

Tales from the Other Side

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When a loved one is diagnosed with a life limiting illness or disability, the person who has just become the caregiver assumes a long-term responsibility. This sudden shift can be difficult and can alter the caregiver's life substantially. But what about the care recipient whose life has also just changed dramatically? Although everyone has their own individual needs, there are a few things that everyone wants, or doesn't want, from their caregiver.

Everyone Wants to be Heard. Caregivers often focus on the needs of their loved ones and on tasks essential for their health and comfort. They may "take charge", which both helps deal with their own mixed emotions and provides momentum for the new role. This 'bulldozer attitude' may be resented by the care recipient and can result in missed opportunities to communicate or comfort the loved one, who may need a shoulder to cry on or someone to just listen. When they complain about pain or feelings of depression, your first instinct may be to help by running to the drug store for medication or to say "let's go out to visit some friends". Yet such activities may not be what your loved one needs in the moment. Try saying, "I'm sorry that you're having such a rough day" or "Can you tell me more about why you're feeling down?" Such statements show that you care, and that you are listening. It's important to maintain open communication with your loved one and to remember they will feel different and communication will change as their disease progresses.

People Don't Want to be a Burden. Care recipients are dealing with feelings of losing control, as their roles shift and their spouse, child, parent, or friend becomes their caregiver. 'Joan', for example, is caring for

her mom, who has advanced heart disease. She still lives in her own home, and Joan visits her daily. While bringing dinner, Joan lists items she wants to discuss with her mother about her living situation and the state of her home. Her mother simply replies, with a sigh, "Yes, mama", conveying a message of her concern regarding their switch of roles and her own feelings of helplessness. Had Joan said instead, "How can I best help you today, Mom?", the response may have been better, with her mother feeling that she had some control over her situation. She might well have revealed more about her feelings that day.

Diagnosis of a serious or progressive illness leaves your loved one feeling vulnerable. They don't want to become a burden, especially if they are used to caring for everyone else. They don't want to lose their independence, become a financial burden, or take up their family's time and energy. Remember while it may be important to work on practical activities, such as paying the bills or fixing the house to sell, you need to be sensitive. Watching someone else plan one's life can be traumatic. Your loved one wants to believe that he or she will continue to be a contributing member of the family. Experts agree that this is consistent across all age groups and cultures.

Have you ever wondered ...

- *How do I plan for future healthcare when I am not sure what my needs will be?*
- *What qualities do I look for in a substitute decision maker?*
- *What are the main values and beliefs that shape my quality of life?*

... our workshop on **Advance Care Planning: Getting Started** can help.
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