it is an excellent spot to keep all documentation organized. You may need a second binder just for the transplant process.

- Share information with other family members, with permission from the patient, using the notebook as a reference.
    - This helps to keep everyone educated about the extraordinarily complex process.
    - It may be helpful to make a copy of some of the pages, particularly a medication list, handy for family members to use as a reference.

Using the Binder and Notebook

- If you are dual-caregiving, such as between two parents, the notebook can be useful to write down what happens on a day-to-day basis with your loved one.
    - Hand it off to the next caregiver, so everyone stays up-to-date on the status of your family member.

> “One person caring about another represents life’s greatest value.”
>
> JIM ROHN

Finding a Transplant Center

- This is a concrete way you can help your loved one.
- After finding out from their insurance company which intestinal transplant centers are in-network, you can make some phone calls and research what is needed to get appointments at each center, who the doctors are, what the criteria is, where they are located, etc.
- You could use a separate notebook or a section in the binder to write down everything you find out. Share this information with your loved one.
- A useful tool for comparing transplant centers is the Scientific Registry for Transplant Recipients (SRTR) here.
- You can also visit the Transplant Unwrapped's ***Transplant Center*** page.

Intestinal Transplant Evaluation

- Once your loved one has been recommended by the medical team to go through a transplant evaluation, and the insurance company has approved the evaluation, the most important thing to remember is to KEEP CALM!

- This does not mean that a transplant is in the future for sure.

- The evaluation can point to a variety of different treatment options, one of them being a transplant.

- A **transplant is rarely**, except in a life-threatening health situation, an **absolute must.**

- It still will be **your loved one's choice** and one that needs to be weighed very carefully.

- By now, you will have learned that an intestinal transplant is the most difficult transplant and is not the same as a kidney or liver transplant.

- You will need to help your loved one through some **tough and emotional decisions**.

- If a transplant is chosen, a move and large change in your lives will most likely have to take place.

Preparing for Transplant Evaluation and Clinic Appointments

- It is a good idea to prepare for any doctor appointment your loved one has since most of the time, appointment slots are limited, and the physician only has a short time to spend with you.
    - If you come prepared for the appointment, then you will be able to accomplish everything in a short period of time.

- It is beneficial if the same caregiver attends all of the appointments with the transplant patient.
    - This allows everyone in the appointment to be on the same page, previous questions will not be asked, and valuable time will not be wasted.

    - If this is not possible, be sure to brief the other caregiver who will be attending the next appointment on what occurred at the previous appointment.

    - This is a great time to have a notebook where you wrote down all of the appointment information to trade-off.

Preparing for Transplant Evaluation and Clinic Appointments

- The **day before** your visit, go through your binder to **review** your patient's health history, medications, past surgeries, past treatments, symptoms, and other relevant information.
    - This is important, so all of the information is at the forefront of your mind and will allow you to answer any of the doctor's questions quickly.
    - As the **caregiver**, you need to help keep the **facts straight** for your transplant patient.
    - Your loved one is probably feeling sick and anxious and will not have a clear mind while in the appointment.
    - If you prepare and have accurate information, it will help you answer the health history questions the team may have.
    - **Review** the history information with your **loved one** to ensure you are on the **same page.** You do not want to upset them by telling the team something your loved one doesn't think is accurate.

- Prepare any questions for the transplant team, including your questions and those of your loved one.
    - The day before, sit down and discuss the questions you both have for the transplant team with your loved one.
    - **Write down all of your questions** and agree who is going to ask each question.
    - Also, write down the issues your loved one is experiencing, including any new symptoms or problems that may have started since the last appointment.
    - Make sure you and your loved one are on the same page before the appointment.

> “Impossible situations
> can become possible
> miracles.”
>
> *ROBERT H. SCHULLER*

Topics to Ask About Include:

- Possible treatment options, including transplant types and gut rehab options, or other choices besides transplant.
- Benefits and risks of transplant.
- What the evaluation process looks like: timeframe, tests, and procedures involved.
- Who is on the transplant team and how do you to contact each person.
- Transplant center statistics for intestinal transplant (how many does the center do per year, survival rates, outcomes).
- How close you must be to the transplant center and how long you must stay in the area after the transplant.
- The transplant caregiver requirements.
- Prognosis and outcomes of each possible treatment option.
- Lifestyle changes associated with each treatment.
- Financial costs and coverage associated with transplant.

Educating Yourself

- **Preparing for an appointment** includes **educating yourself** about your loved one's condition and possible treatment options.

- It helps to enter an appointment with some background knowledge so you do not feel overwhelmed when the transplant team starts talking to you and your loved one.

- The internet can be an extremely helpful place to find information and a very scary space to find information.

