



American Association of
Kidney Patients

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Home Dialysis: Together You Can!

When kidney patients begin to look at treatment options they have a lot of choices. While not all treatment options are right for everyone, choices include transplantation, hemodialysis and peritoneal dialysis. If patients choose dialysis as their form of treatment, they next need to consider if they want to receive these treatments in a dialysis facility or at home. Although home dialysis regimens are considered “self-care” procedures that can be performed fairly independently, patients often need the help and support of family members or friends. A helper or “caregiver” can be defined as an individual who is closely involved in caring for the patient and helping that patient cope and manage their chronic illness during the patient’s course of treatment (Gayomali, Sutherland & Finkelstein, 2008).

Helpful research exists in the area of caregivers’ emotional, social, physical and financial lives (Beanlands, Horsburgh, Fox, Showe, Locking-Cusolito, Pare, et al., 2005). People do not all experience and feel things in the same way, however, a lot of caregivers have reported feeling overwhelmed at first. Some of the main stressors identified by caregivers include difficulty in the physical care of patients, in the scheduling of treatments and in the management of household financial affairs. Sleep loss and disrupted sleep were reported as other caregiver concerns. Caregivers felt coping was difficult at times, especially when their loved one’s condition was worsening and independence was decreasing. Some caregivers initially say that caring for their loved one felt like a second job.

In some situations, beginning home dialysis can create a role reversal between partners. One example of role reversal in a relationship would be a husband’s role as protector and provider in the family changing as he begins dialysis, since his wife (the caregiver) now assumes that role. Loss of independence can increase further if the patient loses their job, or is unable to work. While the scheduling flexibility of home dialysis allows for more people to work, some are just too ill in the beginning to continue their jobs as before.

Giving care to a home dialysis patient also requires a lot of learning. Most people know nothing about dialysis, and learning to work a hemodialysis machine or peritoneal system can be confusing at first. Caregivers also have said that the first few days of independently putting the patient on the machine can be stressful.

While caregivers and patients may feel some of the above stressors, home dialysis has many benefits. Studies suggest that home hemodialysis allows for more hours of blood cleansing dialysis than a kidney patient would typically receive in a conventional, three times-a-week dialysis center-based program. According to data, home dialysis can be done on a daily schedule, nocturnally (while you sleep), or on a four-day-a-week schedule. Patients doing these types of dialysis had better heart health, blood pressure and some measures of quality of life than those in conventional treatment (Pallarito, 2009). Doing home dialysis allows for the patient to dialyze when and where it's convenient for them. For example, one could dialyze in their living room, while watching a movie, reading a book or socializing with friends. The following bulleted list contains tips given by patients and caregivers from their own experiences with home dialysis. Considering these tips may lessen the effect of the stressors listed above.

Helpful Tips from Patients and Caregivers:

- Patients should speak with their doctor and decide if home dialysis is the right option for them. It is important for patients and caregivers to review their finances to ensure the feasibility of this option. For example, with conventional home hemodialysis the yearly cost of water could exceed \$800 a year, which is not tax deductible. **However, newer home dialysis machines add little if any extra cost to a patient's water bill.**
- Patient and caregivers need to talk open and honestly with each other. Both people, regardless of the nature of the relationship (friend, wife, husband, partner), need to be 100 percent onboard with this decision to minimize the chance of resentment or bitterness in the future.
- Caregivers need to make sure they allow the patient to retain some of their independence. It is important caregivers not do everything for the patient. If the patient is not involved in their care, they lose what is left of their independence and the caregiver begins to lose their freedom and time. When this occurs, the caregiver can begin feeling hostility toward the patient.
- After the caregiver and patient receive training on the home dialysis option of the patient's choice, it is important to have a system in place. Both patient and caregiver need to know when the patient needs to dialyze, what equipment is needed, and have it neat, organized, and easily accessible.
- Be prepared for emergencies. Patients and caregivers should have telephone numbers accessible in case of an emergency. They should also know what constitutes an emergency, so in the event one arises they can identify it and quickly and effectively manage it.
- Ask your social worker about counseling services. Counseling can help patients and caregivers cope with issues or concerns related to the change in their lives. Home dialysis requires a big adjustment in both the patient and caregiver's lives and may create feelings that need to be processed in a therapeutic setting. The social worker may recommend counseling as the patient begins home dialysis or the patient and caregiver may decide later that counseling may be useful.
- It is very important that caregivers make time for themselves. Caregiver's should continue to enjoy activities, such as reading a book, going for a walk, visiting with friends or just going to get a coffee. Taking care of YOU first is the only way to care for someone else.

Patients and caregivers report that stressors greatly subside once they have accepted and adjusted to

home dialysis as their new way of life. If both the patient and caregiver ask questions, accept help and are open with each other, home dialysis can work fine as a treatment option.

References

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Amber Maneca is the Patient Services Coordinator at the End Stage Renal Disease Network of New England. She earned her Masters in Social Work from Springfield College in 2009 after training at a large dialysis center. She has authored a qualitative study entitled "Adults Living on Hemodialysis: Their Feelings on Religion and Spirituality."

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- **Written by:** Amber Maneca, MSW
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