



# LIVING WITH YOUR TRANSPLANT

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EDUCATIONAL ADVICE,  
TIPS, AND TOOLS FOR  
TRANSPLANT RECIPIENTS

**ASTELLAS CARES™**  
TRANSPLANT

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The information contained in this brochure is provided for educational purposes only and should not replace discussions with a healthcare professional.



# BEING PREPARED

Taking care of yourself is an essential part of the transplant journey. Being realistic about your recovery can help you keep a positive outlook, even if you face challenges along the way. And, knowing what to expect down the road can help you stay on course throughout the transplant journey.

It's important to know that you are not alone. Your transplant team is dedicated to your health and well-being before, during, and after your transplant. Always talk to them about your feelings and concerns. Other transplant recipients can also be a source of information and inspiration.

This guide provides educational advice, tips, and tools that may help you prepare for the road ahead.



# SETTING EXPECTATIONS

Each stage of the transplant journey can bring new challenges and new accomplishments. Setting realistic expectations can help you prepare for the road ahead.

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## **BEFORE THE TRANSPLANT**

Waiting for a donor organ can be a very stressful time. In fact, many transplant recipients feel like the wait is the most stressful part of the transplant experience.

Potential causes of stress before a transplant include:

- + Uncertainty of organ availability
- + Worsening health
- + Worrying about burdening others
- + Guilt over the organ donor
- + Financial concerns

However, the waiting period is a good time to prepare yourself for what's ahead and get used to the idea of receiving a transplant. It is important to be informed about your health and about organ transplantation. Ask lots of questions and become educated about the transplant process, procedure, and recovery.

## **RECOVERY**

You may feel better than you did before the transplant. Many people are joyful soon after a successful transplant surgery. There is often relief that it went well and hope for the future. With time, however, other feelings of worry or fear may arise. It's natural to have these feelings and concerns.

Potential causes of stress soon after surgery include:

- + Worry about whether the new organ will “work” the way it should
- + Concerns about going home and managing your health on your own
- + Fear of organ rejection or infection

Remember that you're not alone. Your transplant team is there for you after you leave the hospital. Also, maintaining contact with other transplant recipients who have been through recovery can be very helpful. Your social worker can recommend a local support group, or you might want to join an Internet-based chat forum for transplant recipients.

## **YEAR ONE**

The first year after a transplant can be a big adjustment. Don't get discouraged. Take it one day at a time. It's important to continue taking all your medications as prescribed and maintaining a healthy lifestyle.

Some potential causes of stress during the first year include:

- + Disappointment with the speed of recovery
- + Fear of organ rejection
- + Difficulty sticking with a complex medication schedule
- + Physical and emotional side effects of medications
- + Issues with body image
- + Changes in relationships

If you feel overwhelmed by the challenges during the first year after your transplant, talk to your transplant team. They can provide strategies to help you through the tough times. Also, make sure you know the signs of organ rejection so that you can take action as soon as symptoms appear (see page 22 for common signs of organ rejection).

## **BEYOND THE FIRST YEAR**

By now, you are probably a pro at taking your medications and following a healthy lifestyle. Of course, it doesn't mean that there aren't challenges and risks.

Potential issues beyond the first year include:

- + Managing side effects
- + Controlling weight
- + Fatigue
- + Financial issues
- + Ongoing threat of organ rejection
- + Day-to-day issues and problems that may resurface as life becomes more routine

It's important to realize that life after a transplant may not be exactly the same as life before a transplant. You may need to adjust your expectations along the way.



# PHYSICAL IMPACT

The medications that are important to your recovery and that help prevent organ rejection may have side effects that can change your appearance or cause other health issues. Even if you experience side effects, it is important that you continue taking your medications as prescribed and contact your transplant team right away.

## HEALTH CONDITIONS

The medications you're taking can increase the risk of other health issues such as high blood pressure, diabetes, and high cholesterol. Here are some tips to help you stay healthy:

- + Don't smoke
- + Eat a low-salt, low-fat, high-fiber diet
- + Exercise
- + Manage your weight



# MANAGING THE UPS AND DOWNS

Like many transplant recipients, you may feel sadness, fear, guilt, or stress as well as euphoria, relief, and gratitude. If you're feeling overwhelmed, your transplant team may refer you to a therapist or a support group where you can talk to other transplant recipients who have faced similar issues.

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Here are some things you can do to help reduce stress:

- + Listen to music, read, garden, go for walks, meditate
- + Find hobbies you enjoy (eg, cooking, painting, writing, photography)
- + Participate in social activities
- + Eat a healthy diet and exercise
- + Get plenty of sleep
- + Talk to family, friends, and other transplant recipients about your feelings

Your primary caregiver may also be dealing with his or her own emotional rollercoaster while taking care of you. Recognizing all of the help and support that your caregiver has given you will likely make him or her feel useful and appreciated.

## **GETTING OVER THE GUILT**

Guilt is a common reaction after a transplant. Some people may feel guilty that they received an organ while others are still waiting. Those who receive a living donor organ may feel guilty for what the donor has sacrificed. Those who receive a deceased donor organ may also feel guilty that someone died so they could receive the organ. Taking good care of your organ is a way to honor the donor. Some people also find it helpful to write a letter to the deceased donor's family. Although organ donation organizations don't allow transplant recipients to contact the donor families directly, you can send a letter through your transplant team.







## RETURNING TO DAILY ACTIVITIES

Resuming daily activities after a transplant is a pivotal phase of the journey. Regaining independence and getting back to a regular routine are important goals of the recovery process.