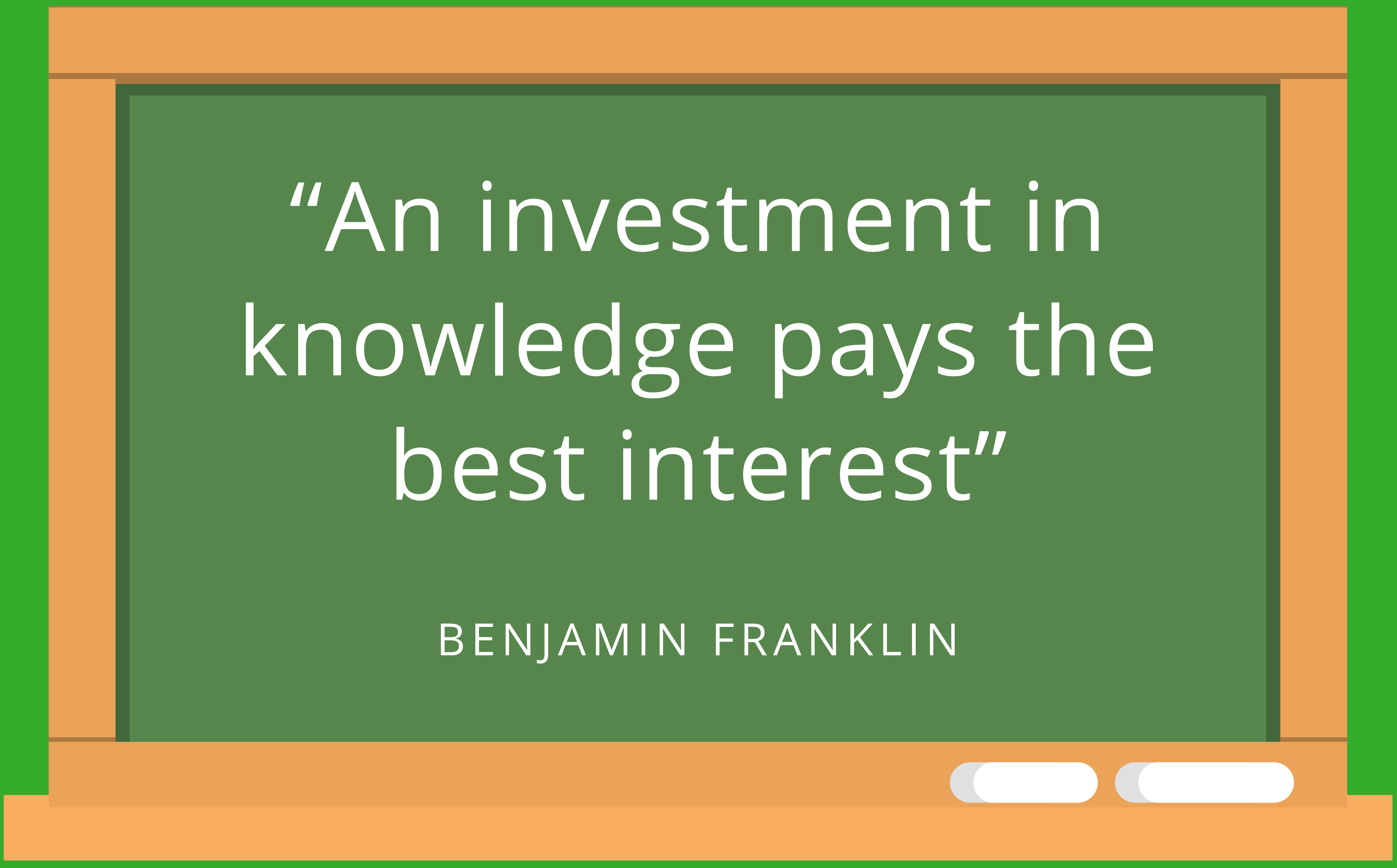
    - Be sure you are **using credible sites** that are coming from well-known sources.

    - Remember that not all patients have the same symptoms, experiences, side effects, complications, or outcomes.

    - If you have a hard time finding credible sources, you can always ask your transplant team for recommendations or visit Transplant Unwrapped's site for more information on intestinal transplant.

Educating Yourself

- You may find many sites filled with patients who are telling their stories full of their successes, fears, and disappointments.
    - Remember that this is one person’s experience and should not be taken for all presented.
    - If you find yourself **feeling overwhelmed,** confused, or way too worried, **stop reading** information from that site.
    - If you see your loved one doing the same, gently guide them away.
    - **Write down** any **unmet questions** from reading things on the internet that you wish to know and bring them to the transplant team.

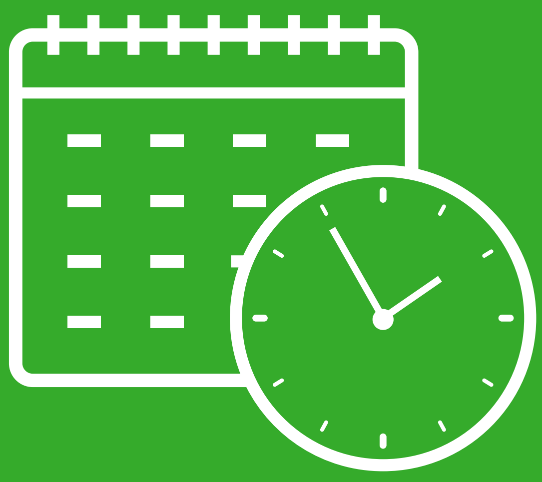


“An investment in knowledge pays the best interest”

BENJAMIN FRANKLIN

The Appointment

- At the beginning of each appointment, in your notebook, record the date, the people in attendance, including the medical professionals.



- In your notebook, throughout the appointment, record what is said, any new treatment or medication recommendations, medical terms, possible diagnoses, etc.

- Write down any questions you think of in the middle of the appointment so you will remember them at the end.

- It would help if you took notes because your patient needs to stay focused on the interaction with the medical staff. They can often become overwhelmed, emotional, and most often do not feel physically good enough.

The Appointment

- Make sure that you and your loved one understand everything that is being said at the appointment.

    - If something is unclear, ask for it to be explained differently, or perhaps for a diagram to be drawn.

    - Ensure you understand why the team is ordering every test or procedure and why each new medication is being prescribed or changed.

- At the end of the appointment, look through the notes you took and summarize with the team to make sure you have recorded everything accurately.

- After you leave the appointment, review your notes with your loved one so you can make sure you both are on the same page and understood what was said, adding or changing anything in the notebook if there are discrepancies.

