

# My ACES® Support Team

## SUGGESTIONS FROM THE TRANSPLANT LIVING COMMUNITY OF HENRY FORD HOSPITAL

**Primary and secondary caregivers:** This is your number one person in charge and your best personal advocate. This person will have decision-making powers if ever you are not capable or are incapacitated, to make competent decisions about your care. This is often a spouse, partner, or very close relative or friend. Many times they also handle the bulk of the hands-on day-to-day care and arrangements. This person knows your personal wishes and will stand by them.

Sometimes it is too difficult for spouses or close primary caregivers to handle daily care plus all of the other responsibilities, so another person is asked to act as an additional caregiver. This second caregiver helps to lighten the load on the primary caregiver to avoid burnout, or physical and emotional exhaustion. They have the ability to oversee the whole team and help keep the primary caregiver focused and emotionally grounded. A very close friend who has been on the scene for a while and is familiar with the ongoing situation and is trusted to support both the patient and primary caregiver often holds down this second caregiver position.



**Drivers:** The primary caregiver cannot do all of the driving, and needs to sometimes be at home base or work to handle things there. Drivers should be able to arrive very early in the morning to pick up post-transplant patients and get them to the hospital transplant clinic for blood draws by 7:30 am, which sometimes means being on the road by 5:00 am or earlier. Shortly after transplant hospital discharge patients are required to report to the clinic for check-ups and blood draws. These appointments are required, and need to be timely for medication purposes. Drivers are often adult children, neighbors, friends, or church/community volunteers who only have the responsibility of driving to and from the hospital for the first few weeks after transplant.

**Pharmacist:** Of course, you will have a hospital-based pharmacist. But, you will need someone to initially take charge of your medications at home. Primary care givers often take charge of this, but it is helpful to have a second pair of eyes to help organize, schedule, and verify the identity of a number of medications. It is most important to have someone in this position to work with the primary caregiver during the first week home after transplant. Once medication charts and schedules are set up and everyone becomes familiar with them, this position is no longer needed. Your secondary caregiver is often the best person to take on the pharmacist job when you first come home. That first day home is actually more stressful for the primary caregiver than the patient.





**Comedian:** Everyone needs humor in his or her life and in transplant it is vital to have a daily dose. Children need to be involved in the transplant process, and what better way to help take away some of the underlying fears of transplant than to assign them the job of comedian? Teens who have a tendency to withdraw in times of stress would benefit everyone if given the opportunity to bring laughter to the household. Friends and family can also bring smiles and laughter instead of sad or concerned faces into your home. Specifically assign someone the job of making people laugh.

**Cooks and Special Helpers:** Since primary caregivers have plenty to do, it is a great help to have others helping with day-to-day meals and household duties. This is especially important when repeated hospitalizations are needed prior to or after transplant, or when long-term hospital stays are required. A primary caregiver cannot be expected to be both at home and advocating bedside at the hospital too. After transplant, it may be a full time job providing bedside care until the patient is able to get up and move about independently, so primary caregivers need a break. Family and friends often fill these positions and then church groups or community volunteer groups fill the gaps if long-term situations become apparent.



**Exercise Buddy:** This is someone who will help you get out to walk on a daily basis for very short periods and then for much longer walks as you gain your strength at least two to three times a week. Walking is key to your health both before and after transplant. It helps you prepare for surgery, and speeds your recover after. A primary caregiver can fill this position initially, but it helps for the long term to have someone else in this position as well. Family members, teens, neighbors, or friends are great candidates for exercise buddies. Make sure that those in this position make it part of their regular schedule so that there is consistent dependability.



**Spiritual Caretaker:** Often this position is filled with a religious advisor, but to a transplant recipient it is more than that. Spirituality in transplant is not morality, psychology, or religion. It is the human spirit seeking purpose and meaning on a very individual level and explores personal faith, hope, loyalty, and love. People facing transplant many times unknowingly try to prepare themselves spiritually through a life review process that addresses a wide range of emotions and the state of simply being human. They often show signs of spiritual pain through fear, anger, bitterness, despair, depression, loneliness, hopelessness, confusion, rage, apathy, shame, hatred, helplessness, and vengefulness. A spiritual advisor can be a dear friend, colleague, or church member who is easy to talk with, is non-judgmental, a

great listener, and is somewhat removed from the immediate family. A religious advisor may also be a spiritual caretaker but may have limited availability so a team effort is best here. Many times the spiritual caretaker listens to the fears and concerns of the primary care giver and family members as well. The spiritual caretaker's main job assignment is to really listen with compassion and care.