



Long Term Care: an Emotional Journey for Family Members

Many times, moving a loved one into a long-term care facility is a true act of love and unselfishness. If the caregiver and the care recipient cannot leave the house, you have both become very isolated. Imagine mom being able to go outside her door to find someone to talk with. There are activities, meals to be shared with friends, and a barrier free area where she can roam.

When a person is no longer safe living at home, or when a caregiver can no longer provide the care needed, many feelings arise. There is no right or wrong way to feel. Each person is unique and each situation is unlike any other. When you move a loved one into long-term care, what are some common emotions that a caregiver might feel? How can you deal with these emotions?

Anxiety

What should I expect? What if my family member hates it there? What do I do if I need help or advice?

- You will be faced with a lot of paperwork the first day. Don't be afraid to ask to have each document explained to you. If you are feeling overwhelmed, you can ask to take the paperwork home to read it through.
- Visit the facility at unexpected times to get a clear picture of the routine. You will be able to identify when something is out of the ordinary.
- Get to know the staff. It's normal to ask a lot of questions about procedures and routines.
- If the facility doesn't seem to be a good fit for your family member, you may want to consider moving to another facility. While moving is hard, finding the right fit can make the difference between continual anxiety and a happy, successful living environment.
- If you need help or advice about long-term care facilities, contact the Long-Term Care Ombudsman to discuss the situation and/or request assistance resolving an issue.

Anger and Resentment

This is not the way you planned this part of your life to go. Long-term care is expensive. You may be angry about the money being spent on your family member's care. You may resent the facility staff for not doing the things you always did at home: like making sure your family member had his newspaper and coffee first thing in the morning. You may feel like a failure and angry with yourself.

- Talk with the social worker about available payment programs, like long-term care insurance, veteran's benefits, and Medicaid, and how to qualify. Medicaid can pay for the nursing facility stay when someone runs out of money. The Department of Veterans Affairs may be able to provide financial assistance to veterans and dependents who qualify.
- Talk with the director of nursing about the routine you had at home. The staff can make sure your family member gets his newspaper and coffee first thing in the morning. Provide feedback about what is or is not working. Staff can only fix the issues if they are aware of the problems. The Long-Term Care Ombudsman can help to get issues resolved if you are not satisfied with the facility's efforts.

- Attend care plan meetings to get an update on the provision of care for your family member and provide feedback and suggestions. You do not need to wait for these meetings to express concerns. Visit with staff as concerns arise, so your anger and resentment will not build.
- Write down questions as they arise. Talk with the social worker or the director of nursing to learn the answers to your questions. Share successes with the staff at the care plan meetings.

Guilt and Regret

It is very important not to confuse guilt with regret. Guilt is what we feel when we do something that is wrong or hurtful towards another person. Regret is sorrow over something that has happened. Let's use the example of a daughter faced with moving her dad into the nursing home because his Alzheimer's disease has progressed and it is no longer safe for him to be at home. Family and friends may not see the day to day challenges. As the primary caregiver, you do see what is happening day after day and know when assistance is needed. Or, as a caregiver, your stress level or health has deteriorated to the point where it's time to return to being a family member and not the primary caregiver. It is important to make your health a priority. Family and friends can only make you feel guilty if you let them.

- Is there a support group available in your area? Contact the Iowa Family Caregiver Support Program to talk about how you are feeling, or to find a support group near you.
- Become a volunteer at the facility. Enriching others' lives can be very rewarding.
- Attend the facility's family council meetings. If there is no family council, help create one. The Long-Term Care Ombudsman's Office can provide you with information.

Depression and Grief

Caregiving is hard work. It can take over your life. Even though you may be exhausted, when the move is finally complete, it is not uncommon to feel depressed for a short while. Your life has just taken a serious change in direction and it takes time to adjust. Allow yourself to be sad for a while each day.

- Don't be afraid to reach out to others or talk to a professional to work through your feelings.
- Do one thing for yourself each day: read a book, go on a walk, go out to lunch with friends, go to a movie, or focus on hobbies you enjoy.
- Remember that your caregiving duties haven't ended, they have just changed. You still have a very important role.
- Find little ways to move forward with your life now that you have time for yourself.

Relief

If you have been the primary caregiver, you will probably feel a sense of relief-mixed with anxiety, guilt and fear. You are now able to be home alone, to sleep all night, to relax and read a book in your favorite chair or go out to eat with friends. These are pleasures every caregiver needs to enjoy.

Turning over the daily tasks of caregiving to a professional allows you to once again focus on yourself and maintain your health and strength. Relationships can improve and flourish when you can focus on each other and not caregiving tasks.

Resources

- Office of the Long-Term Care Ombudsman: 1-866-236-1430
- Family Caregiver Support Program: 1-800-532-3213