    - Do not wait to do this until later in the day or the next day as you will forget, and things will become jumbled.

Caregiver Requirements and Helpful Hints

- Most centers require that the patient have a caregiver with them 24/7.
- This is one of the hardest things for many families as it may mean moving, change of work status, financial hardship, and other life-changing family circumstances.
- If your loved one is approved for a transplant, you may have to move for the time before as your loved one waits for the organs and must stay in the area for 6 months or more after the transplant is complete.
- This move may happen quickly after being approved and put on the list.

Money Saver

If you must pay for parking, ask if there are any reduced rates, passes, or multi-day reduced rate tickets available. Often times area hotels will have shuttles to and from the centers. Ask about availability and schedules.

Important Things to Figure Out for Your Patient During the Evaluation Process

- Discuss with the team what living accommodations they recommend and make sure to visit them during the evaluation process.
    - A transplant social worker may be able to help you find special rates at hotels or if there is a local Transplant House or Ronald McDonald house.

- Write down every bit of information you can about each option, including cost, transportation options, and distance from the transplant center (during the transplant process, the patient has frequent, if not daily, appointments at the beginning).

- Make sure to have all contact information for each place of accommodation written down for easy access.

- Write down the steps of the process after testing is done to understand what leads up to the possible listing.

- Ask about the timeframe.

- After testing is completed there typically is a Selection Committee Meeting, a treatment plan proposed, and a decision by your loved one must be made.

- If a transplant has been recommended, then there may be another step that is a letter to another committee or consortium.

- Also, the insurance company has to give final approval for the transplant before the patient can be listed.

Helpful Hint

Evaluation appointment days are long and tiring. Bring bottled drinks and on-the-go snacks for you and your loved one. Your loved one will greatly appreciate one of their favorite snacks after a long day of appointments.

Getting Listed

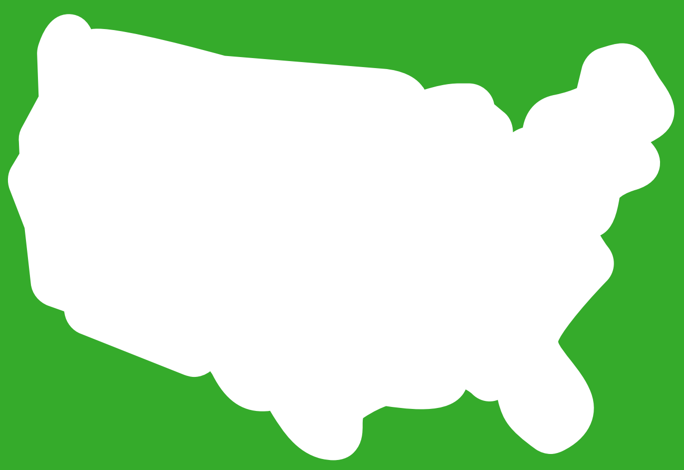
- After the evaluation is completed, there is a process that happens before the patient is placed on the waiting list.
  - The time that you are waiting to hear about the next step feels long and stressful!

  - If you are far away from the center and will have to move, it feels even more stressful!

- If your loved one gets the go-ahead from the center and insurance to get a transplant, ask for a few days or even a week or so before being put on the list, if medical status allows.
  - This gives you time to pack, take care of getting everything in order, and a chance to take a breath.

- The transplant will happen even if you take a few extra days.

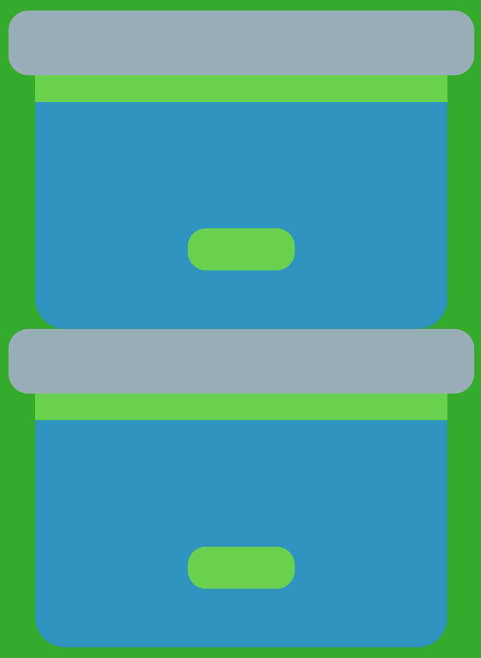
- The whole process will be a little less stressful if you pause for a moment.



If You Must Move:

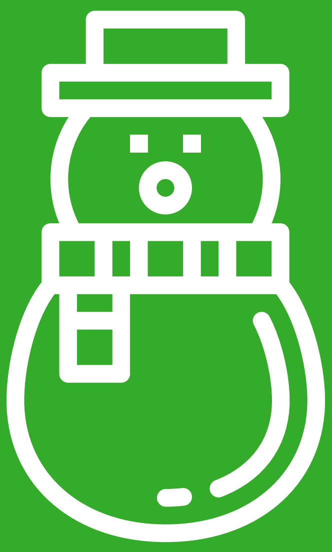
- Take a few of your own favorite items along, so you are as comfortable as possible, whether it be pillows, blankets, a favorite cup, or dish.
    - Some familiar things from home go a long way while you are waiting!

- If you can to drive there, pack a few items up in a bin or two.
    - These can be used as extra storage wherever you are staying.



- Do not forget to think about weather changes between where you live and where the center is.
    - It may be hotter or colder than you are used to!

    - Packing gloves, a winter coat, shorts, an umbrella, or a raincoat may not immediately occur to you, but you will be there for an extended period of time!



