

# Lessons from the front

A Dementia Caregivers Survival Guide

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## Personal timeline

- 2012 spouse quits job after some performance issues.
- 2013 friend expresses concerns about memory “not like him”
- 2014 found new primary care doctor, referral to neurologist, diagnosis
- 2015 trips to UCSF for second opinion, 4 clinical trials, complete paperwork for disability, estate planning
- 2016 found/created support group (depression 2014-2016)
- 2018 first cancer diagnosis (surgery, then ignore)
- 2019 second cancer diagnosis, **spouse to care home**, surgery, recovery
- 2020 covid-19
- 2022 repartner

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## Tips for survival: dealing with yourself

- Acknowledge the terrible nature of the illness
- Your sadness doesn't help your person, but it helps you, sometimes
- Detach your ego from your person: awkward remarks, dress, grooming
- Change your perspective. Go larger or smaller, longer or shorter.
- Go outside.
- Do something creative whenever you can. Small is fine.
- Comfort yourself with a plan. Amend as needed. Daydreaming counts
- Your heart will be broken, time and again. Feel the way that lets it expand to compassion for more people, once you have the capacity

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## Tips for survival: dealing with your person

- Lower your standards. Repeat as needed.
- Practice being the big dog early to establish a pattern. Don't let dementia drive the bus
- As your person diminishes, honor the old person, but deal with the new one
- Every solution is temporary
- Don't hold yourself to an impossible standard of care. (How much dental is necessary?)
- Don't tell the complicated truth. Tell the truth that you can get behind and that can be heard. Therapeutic lies are a necessity.
- Don't put everything on hold because change would upset your person

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## Tips for survival: dealing with others

- Ignore other people's medical advice. My personal favorite: "Western Medicine really understands nothing about Alzheimer's"
- Don't take responsibility for other people's sadness about the situation. Their sadness doesn't help your person or you, but it may help them.
- Find others in your situation to laugh and to cry with. Be real.
- Get practical help: Adult day. Daytime caregivers. Neighbors.
- Feed good relationships. Starve bad ones. (When I hear "If there's anything I can do to help..." I say "Please look after our friendship. I'll still love and make time for you, but you make the effort to reach out." Friendships prune themselves!)

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## Final thoughts

- You are the lynchpin of this process
- If you can't make it, your person can't either
- You must be kind to yourself every day, as you will never be your ideal caregiver, who is an angelic doormat, and possibly a martyr



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