

## Why is a Caregiver Required? Information for the Recipient and Caregiver

As a Kidney Transplant Candidate, you will face certain challenges which will impact your life, the lives of your family, and your support network. The following information explains why the transplant team **requires** all candidates to have on-going support **after** transplantation and what your caregiver/s need to know in order to maximize your chance for a successful transplant.

**The role of the caregiver is to provide support for at least 1 month after the surgery while the patient is recovering. After the transplant, the ultimate goal is to help the patient attain as much independence as possible. Because each transplant patient is unique, some patients heal rapidly and attain independent functioning quickly and others heal more slowly and remain dependent on caregivers for an extended period of time (up to one month after discharge). It is therefore essential that a back-up caregiver also be identified.**

### The Caregiver's Role After Transplant:

The **initial recovery period** after surgery is challenging.

- The patient needs support **24 hours a day, 7 days a week for a minimum of four weeks.**
- The patient is at risk for **infection and rejection.**
- The patient has to take **a lot of medications at specific times during the day and evening**, and there may be side effects.
- **Communication** with the transplant team is essential.
- Emotional highs and lows are common. Some of the reasons for this are: **gratitude and relief** at finally receiving the transplant; fear of organ rejection and other complications; and perhaps **sadness or guilt** over the fact that someone died in order to make this transplant possible.
- Finally, it can be **frustrating** to face the amount of time and work it takes to get back to “normal”— and realizing that there may now be a “**new normal**”. Therefore, it is essential that the kidney transplant patient has a caring support person to help throughout the transplant process.

**Medication Management: As the support person**, your first priority is helping the patient take the correct medications. Newly transplanted patients leave the hospital with 10 or more new medications. The medications have complicated dosing schedules and it is common for patients to take 20-30 pills a day for the first few weeks.

The support person must make sure the patient takes the right medications at the right time. This means learning the names and being able to recognize what each medication looks like, thoroughly understanding why the patient is taking each medication, waking the patient up if they are asleep in order to give the medications on time, and communicating with the transplant team at Stanford about any side effects the patient may be experiencing.

**With regard to medical concerns, your transplant coordinator will be your first point of contact.**

**Appointments:** After the transplant, patients have several weeks of intensive outpatient follow-up appointments as well as frequent blood work—and they are **not allowed to drive for up to thirty days!**

**For the first four weeks** after the transplant, the support person will take the patient to Stanford Hospital and Clinics (SHC) up to **2 times a week**. During the **second month**, the patient will return for follow-up clinic visits **every week**, and during the **third month**, the clinic visits are scheduled **once every two weeks**. This schedule is based on the assumption that everything is going smoothly. As with all medical conditions, there can be issues which arise that require the patient to return to the clinic more often - or be re-admitted to the hospital.

**Relocation:** If the patient lives **more than 100 miles from SHC**, the patient and the caregiver must move closer to the hospital **for up to the first four weeks** after surgery. There are various housing options available which your social worker can explain and help you arrange when the time comes.

**Emotional Support:** Most patients have intense emotions associated with transplant. They may be overjoyed at finally receiving a transplant—or feel let down. They may experience unexpected guilt over getting a transplant before others who are waiting - or have thoughts about the donor's family. This is an emotional time and the transplant social worker is available to provide emotional support, teach coping skills, make referrals if needed, and offer suggestions.

Realistic fears of rejection and infection—as well as actual complications can affect a patient's emotional state. Being able to talk about these frustrations is extremely helpful. Being a good listener can do wonders. Patients absolutely require the love, emotional support, and logistical support of their caregiver to make it through this very difficult time.

**In Summary: PATIENTS CANNOT GO THROUGH TRANSPLANT ALONE!** We require that patients have a support plan and a caregiver available **24 hours a day, 7 days a week for up to the first month** after discharge from the hospital. This does not have to be the same person. Many families take turns caring for their loved one.

Please ask the Social Worker about the **Family Medical Leave Act and Paid Family Leave** which may help in the event the caregiver needs to take an extended leave of absence from work.