If You Must Move:

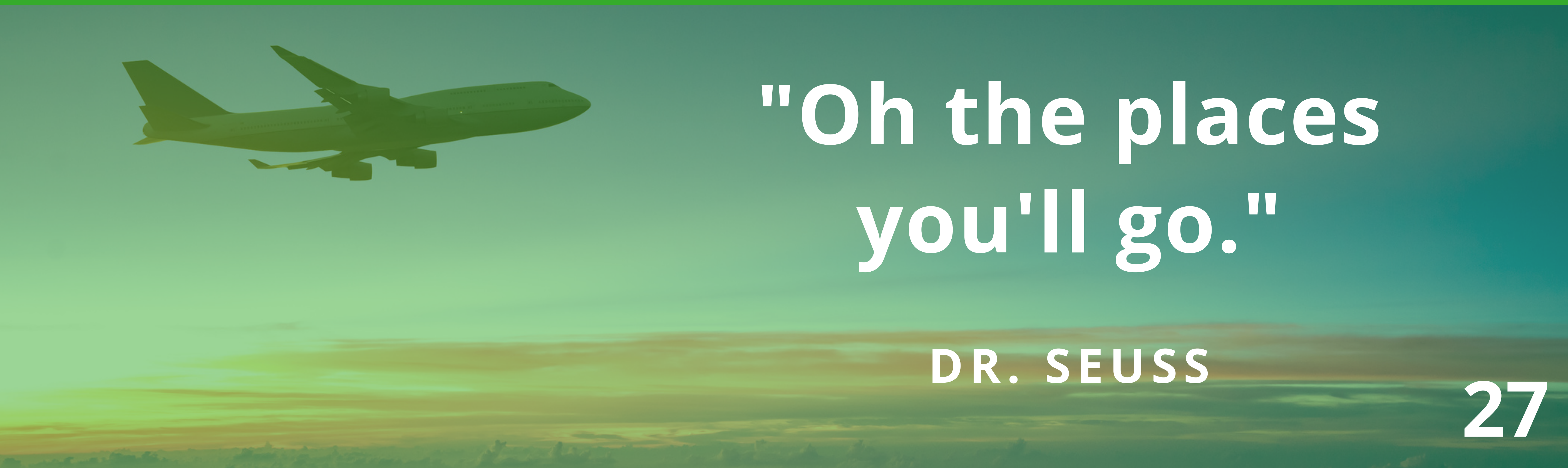
- Bring along an extra charger for handheld devices.

- Try to bring the minimum amount.

- Consider furnishing a rented apartment near the transplant center with furniture from thrift stores or inexpensive options since it is only short-term. You only need the bare minimum.

- Help your loved one organize all the medication and supplies that must be moved.
    - If you are flying, check with the airlines as most allow bags packed with medical supplies for no additional charge, but they can not be mixed with other items.

    - There are people at the airports that can help you move large amounts of luggage or point you in the direction of a luggage cart to use.



"Oh the places you'll go."

DR. SEUSS

Financing a Transplant: How You Can Help as a Caregiver

- Your loved one cannot be officially listed for transplant until their insurance company approves it, whether this is public (Medicare, Medicaid) or private insurance.

- That being said, insurance will only cover the **medical costs** of transplant and you and your loved one will still have the **non-medical costs** such as transportation and lodging.

- Before you move to the transplant center, you and your loved one need to make a **budget and financial plan** as to how these non-medical costs will be covered.

- Please visit Transplant Unwrapped's website or financial resources page for more information on this topic.

Waiting List

- The waiting time can vary greatly while waiting for a transplant.

- Make sure you have asked the team what you should expect, but understand that they have no control and it is just a guess.
    - We have known people to get “the call” in under 24 hours, and others wait for 1- 2 years.

- The waiting can be emotionally draining for your loved one as they already do not feel well.
    - Your patient may experience a wide range of emotions including, hope, fear, excitement, and anxiety.

- Now is the time for all of the love and support you can give to them and a time for you to rally all the resources you can from family and friends!

Waiting: The Difficult Part for Both Patient and Caregiver

- After all of the many appointments your loved one has gone through while getting diagnosed and evaluated; the waiting time may feel like not much is happening.
    - A treatment plan has been made (intestinal transplant), and no more diagnostic tests need to be done.

- As a caregiver during this time, you need to make sure your loved one stays as healthy and positive as possible.
    - The stronger they are going into transplant, the better the outcome.

- Be your loved one's cheerleader when they are frustrated with the wait or feeling down, reminding them they are doing everything possible to prepare for when "the call" comes.

“Patience is not the ability to wait, but the ability to keep a good attitude while waiting.”

Waiting: The Difficult Part for Both Patient and Caregiver

- Ask the transplant team **when they should be contacted** if your loved one's symptoms change or worsen.
    - You must remind your transplant patient that everyday symptoms do not need to be reported, as these are what led to the diagnosis and are the reason they are receiving the transplant.

    - **Drastic or sudden changes** usually warrant a call to the team, but always refer to your transplant team for specific instructions.

- While on the waitlist, **always carry** your **notebook** with you.
    - Make sure it contains the contact information for your loved one's transplant center, a list of current medications, relevant medical history, and allergies.

    - Always have a copy of their insurance card and ID.

    - You **never know when the call** will come, and if you are out and about, you may need to go straight to the transplant center.

The Waiting: Helping Your Loved One Be Prepared for "The Call"

- Have a bag packed with hospital essentials for both you and your loved one to 'grab and go.' Download our hospital packing checklist as a helpful guide.
- Help arrange who will take care of your loved one's children or pets when the call comes.
- Help arrange who will take care of your loved one's household needs, such as getting the mail, cutting the grass, taking out the trash.
- Have a plan for who can take care of your loved one's finances and bills for when they get the call and are in the hospital recovering for an extended period of time.

