



## The Role of the Support Person

The Portland VA Transplant program requires a potential recipient to identify a dedicated primary and secondary support person, also referred to as a caregiver, before being listed on the United Network for Organ Sharing (UNOS) waitlist. Both primary and secondary supports must be evaluated and cleared by the Social Work team in Portland. This is not an evaluation that can wait to occur when a potential organ offer is being made.

It is common for family members to serve as the support. In situations where family members are unable to serve as support, close friends have been asked to fill this role.

Our goal is for you, as the support person, to be well-informed and step into this essential role. We want you to have the necessary information, resources, and support to not only *get through* this recovery process but for both you and your loved one to *thrive* post-transplant. In addition, we strongly recommend any support person be fully vaccinated against COVID-19 to protect themselves and our Veterans.

Caring for a transplant patient can be physically demanding and emotionally draining. Participating in the recovery of a loved one from a challenging surgery can stir up many emotions. It is expected for even the most optimistic caregiver to experience feelings of being overwhelmed, question their capability as a caregiver, and second guess decisions regarding care needs.

## Why is a Full-Time Support Necessary?

While recovering from the transplant, the patient may feel physically weak and unable to follow a very time-sensitive medication regimen independently; therefore, there must be a full-time support person available.

Once the patient is discharged from the hospital, both the patient and support person will stay the remainder of the post-transplant period at the lodging facility, a part of the VA campus located in Vancouver, WA. You will share a room equipped with two individual hospital beds, refrigerator, private bath, Keurig, and a television. As a support person, your role will be very hands-on, and you will be involved for the entire post-operative recovery period. Some of the responsibilities would include:

- Checking and documenting daily weights, blood pressures, temperatures, blood sugars, and in some instances administer insulin shots.
- Helping ensure that the patient is adhering to the medication schedule provided.
- Monitoring and notifying the transplant team about changes in the patient's condition, (e.g. signs of infection).
- Keeping track of medical appointments for both lab and clinic days.
- Accompanying and ensuring the patient gets to and from appointments on time.
- Be readily available for teaching sessions from transplant coordinators, hospital nursing staff, pharmacists and dietitians.



- You may need to change surgical dressings and drains.
- You would be in charge of the shopping, meal preparation, medication pick-up, cleaning, and laundry.
- Depending on the patient's mobility, you may need to assist with things like bathing, dressing, and grooming, while the patient is building up their energy and endurance.
- You need to ensure that the environment is safe and that the patient is making safe decisions.
- Provide much needed encouragement and emotional support to the patient.
- Communicate with the transplant team as soon as you realize that there may be challenges in fulfilling any of these responsibilities.

## Being a Support Person is a Stressful Job

The post-transplant road to recovery can be smooth, or there may be delays along the way. There are several skills that can be utilized to help manage your support role successfully.

- **The first is flexibility.** Be prepared to adapt. There will be medication changes, changes to appointment times, the patient may experience mood swings & have medication side effects. The stay in Portland/lodge may be extended if there are complications or care that requires staying close to the transplant team.
- **Advocate for your loved one.** Ask questions and get answers. Be politely assertive and ensure the patient's needs are being met.
- **Take time to recharge for yourself.** Set aside some time during the day to take mini breaks. Read a book, take a nap, or go for a walk.
- **Being away from home.** You will be away from home for a minimum of 4 weeks for kidney and several months for liver recipients. This requires making some financial considerations for both home expenses and for your stay at the lodge. If you have pets, you need to make arrangements for their care and have a back-up plan in place if that original plan falls through.
- **Being away from pets.** Pets are **NOT** allowed at the lodging facility for safety and infection control reasons. Alternate plans must be made well in advance to identify someone you can trust to care for your animals at home and/or have them boarded at a facility. Any patient needing a service animal will be housed somewhere else.
- **Being away from loved ones.** Have a reliable care plan and someone you can trust to care for your loved ones whose care you are responsible for at home (ex: children, parents, grandparents etc.).

Support persons play a significant role in the success of a transplant. Support is vital in providing both physical as well mental support throughout the post-transplant recovery period. The key for all parties involved is to remember that all are working towards the same shared goal, and that is to make this transplant a success that allows our Veteran the opportunity for a new life following their transplant recovery.