

What does “Quality of Life” mean when caregiving?

By Debbie Selsavage, CDP

When you are in a care partnering role things may become overwhelming at times, we may feel sadness, depression, and even become anxious. We may become more isolated and mourn the loss of happier days. You may not think of anything but doing what I need to do to get through the day. But the next day will be the same, and this is not good for either of you.

This is not a “sprint” this may be more of a “marathon,” and the best quality of life for both is to plan for that marathon. People that are in the journey of Alzheimer’s and forms of dementia (after the diagnosis) could be an average of 8-to-12-years in this journey, you have to learn how to live if possible.

We have addressed support that may be needed in previous articles. This is more about the care partner finding a “Quality of Life” in this role, if we do not address this, we may not be able to continue this journey.

Care partners shouldn't overestimate their ability to care for their person, whether that involves bathing, dressing, grooming or lifting them into bed or a wheelchair. These activities could be strenuous and unsafe for both of you. This is addressing the physical, we haven’t even mentioned the emotional side of this.

This is not a weakness or the lack of being able to care for this person through this journey, a support team will be required, sooner rather than later.

Being a care partner your focus is the well-being of your loved one, so we put our own well-being on the back burner, not good! What we are avoiding is called many things, but “Self-Care” is the most common, this is not “Selfishness” or being selfish, this is important for not only the duration of the journey, but your “Quality of Life”. Who will be there if you are not!

A care partner can maintain a quality of life by prioritizing self-care, building a support network, setting realistic expectations, managing stress, engaging in physical activity, maintaining healthy habits, hobbies, and seeking professional help when needed, all while providing quality care to their loved ones.

Here are some things to consider for your quality of life:

- **Self-care:** Prioritizing your own needs like adequate sleep, healthy eating, exercise, and hobbies to prevent burnout.
- **Support network:** Building strong relationships with family, friends, and finding local support groups who can offer emotional and practical support.
- **Professional support:** Utilizing local professional services like respite care, counseling, day programs.

- **Effective stress management:** Learning coping mechanisms to manage stress, such as deep breathing exercises, mindfulness practices, and time management strategies.
- **Realistic expectations:** Understanding the limitations of caregiving and setting attainable goals to avoid overwhelming oneself.
- **Communication skills:** Openly communicating needs and concerns with family members, and healthcare providers, be open to accept support.
- **Education and training:** Staying informed about care and accessing relevant training to enhance caregiving skills.

Some Challenges that Care Partners face:

Emotional strain: Dealing with the stress of managing someone's health needs, potential behavioral changes, and grief.

Physical strain: Managing demanding physical tasks depending on the person's needs.

Social isolation: Feeling disconnected from social activities due to caregiving responsibilities.

Financial strain: Potential financial burdens associated with caregiving costs.

To best live as a care partner, we should prioritize maintaining a consistent routine, providing reassurance, avoiding arguments or correcting, respecting their feelings, and actively seeking support for themselves by utilizing respite care and community resources, while allowing your loved ones to maintain as much independence as possible within their capabilities. Trying to be as patient as possible.

Thinking of yourself is also thinking about your loved one, because you want to provide them with the best care. Do not do this alone!

As our slogan goes: I believe, "We all Deserve the Best."

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