Communication Responsibilities for Caregivers

Communication with the transplant team is critical pre-and post-transplant. If any vital information changes, you must immediately contact your transplant team of these changes:

- If your **health insurance changes,** you must promptly inform the team- not informing them may jeopardize your transplant care.

- If your **address or phone number changes**, you must promptly inform the transplant team- not informing them may result in a missed organ offer.

- If you are **leaving the area** for some reason, always **inform your transplant team** of where you are going and how long you will be gone- they will inform you if this warrants placement on status 7 or ‘hold’ status or if you will still be ‘close enough’ to remain active on the waiting list.

- If you are still seeing doctors other than your transplant team, you must inform your transplant team if any **medication changes** are made- this includes over-the-counter medications and prescription medications.

Communication Responsibilities for Caregivers

- During this time, others will want to hear about the patient and the experience, and they will not understand the waiting.

- It is very **draining to a patient** to have to answer the same questions over and over.

- Setting up a CaringBridge (www.caringbridge.org), group email, or another **support site** can be beneficial.

- Some patients like to manage their own – if so, ask their permission to have author access as there will be days they will be unable to reach out.

Communication Responsibilities for Caregivers

- Some patients prefer to allow their caregiver (you) to take care of this completely and/or ask to review the post before it is sent out.

- Find out which way your loved one wants to have this handled.

- A group text is the least desirable as replies will overwhelm everyone’s phone!

- Give **weekly updates** if possible.
    - This keeps your loved one from having to answer too many "how are you" texts.

Tip from a Transplant Patient

When people have the chance to visit me or see a picture of me on a social media site, the saying I hate the most to hear is "You look great." This may seem like an uplifting comment, but I am usually suffering invisibly on the inside and this statement makes me feel like you think nothing is wrong.

Communication Responsibilities for Caregivers

- Encourage others to contact your loved one on the site in reply to the update.

- You can also encourage others to send funny memes, jokes, a word of encouragement, a photo they took, or a story about their day to help change up communication and make it **as normal as possible** for your loved one.

- Nobody likes to talk about how they feel **every single moment**!

- If multiple family members want to know the “nitty-gritty” of each appointment, set up a way to do it as a group to avoid the fatigue of explaining over and over.

Communication Responsibilities for Caregivers

- **Marco Polo app** is one way that you or your loved one can record overviews of what is happening. This allows family members to listen and respond on their own time.

- Keeping **everyone in the loop** is helpful, but not asking the patient to respond over and over reserves their energy for making it through the day.

- If your loved one is having a challenging time, do not be afraid to ask friends and family to not communicate with them for a period of time and/or only **send messages through you.**
  - Your job as a **caregiver is to protect** your loved one.

- On the other hand, do not be afraid to **ask for** communication full of love and **support** when your loved one needs it as well!!!
  - Make the same requests for yourself as you need to **protect your energy,** so you have it for the patient!

Communication Responsibilities for Caregivers

- Family and friends will ask how they can help. Make sure you take them up on this.

- The process is long, painful, lonely, overwhelming, and sometimes scary.

- **Asking for the support** that others want to give is important for both you and your loved one.

- Ask for **notes of encouragement** and prayers (if your loved one wants them), whether it be electronically or in the mail.

- Ask for $5 gift cards to the grocery store, Target, Amazon, Walmart, Starbucks, etc. Many can be sent electronically.
    - You will have many living expenses, and **a treat** is especially heart-lifting!

Insight on Care Packages

Sent gifts and care packages are nice, but oftentimes a transplant patient cannot eat what is sent or can only color so many pages! You also want to avoid accumulating too many things in your temporary location. Ask friends and family to be mindful of this.

Communication Responsibilities for Caregivers: The Difficult Conversations and Advance Care Planning

- A transplant is a very complex surgery, with the potential for **very serious complications** and the possibility of death.

- Even before your patient is listed for transplant, you should talk with your loved one about his or her beliefs and wishes for end-of-life care.

Advance care planning includes:

- Learning what **life-sustaining treatments** are available (i.e., artificial nutrition, mechanical ventilation, resuscitation) and deciding which of those treatments your loved one would want if they required them to remain alive.

- **Communicating** with your loved one about his or her spiritual beliefs about death or dying.

- Make sure your loved one has a **medical power of attorney** assigned.
  - In general, it makes the most sense for the primary caregiver to have this responsibility as they will be with the patient 24/7.

Communication Responsibilities for Caregivers: The Difficult Conversations and Advance Care Planning

- Once you have gathered this information, you must prepare the **legal documentation** of your loved one's end-of-life preferences (advanced directives) and file them with the transplant center and other relevant physician offices.

Advance Directives

Set of documents that allow your loved one to identify his or her wishes for care at the end stages of life, in the case he or she is not able to do so at the necessary time.

Living Will

Includes information about patients wishes on topics such as:

- DNR (do not resuscitate).
- Artificial hydration and nutrition.
- Life-sustaining equipment like ventilators.
- Instructions about being an organ or tissue donor.

Medical Power of Attorney

- Names a patient's healthcare proxy.
- Whom the patient designates to decide on end-of-life care if the patient is unable.
- This person can also make treatment. decisions if the patient is incapacitated for some reason.

Advice on How to Handle a "Dry Run" as a Caregiver

- A **“dry-run”** is what it is called when your loved one gets a call for organs, gets to the hospital, and at some point along the way, the organs are deemed not transplantable.

