

Halt. Take a Pause. Step back. These are things we rarely get to do when we are a care partner. Any caregiving situation that involves chronicity can be hard, but being the primary care partner for someone living with dementia can be even more difficult. Even if our loved one is in a facility, and we are not doing the 24/7 physical care, chances are we are still expending a tremendous amount of emotional, physical, and spiritual care energy.

H.A.L.T. What does that mean? Hungry. Angry. Lonely. Tired. Recognize these words? At various times they may encompass your entire world and it is easy to lose perspective. Dementia and other chronic illnesses can make your life and world feel very small.

HUNGRY. When our loved one is diagnosed with dementia, we are hungry. Hungry for the life we had “pre-diagnosis.” Hungry for the relationships we had – not just with the person diagnosed, but with our friends and family. Our world is changing. Your life partner eventually will no longer be your supportive companion. The people in your social, spiritual, and family lives may no longer desire to be the supportive people they once were. For one reason or another, it might be too difficult for them to embrace the changes in your life and be a companion in your dementia journey.

ANGRY. We are angry. The diagnosis totally sucks – literally! Sucking the life out of our loved one’s brain. Altering the familiar. Destroying the connections. Changing our outlook on the future. We have our history but have lost the future as we once envisioned it. If we can’t embrace and accept the changes that are happening and that lie ahead, we can become angry and bitter. If we are honest with ourselves, we are grieving and anger is just one manifestation of grief.

LONELY. Dementia is an isolating syndrome. Isolating for the Person Living with Dementia (PLwD) and for the people around them. The person with dementia has a dying brain. They may become increasingly quiet and withdrawn, mean, or hallucinate as their senses are changing and diminishing. When they are in the liminal space of knowing they are losing cognitive ground, they might disengage. If they were social, it can be awkward and frustrating for us when we don’t know how to engage them or when we get responses that are inappropriate or don’t make sense to us. We are in uncomfortable, unfamiliar territory. For the care partner, it can be awkward and difficult to explain why your loved one is shouting or touching or not answering at all. Without connection, without support, dementia is isolating and lonely.

TIRED. Wow. Remember the days of being a new parent? Those nights without sleep with an infant? The frenetic energy of a toddler whose curiousness abounds but their safety switch is not on? No rest for the weary! Dementia is exhausting for everyone. For the PLwD, the struggle to connect words, remember faces, figure out how to use once familiar objects, and to compensate for their deficits, all require huge amounts of energy.

For family and friends, the weariness may take on physical, emotional, and spiritual dimensions. You are bone tired from trying to keep up with, keep ahead, anticipate, keep them and you out of harm's way.....Folks with dementia can be abusive verbally and it can take an emotional toll on a care partner – they might not mean it but with the filter gone, even the best of us can get thin-skinned. Grief is your burden too – there are losses on so many levels. Spiritually, you might feel abandoned by God. The rituals and fellowship that once gave you comfort may become a burden.

Where does H.A.L.T. leave us? *Empty*. These things can destroy us or we can be aware and move through them. The brain of our loved one is losing connections and for that reason it is imperative that we as care partners, family, and friends make our connections strong and we support one another. It is in those relationships that we find the grace and strength to carry on. Those connections recharge and fill us.

So, pause. Take a time out. Do what you need to do to care for yourself. Halt *not* H.A.L.T.

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