



Relationship Dynamics between Patients and Caregivers

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When a Patient Does Not Accept Care

A patient might not want to accept care because they:

- don't want to bother their caregiver.
- are not used to receiving help.
- don't realize the transplant process requires so much help.
- feel weak if they ask for help.

During evaluation, the transplant team wants to see that the patient can accept care and:

- understands the transplant process involves both the patient and caregiver.
- has enough support to get through the process.
- can take their medications regularly. (Patients who don't take medicine correctly are more likely to experience organ rejection)
- will follow recommendations of medical providers.

A patient who can't accept care might not be approved for the transplant waitlist.

Help your patient accept care before and after transplant:

- Be patient, gentle, and empathetic.
- Try to understand why they don't want to accept care. Ask open-ended questions like:
 - "What are your concerns?"
 - "What do you think other people will think of you if you accept this care?"
 - "How would you like to be supported?"

- Actively listen to the patient without interrupting.
- Don't tell the patient they are overreacting or shouldn't feel that way. (They might stop saying how they feel or resist care even more.)
- Start small. Help with small tasks and slowly increase how much care you offer. This might comfort patients who worry about losing their independence.
- Talk with the patient about why accepting care is important. Remind them they have a better chance of being on the transplant waitlist. (Be patient – do not try to scare them.)
- Ask the transplant team for help talking with the patient.
- Encourage the patient to talk with a counselor, social worker, or psychologist. This might help if the patient is refusing care because they are anxious or depressed.

Marital/Relationship Stress Related to Caregiving

If you are a caregiver for your spouse or partner, the change in your relationship can be stressful.

You and your partner share feelings and experiences from before the transplant, but it can still be hard to adjust to new roles and responsibilities.

To start, try to understand the feelings you both might have during the transplant process.

- Your partner might feel useless or like they are a burden.
- You might feel:
 - stressed as you balance work, family, and caregiving responsibilities.
 - [exhausted, with low energy, and limited sexual desire](#)¹.
 - resentful towards your partner.
- You both might feel:
 - a loss or intimacy.
 - tension in the relationship.
 - emotional, physical, social, and sexual changes in your relationship.

Look for ways to balance the roles of caregiver and partner.

- Make a list of what you can and cannot do for your partner (the patient).
- Write down the caregiver responsibilities that cause you stress.
- Share your thoughts with your partner.
- [Ask friends and family for help](#)¹.

Throughout the transplant process, communicate openly and honestly. Talk with each other about:

- how you feel.
- your individual and shared experiences.
- caregiving responsibilities.
- decisions you can make together.

¹ <https://www.myast.org/caregiver-toolkit/self-care-for-the-caregiver>

- changes in sexual intimacy.
- your expectations and needs as a couple and individually.

Talking honestly with your partner can prevent:

- serious misunderstandings.
- damage to the relationship.
- resentment.

Focus on yourselves individually and as a couple.

- Plan time to be alone. Give yourself space to relax and recharge.
- Spend time together as a couple, not caregiver and patient. Talk and do activities not related to transplant.
- Ask friends and family for help with specific activities, like:
 - driving to medical appointments
 - household chores
 - going to the pharmacy or grocery store
 - learning more about transplant
 - bringing a meal
- Consider [individual and couples counseling](#)² (if you are both interested)
- Hire [in-home health aids or respite care](#).²
- Learn about [financial resources](#).³ During the transplant process, you and your partner might:
 - need to work less.
 - have less income.
 - have more medical or daily expenses.
- Ask your transplant team about options if you and your partner are worried about having children after transplant.
 - Don't wait until after transplant.
 - Before transplant, make a reproductive plan with different options based on different recovery outcomes.

If you are a caregiver for someone who is not your partner, these strategies can still help you and your partner have a healthy relationship. You must still balance family and caregiving responsibilities.

Role Transition after Transplant

Immediately after surgery, the patient will need more care. Slowly, the patient will become more independent and need less care. Your role as caregiver will become smaller. You might still help with some tasks, but you will spend less time and energy as a caregiver.

² <https://www.myast.org/caregiver-toolkit/self-care-for-the-caregiver>

³ <https://www.myast.org/caregiver-toolkit/legal-and-financial-considerations>

Transitioning from caregiver back to your role of spouse, sibling, child, or friend

After transplant, it can be hard to transition back to your role of partner, sibling, child, or friend. Remember that it takes time to adjust to life after transplant.

- Talk openly and honestly about the transplant experience.
 - How did the process affect each you?
 - How did it affect your relationship?
 - How does it feel to adjust to life after transplant?
 - How did you overcome challenges during the process?
 - How have you grown closer? Caregiving often brings people closer.
- Spend time together, and don't talk about transplant or caregiving.
 - Play board games.
 - Watch a movie.
 - Cook dinner together.
- Acknowledge that life after transplant will not be the same as it was before transplant. You will have a "new normal". You and the patient will both have grown and changed.

Even after you return to "normal life," the patient might still need your help sometimes. It's normal to feel stressed when this happens. Remember to ask others for help.

Questions to Ask Your Transplant Center

- How can transplant affect reproduction (having a baby)?
- Who on the transplant team can help if the patient doesn't want to accept care?

Resources

- [When a patient does not accept care](#)⁴
- [Protecting relationships when you are a caregiver](#)⁵

References

1. Home Care Assistance, "Five Ways to Help a Parent with Dementia who Refuses Care." Retrieved from <https://homecareassistance.com/blog/five-ways-help-parent-refuses-dementia-care>.
2. Gift of Life, "Patient Compliance for Transplant Caregivers." <https://giftoflifehowieshouse.org/bridge-caregiver-support/bridge-post-transplant/patient-compliance-for-transplant-caregivers/>.

⁴ <https://giftoflifehowieshouse.org/bridge-caregiver-support/bridge-post-transplant/patient-compliance-for-transplant-caregivers/>

⁵ <https://caringvillage.com/2019/02/08/keeping-marriage-strong-caregiving/>

3. Select Healthcare Group, “What can you do when a Dementia Patient Refuses Care?” Retrieved from <https://www.selecthealthcaregroup.com/what-can-you-do-when-a-dementia-patient-refuses-care-news-36>.
4. Caring Village, “Keeping Your Marriage Strong through Caregiving.” Retrieved from <https://www.caringvillage.com/2019/02/08/keeping-marriage-strong-caregiving/>.

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