- The transplant is never **100% for certain** until the first incision is made.

- No matter how much you understand that this is a possibility and that the determination that is made is for the best, it still is devastating.

- **Talk to your loved one** about this possibility ahead of time and how they want to handle communicating with others about the call.

- Some patients want to share the whole experience with everyone and tell their whole network as soon as they get the call.

- Others want to alert **only immediate family** and then tell others after the surgery is started. Some do not want anyone to know until the transplant is completed.

Advice on How to Handle a "Dry Run" as a Caregiver

- As the caregiver you should know so that you can **respect the patient's wishes.**

- Make sure that you **follow their wishe**s no matter what you think at that moment or who you may feel that you want to share the news with.

- This is their body, their life, their transplant. They have little control over their health, they **do have control over this.**

- The patient needs to trust that you will follow what they want.

> **"To be trusted is a greater compliment than to be loved."**
>
> **GEORGE MACDONALD**

The Transplant Through the Eyes of a Caregiver

Practical Points:

- Transplant surgery can range from 8-16 hours long.
- The surgeons will update you periodically, but do not become concerned if 5 or more hours go by and you do not hear anything.
- When the surgeon gives you an update, take lots of notes to share with your loved one and family members and friends later.
- Taking care of yourself is of the utmost importance right now! Walk around, stay hydrated, and find a place to take a nap.

"Adopt the secret of nature: her secret is ***patience***."

RALPH WALDO EMERSON

Helpful Hints to Qualm Waiting Boredom

- Make sure you know the **hospital's WiFi** and how to use it.

- Consider **gifting yourself a subscription** to Netflix, Hulu, or Amazon, so you have some things to watch during long surgery and hospital days.

Before you come find out what **free** apps your l**ocal library** has for library card holders:

- **Overdrive or Libby**: eBooks and audiobooks, including popular fiction, nonfiction, and technical titles. Check out up to 25 titles at a time. Compatible with most Apple, Android, Windows, Kindle, and Nook devices.

- **Hoopla:** Music, movies, and videos to play on your computer, smartphone, or tablet—with eBooks, audiobooks, and comics too.

- **RBDigital:** Digital magazines just like their print editions, including both current and back issues. Titles are always available, with no holds, unlimited checkouts, and no due dates. Compatible with Apple, Android, and Windows.

The Transplant Through the Eyes of a Caregiver

Michele's Insight

Sitting through the transplant surgery was one of the hardest and scariest, yet most exciting and most hopeful times of my life. After seeing all of my loved one's suffering, with hopes and dreams snatched away, the transplant felt like our last hope for a chance at a more normal life. Understanding that an intestinal transplant was reserved for only the illest individuals and that so few are done helped me to focus on what the success of this transplant would be. My healthy normal would not be my loved ones healthy normal.

Cautiously optimistic became my phrase for how I felt. Understanding that there would be good and not good outcomes for my loved one helped and continues to help us live our best lives. Having my loved one go through the transplant is freeing in the sense that we no longer had to find a diagnosis. We knew that everything had been done to help create the healthiest life possible.

No matter how trite it sounds, and what else your loved one has gone through, this will be the toughest recovery they will ever know. I needed to remind myself of that and to make sure I helped my loved one know that this difficult part was actually expected and that they could and would get through it. The next part of the journey was about living life forward and being forever grateful that a donor and their family allowed my loved one a chance at a better life.

Life in the Hospital as a Caregiver

- After an intestinal transplant both you and your loved one will spend many **long days** and **nights** in the hospital.

- Every hospital is a bit different and will have **different visitation policies** and procedures.

- Usually, visitation is more limited in the **Intensive Care Unit (ICU)**, often times only allowing 1-2 visitors per patient.

- Once your loved one moves to the regular transplant floor, **visitation rules** may be **expanded.**

- As the primary caregiver, your loved one relies on you to help navigate the numerous medical providers that frequently enter the room with loads of new information.

Life in the Hospital as a Caregiver

- Your loved one just had major surgery and will be on many medications, without a clear mind.
    - You need to help by **writing down** everything that is said and keep a thorough record of your loved one's day to day symptoms, tests, medications, and information brought to you by the medical team.

- **Medical team rounds** may occur at all times of the day.
    - Most often, in a teaching hospital, residents will round early in the morning.
    - Attending physicians and the rest of the team will round later in the day and even in the evening.
    - If you want a chance to leave the hospital, but do not want to miss the doctors, you can try and ask the team the day before if they have an idea of when they may be coming around the next day.
    - Sometimes the team will try to give you a general idea to help accommodate caregivers who need a well-deserved break.

Life in the Hospital as a Caregiver

While recovering after transplant, your loved one may not feel like talking very much with you or anyone.

Some questions that can be helpful during this time include:

- **Do you want to see visitors or do you prefer some time alone?** Although visitors are wonderful, sometimes patients need time for themselves and 'reboot.'

- **Do you want to talk about what you have been through or about other things?** Your loved one doesn't always want to talk about their transplant and complications, but sometimes this will be the topic on the agenda. You need to be sure to offer them both options.

- **Do you want to rest, or can I bring you something to read, watch, or listen to?** Give your loved ones the option rather than deciding for them.

- **Should I eat in the room or leave the room to eat?** Your loved one may not be able to eat anything or may feel nauseous, so the smell of food may be difficult to handle. Asking them their preference about how you should take your meals. This can be very thoughtful during the recovery.

