Imagining the Worst, Making Room for the Best

When someone you love, whether it's a relative, a partner or a friend, is diagnosed with dementia, it's like getting hit with a wave of cold water. It doesn't matter if you saw it coming, or what type of dementia has been diagnosed, whether clinical treatments are available or if you live in the same town or far away. The grief is always undeniable, and the questions always outweigh the answers.

As a licensed social worker and the Family Services Director at Amazing Place, the Houston area's leading resource in navigating dementia and nurturing brain health, I often see caregivers in the early stages of this journey worrying about and imagining the worst. And that's common because there's much to process, and everyone's dementia journey is unique. While there are few easy answers, proactive planning for the future is a key to maintaining a good quality of life while simultaneously facing daily caregiver challenges.

Balancing proactivity and planning with handling emotions and physical tasks of caring for a loved one is an effort that requires a bit of discipline and a whole lot of support. So where to start?

First, recognize that you are experiencing anticipatory grief. This is a term used to describe feelings of loss that families experience as they imagine what life will be like as the dementia progresses or the person they love nears the end of life. It's normal to experience anticipatory grief when caring for someone with dementia and it is part of the overall grieving process.

Being proactive about the future can feel like an added burden to dementia care partners, but the truth is that planning next steps for a loved one's future care can reduce anticipatory grief and bring feelings of control back in your life.

Second, create a circle of support. This is not a journey to take alone, so cast a wide net for people with skills, experience, or expertise that can help you and your family. One of the most important things a care partner can do is learn how to ask for and accept help. Taking this step can help you plan for the best possible outcomes in your situation. In addition to friends and neighbors, your circle may include physicians, ministers, or financial advisers.

Next, make a list of items that can be done by either you or someone who has offered help. Keep in mind that depending on how the dementia journey unfolds, this list can and should be updated as needed. Items to consider are:

- **completing advanced directives**
- **organizing finances**
- **managing household chores, including meals**
- **helping with transportation and doctor's visits**
- **exploring short-term care options, like Adult Day programs**
- **exploring long-term care options, such as in-home care or assisted living and memory care communities**

Planning ahead is important because it can spare a caregiver from having to make difficult decisions in the middle of a crisis. Plus, it allows time to consider the best options and paths for future care while beginning to process the grief of an unknown future.

Keep in mind that proactive planning can have the potential to become overwhelming in and of itself. Exploring palliative care, hospice, or making legal decisions can trigger and intensify current emotional pain, turning management into mourning. When the focus on the future prevents living in the present, it can contribute to depression, anxiety and burnout by living in tomorrow's losses rather than finding hope in today's reality. Finding a balance between planning ahead and staying grounded in the present helps.

Becoming caught in a spiral of "what ifs" may unintentionally rob you and your loved one of the joy that is still available here and now. Even though it's hard, don't allow pain to have the upper hand because joy provides the emotional strength needed to face grief and loss. Making space for joy keeps care partners connected to the present moment and to the good that remains. Remember that it's okay for grief and joy to sit alongside each other; each requiring its own space. Joy is worth fighting for.

One way of doing this is to find a support group or caregiver education classes convenient to you. At Amazing Place we host an array of free English and Spanish caregiver support and education classes in-person and virtually. Knowing that others are having similar experiences

helps unload emotional negativity, and sharing experiences within a peer group helps manage loved ones' behavior and communication issues while reminding you of the importance of self-care.

Also, make time for special activities you've always enjoyed with your loved one. Continue taking walks together and enjoying nature, attending concerts or listening to your favorite music. Visiting museums and spending time with family and friends are treasures to be cherished.

Finally, to manage anticipatory grief and be the best caregiver you can possibly be, it's important to grant yourself some grace and take time for personal joy. Creating spaces that make you happy and using your innate skills and talents replenishes emotional strength so go ahead and make plans with friends, learn something new or relearn a favorite hobby. Taking time for yourself should not be a guilt trip, it's a portal for empowerment.

When you start imagining the worst, remember that you are not alone and there's much you can do to make room for the best!

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