



“You Need a Stem Cell Transplant” What’s Next?

When you hear a diagnosis of leukemia, lymphoma, blood cancer, or a debilitating blood disorder, the mind seems to race and freeze at the same time. It is hard to take in the information. And when the disease has progressed to the point where a marrow/stem cell transplant is the best option, the shock starts anew.

Here are some things every potential transplantee must consider and understand.

The Fear: internet is filled with horror stories. Combat fear with the latest facts; get educated.

The Early Decisions:

- When to get a transplant – there is a window of opportunity before your body weakens too far.
- Insurance and finances – so much to learn about; apply for Disability; financial support resources
- Where to get the transplant – learn about centers close to home... what is “the best” place?
- Find a matching donor – immediate family, then the donor registries
- Organizing your personal care team – who will care for you through transplant recovery
- Prepare your immediate family for your upcoming absence from regular, daily life activities
- Prepare your caring community (family, friends, neighbors) so they can help you
- Explore SCT patient support resources so you can go through this with transplant buddies. Be the Match® has a Patient Support program that will match you with someone who has been through a transplant.

The transplant journey:

- It’s a roller coaster for everyone, and each patient gets a unique ride
- Expect the unexpected
- Trust your transplant team
- Be a good patient – make healthy choices, avoid the public, avoid germs
- It is a lonely time, even when surrounded by your medical team. Depression will happen.
- Graft vs. Host Disease – different for each person
- Learn to breathe, meditate, or pray; move your mind out of your body
- The 100 Day Timeline – be patient if your body doesn’t respond like clockwork.

Dealing with Family Expectations:

People want to help; they often do not know how.

- Give them information or refer them to resources so they can learn more.
- Be clear on what is helpful to you.
- Ask for what you need. No one can read your mind.
- Some of the meds will make you angry and you will wonder how you ever lived with this group of crazy, insensitive people.
- Reach out to support resources. You don’t need to suffer!

Another New Normal Post-Transplant:

- Always wondering what is going to happen next.
- New immunizations.
- Body ailments – determine whether it’s due to the transplant or just a regular part of life.
- Brain is cloudy for awhile; Energy is slow to recover.
- Brand new perspective on the world and your place in it. What is next for you?
- Learn how to dream and plan again.
- It can take several years to heal. Be patient!