Life in the Hospital as a Caregiver

Michele's Insight

Being patient and understanding can be very difficult when you are both tired and stressed. While you may not be experiencing your loved one's raw physical pain; your heart can feel like it is being torn in two when the pain becomes unbearable for the patient or a complication after transplant arises. Take the time outside of the room, preferably far away, to express your fears, concerns, and sadness to others. Crying tears of frustration with your loved ones is ok and normal, but try and share the most intense of your emotions with others. Your loved one needs to express the depth of their personal hurt and not feel like they need to comfort you or feel bad that they are causing you pain.

After transplant surgery and during treatment for rejection, your loved one will be given large doses of steroids. This will make them feel way more emotional than they ever have. Some refer to this as steroid rage. They will strike out at the safest person around – you. This can be extremely upsetting for both of you. Do your best not to take it personally and do not react. Just because they vent it out does not mean that they actually feel this way. The steroids exaggerate their emotions. You can try to talk the patient down calmly, but if they are unable to stop, make sure to take a moment to leave, reminding your loved one how much you care about them and understand that this is way more difficult than you can even imagine. Sometimes the patient does not even remember the incidents. These incidents are definitely ones to not hold on to and give yourself a little reward for handling it well!

Preparing for Discharge: The Caregiver's Role

- **Stock up on essential**s from the store! This includes healthy and easy to make food for yourself and any food or drink any food that the patient can eat.

    - You may want to **stay away** from any food or drink that is either the patient's favorite that they can’t eat (so they don’t feel quite so sad) or that had **too much smell** that could make them feel ill.

- Have **lots** of laundry detergent and sanitizing **cleaners** on hand.
    - Cleaning and sanitizing surfaces daily (if not more often) is essential.
    - After a transplant, the patient is the most **immunocompromised** than they ever will be.
    - Even though you are with them all the time, you may be in situations they are not, and you could carry germs back to them!

- **Hand sanitizer** is helpful, as is soap and water.

- Have notebooks, binders, medications, all handy and organized.

Transplant Recovery: The Caregiver's Role

- Once your loved one leaves the hospital, **you** will have to **take over the duties** that the nurses had been taking care of.
    - You also will have household duties the patient cannot perform because they are recovering from a major operation.

Some of these responsibilities may include:

- Watching the patient for **new symptoms** or problems and reporting them to the transplant team, if necessary.

- **Preparing meals** and encouraging the patient to eat and follow the transplant team's dietary recommendations.

- Helping to **protect** your loved one from **infection** by keeping the house clean, not allowing sick visitors, and making healthy choices.

- Taking charge of household **cleaning.**

- Taking them to all outpatient **appointments.**

- Taking care of **pets** and/or helping with **children.**

Transplant Recovery: The Caregiver's Role

- Make sure there is a spare set of sheets.
    - Accidents overnight can and do happen.

- Use a separate hand towel if you share a bathroom.
    - You do not want to spread any unnecessary germs.
    - This also means no sharing of toothbrushes, food utensils, drinking glasses etc.

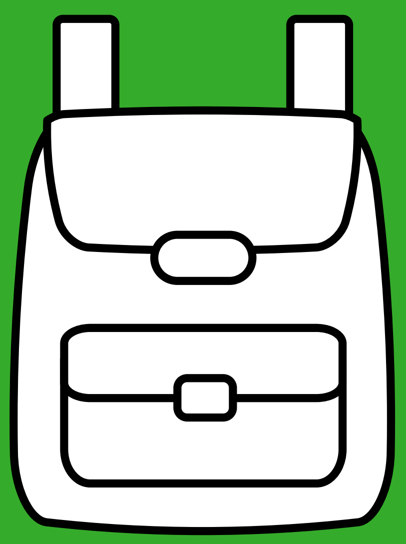
- Find out from your loved one what they think they **would like you to do.**
    - **Don’t assume** anything in the name of being helpful!
    - Your loved one needs your help, but a large part of your help is helping them do for **themselves** to **get stronger**!

Transplant Recovery: The Caregiver's Role

- Be prepared to give gentle reminders and encouragements.
  - Some days they may need to be told to slow down, or that it’s ok to sleep.
  - Other days you may have to encourage strongly to move. It may hurt in the moment, but not moving hurts even more in the long run.

- Especially have phone numbers to the transplant team on hand!

- Have a backpack or bag packed with an extra set of clothes, an extra day of medication (meds for yourself too if you take any) , a medication list, a bottle or two of water, a small snack and stoma supplies always ready.



- You may have to leave for an appointment or a visit to the hospital on a moments notice!

Transplant Recovery: The Caregiver's Role

- One of the biggest responsibilities after transplant and is adhering to and maintaining, a strict medication regimen.

- Even though your loved one may eventually take over this task on their own, they most likely will rely on you to help them with this task in the immediate post-transplant phase.

- Mistakes in medication regimen can lead to very severe health consequences, including loss of the new organ.

To help **manage medications** and help prevent errors, here are some tips:

- Before you are discharged from the hospital, make sure you and your loved one understand every prescription, dosage, and form of each medication.

- Ensure both you and your loved one know what the medication is being used for, what it does, and any possible side effects.

- Be aware if there are any medication interactions.

Transplant Recovery: The Caregiver's Role

- Since you will be picking up the prescriptions from the pharmacy, make sure that the order has your loved one's name on it and includes the correct pills with the correct doses.

- Keep a log of any adverse reactions or side effects your loved one experiences from any of the medications and bring this with you to their follow-up clinic appointments.

- Your loved one will also be responsible for keeping track of vital signs and input/output records.
    - This can be a time-consuming and meticulous task for a patient, especially right after a large surgery such as a transplant.

    - Help your loved one develop a system for taking heart rate, temperature, blood pressure, weight, and other measures as required by their transplant team.

    - Ensure you know your loved one's parameters and when it is indicated to call the transplant team.

