

A Stem Cell Transplant Patient's Advice to Caregivers

Take care of yourself. With so much of their safety and care riding on you and your well-being, it's very important that you and all caregivers care for yourselves as well. Look for opportunities to build a pool of caregivers who know how to safely transport, feed and otherwise support the transplant patient. The more that these responsibilities can be shared with others, the more opportunities for respite caregivers have. When this isn't possible, call on the offers from family members, friends and neighbors to relieve you of some of your other daily chores. Let someone else do the laundry, mow the grass, or make dinner for the kids so you can go to the movies, take a walk, or do whatever gives you an extended break. Daily clinic visits will offer you a few hours of down time from your caregiving duties. Make the best of it.

Every patient is different. While this may seem obvious, it's easy to forget after all of the education that you receive on what to expect during the various phases of transplant. There are real risks involved in stem cell transplants. Good health care teams go to great lengths to make sure patients and their caregivers understand those risks and how to mitigate them.

But educational materials and information sessions can't be customized for every patient, nor can health care professionals anticipate every way that an individual patient's experience might vary from what they've seen other patients go through. As a result, educational materials will anticipate worst case scenarios and prepare you for them. It would be irresponsible to do anything less. Just remember that the person you are caring for may be an unlikely candidate for a worse case fate. I found that the nurses who provided most of my care once I was diagnosed and had a treatment plan in place were pretty good at identifying which patients would handle treatment well and those that would have a harder time. I heard them talk about things like attitude and maturity; but most of all I heard them talk about the importance of a patient's general state of health when he or she entered the stem cell transplant process. Healthier folks tend to fare better than those with diseases in addition to cancer and whose general health is already poor.

Pay attention to what you're taught and keep the information you're given handy because you may need it. But pay attention, too, to the person that you're caring for and don't assume that he or she will need every bit of the care that educational materials discuss.

Be prepared for curve balls. Every good caregiver wants to do what is best for the person that she or he is caring for; but sometimes what's best can't happen. As part of our education for the stem cell transplant process, we were told that I needed plenty of protein, ideally 104 grams every day. The precision of that goal sank in and my in-home caregivers—saints that they are—felt that it was their responsibility to see that I achieved that goal. What none of us anticipated was the devastation that the chemotherapy I received the week before my transplant would have on my digestive system.

We were warned that the chemo I would receive the week before the transplant would have delayed effects that could be especially hard on the mouth. But nothing prepared us for the pain of swallowing caused by the Melphalan I received the week before. Neither the Magic Mouthwash nor the low dose oxycodone that were prescribed did much to dull the pain. Consequently, I didn't eat or drink much, to the great consternation of my caregivers who were afraid that they were failing me. Even the liquid protein products that they had made sure I had on hand were too hard to get down.

I watched the weight of the world slide from one of my caregivers during a clinic visit when she heard the doctor all but dismiss the fact that I wasn't drinking or eating. He knew it was temporary and that the health care team would keep me infused with critical liquids and nutrients during my daily clinic visits. But neither of us really understood that until then.

So once again, take your education to heart; but be prepared for curve balls. That's why the daily clinic visits after Day Zero are so critically important.

Too much emerges day by day to plan too far ahead. Don't torment your transplant patient with questions early on about the foods they like and what they think they'll want to eat. Once their taste buds and digestive systems have recovered there will be time enough to treat them to their favorite foods. But during the days or weeks just after transplant let them tell you what they think they're up to eating and drinking. Do what good basketball players do and keep your knees bent so you can pivot quickly. Frequent shopping runs may be in order to adjust to the patient's changing tastes.

Let the patient do the safe things that s/he wants to and can do. The transplant process will zap a lot of the patient's strength and stamina. I remember days when I wondered if there were any oxygen-carrying blood cells left in my body! I was winded after taking a shower—with the pre-shower Press N Seal preparations to cover my catheter and sometimes a backpack of drugs and portable infusion equipment to contend with. Even so, it's important that transplant patients stay as active as they can be, despite the many restrictions on their activities. Outpatients have advantages over inpatients because they have to get to and from daily clinic appointments and they have opportunities to do "clean" jobs like putting away clean dishes and folding and putting away clean clothes. Encourage patients to walk around, to climb stairs when appropriate, and do what they can to maintain strength and agility. They need both to withstand the effects of treatment and achieve the speediest possible recovery.