## **GOING BACK TO WORK**

If you were working before the transplant, returning to work may be a priority. How much you can do depends upon the type of work you do and how well you feel. Your transplant team will tell you when you can return to work. You might need to start out part time or work from home. Give yourself time to get back to a full workday. Talk to your boss about your situation and discuss the options. Your transplant team can also talk with your employer and give them the information they need.

If you are unable to return to your job, you may want to explore other employment options. This may involve job training. Your social worker can help you find local vocational programs that can help.

## **DRIVING**

Many transplant recipients are able to drive within 4 to 6 weeks after surgery. Your reaction time may be slower, so be sure to talk to your doctor about when you can drive.

## **TRAVELING**

You may be told to avoid traveling during the first few months after your transplant. When your transplant team says it's okay to travel, here are some tips to follow:

- + Pack medications in your carry-on bag, not your checked luggage
- + Pack more medication than you will need in case of a delay returning home
- + Locate the local pharmacy before you travel
- + If traveling to a different time zone, set an alarm so you take your medications at the same time you would if you were home
- + Bring a basic first-aid kit





# STAYING THE COURSE

The transplant journey continues well beyond the recovery phase. It's a lifetime commitment. You will need to monitor your health and well-being daily, continue taking your medication as prescribed, and continue maintaining a healthy lifestyle.

## **KNOW THE SIGNS OF ORGAN REJECTION**

Once you are out of the hospital, you are your doctors' eyes and ears. You will need to tell them how you are feeling and what symptoms or side effects you are experiencing. This information will help your doctors make decisions about your treatment.

It is important that you know the signs of organ rejection so you can take immediate action. Organ rejection can usually be reversed if it's caught early. The signs of organ rejection vary by type of organ transplant, so be sure to get a list of signs from your transplant doctor.

In the box below are signs and symptoms common to most types of organ transplants. Call your transplant team right away if you experience any of these health issues.

One way to help reduce the risk of organ rejection is to always take your medications as prescribed by your doctor.

### **COMMON SIGNS OF ORGAN REJECTION**

- + Fever (above 101°F)
- + Redness, swelling, pain, or tenderness at the transplant site
- + Flu-like symptoms such as chills, nausea, vomiting, diarrhea, tiredness, headache, dizziness, and/or body aches and pains
- + Weakness, persistent fatigue
- + Changes in urine: an increased or decreased amount, dark or tea-colored urine, or burning sensation
- + Skin rash or lesions
- + Sudden weight loss
- + Shortness of breath
- + Swollen glands
- + Persistent or severe sore throat
- + Persistent cold symptoms such as nasal discharge, sinus pain, and/or headache
- + Vaginal discharge or burning

## **DAILY SELF-ASSESSMENT**

In addition to the tests your doctor will typically perform at regular follow-up visits, you may also need to monitor certain vital signs at home. Some things your doctor may ask you to monitor include:

- + **Weight**
- + **Temperature**
- + **Pulse**
- + **Blood pressure**
- + **Blood sugar**

On pages 26-27 of this brochure is a chart for keeping track of your vital signs. Ask your transplant team to determine what your goal results are and when you should call your doctor. Make extra copies and fill one in each week. You may want to take your completed charts to your doctor so he or she can see how you're doing.

## **DIET AND EXERCISE**

Always talk to your doctor about starting an exercise program. A typical exercise routine may include:

- 1.** Muscle strengthening with weight lifting and weight resistance
- 2.** Stretching for flexibility
- 3.** Aerobic or endurance activity such as walking, swimming, or bicycle riding

Exercise may help you feel better physically and mentally.

Staying on a diet can be difficult, especially because some medications may increase your appetite. Or, you may have been on a restricted diet before the transplant and now you can eat a variety of foods again. However, the closer you stick to your diet plan, the better you may feel.



Your dietitian can give you specific instructions about your recommended dietary allowances of specific nutrients. Some general tips for following a healthy diet include:

- + Eat high-fiber foods such as raw fruits and vegetables
- + Eat less salt, processed foods, and snacks
- + Eat high-protein foods such as lean meat, chicken (without the skin), fish, eggs, nuts (unsalted), and beans

## **SETTING GOALS AND STAYING FOCUSED**

Setting goals can help you stay focused on the things that are important to you. Maybe you have thought about volunteering and helping other transplant recipients. Maybe there's a new hobby you would like to try. Staying active and doing things you enjoy as you continue the transplant journey may help you stay focused.



## MY TRANSPLANT HEALTH

| WEEK OF                    | MONDAY | TUESDAY | WEDNESDAY | THURSDAY | FRIDAY | SATURDAY | SUNDAY |
|----------------------------|--------|---------|-----------|----------|--------|----------|--------|
| <b>TEMPERATURE</b>         |        |         |           |          |        |          |        |
| Your target »              |        |         |           |          |        |          |        |
| When to call your doctor » |        |         |           |          |        |          |        |
| <b>PULSE</b>               |        |         |           |          |        |          |        |
| Your target »              |        |         |           |          |        |          |        |
| When to call your doctor » |        |         |           |          |        |          |        |
| <b>BLOOD PRESSURE</b>      |        |         |           |          |        |          |        |
| Your target »              |        |         |           |          |        |          |        |
| When to call your doctor » |        |         |           |          |        |          |        |
| <b>BLOOD SUGAR</b>         |        |         |           |          |        |          |        |
| Your target »              |        |         |           |          |        |          |        |
| When to call your doctor » |        |         |           |          |        |          |        |
| <b>WEIGHT</b>              |        |         |           |          |        |          |        |
| Your target »              |        |         |           |          |        |          |        |
| When to call your doctor » |        |         |           |          |        |          |        |

# JOIN THE TRANSPLANT COMMUNITY

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Additional resources on transplant health are available  
at **AstellasCares.com**.