Taking Care of the Caregiver

- Your health is just as important as your loved ones. If you become sick, you will not take care of your loved one when they need you most.

- Taking time to help reduce your own stress, anxiety, and worry is beneficial and a necessity in such a high stress and nerve-wracking situation.

- Have a 'go-to' person for yourself. You need your own person to support you, someone you can talk to and share your emotions with. Someone that you can lean on other than your loved one.

- It will be even more difficult now that you are a caregiver for a transplant patient, but living a healthy lifestyle is of the utmost importance to keeping yourself healthy- Exercising daily, eating well, maintaining a healthy weight, and getting a good night's rest.

Taking Care of the Caregiver

Find ways that you find helpful to relieve your stress and try to do one at least once a week, or even more frequently if possible. Ideas include:

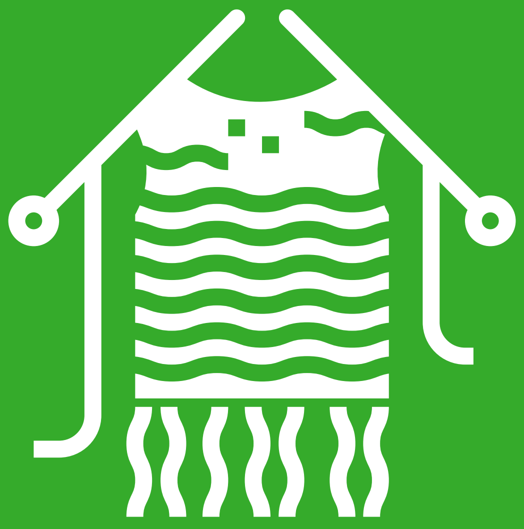
- Indulge in one special treat every day, such as a cupcake or brownie bite.

- Go for a walk in a park.

- Listen to relaxing music and do a deep breathing exercise.

- Practice yoga or meditation.
- Go for tea or coffee with friends or fellow caregivers.

- Start a new hobby, possibly ones you could do in the hospital, such as knitting, drawing, or coloring.

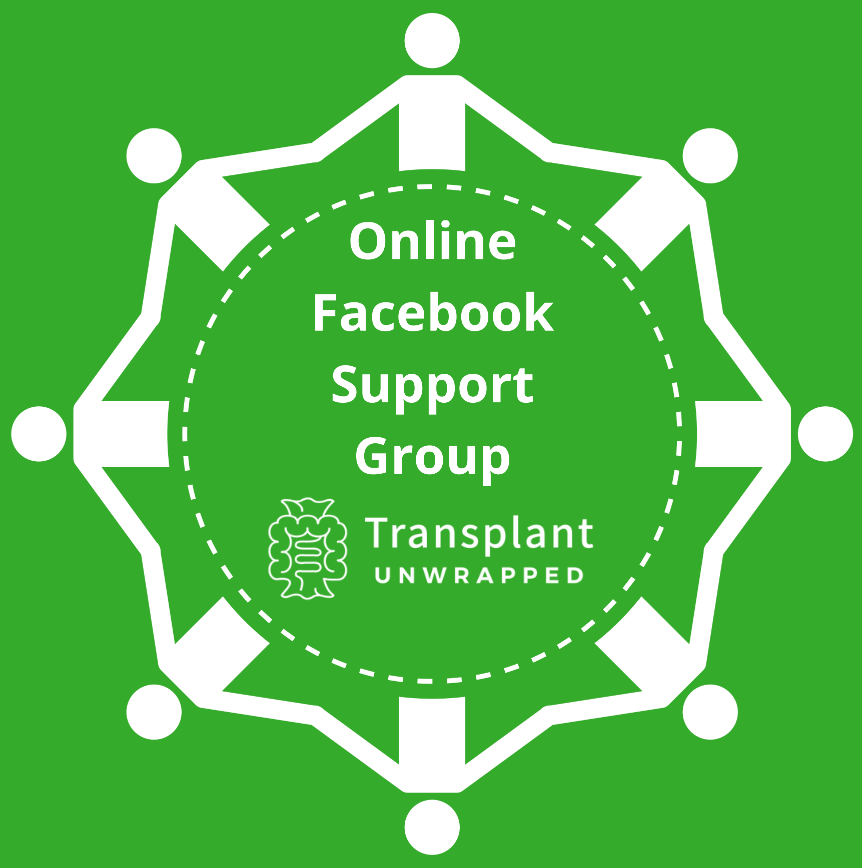


Taking Care of the Caregiver

- Rent a funny movie.

- Get a massage.

- Cook a new recipe.
- Join an in-person or online support group, such as the Transplant Unwrapped **Virtual Support Group Sessions** or **Moderated Facebook Support Group.**



> "Be who you are and say how you feel, because those who mind don't matter, and those who ***matter don't mind***."

DR. SEUSS

Helpful Caregiver Websites and Articles

Next Step In Care: Provides information about moving from one care setting to the next.

Family Caregiver Alliance: State-by-state guide of caregiver resources.

Caregiver Burnout: Article discussing caregiver burnout and how to avoid.

Effective Communication: Article discusses effective communication when you have a cancer patient, but these skills can be translated to a transplant caregiver when speaking with a transplant team.

> “You have two hands.
> One to help yourself,
> and one to help
> others.”
>
> AUDREY HEPBURN

Communication is Key

As a caregiver of a loved one with an intestinal transplant it is important to educate yourself as much as possible. Having a general understanding of intestinal transplant and the individual needs of your loved one will ensure you will be able to be their best advocate and get them the best care possible.

More Info?

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www.transplantunwrapped.org

www.transplantunwrappedkids.org

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