

The only "under" it is not, is understood
is: under-reported, under-funded, under-studied, etc.

We are the shadow army. For every person with dementia there is a caregiver who stands in the shadow of the patient; unseen, unrecognized, under appreciated and under-valued by society at large and sometimes even by our own families.

We fight to preserve the dignity and comfort of our loved ones, not for fame or fortune or awards but mostly because we care. We take on the thankless task of feeding and bathing and toileting; of being another person's brain and social secretary for scheduling doctors appointments; ~~and~~ ^{chauffeur} and cook and housekeeper and so many other tasks great and small that ~~they~~ ^{our loved ones} can no longer be trusted to do for themselves.

Perhaps most discouraging of all, we fight in a war we can not possibly win. They will never recover, there is no long-term cure.

We don't put up with the endless messes and abuse and ~~we~~ put our own lives on hold because we want to be martyrs, we do it because it is the right thing to ^{do} for those we care about.

I offer no solutions - only this suggestion to my fellow fighters: give yourselves a pat on the back once in a while, give each other a hug and a kind word. Tell each other "I appreciate what you do and I can relate to your struggle, even if no one else can."*

As Red Green used to say "Remember, I'm pulling for you. We're all in this together."

When is it my turn for me?

Don't be like the lumberjack who can't stop to sharpen his ax because he is so far behind cutting down trees. You need some self-time as you go just as you need sleep and food. You need to recognise your mental, emotional and spiritual need as well. You need to recharge your batteries and dump your ~~trash~~ trash. Don't become isolated and ground down. If you can't get to a support group, keep a diary (keep a diary anyway) because you need to ventilate somewhere.

The short answer is - it is always your turn for you, you just may need to take your turn in small bites here and there as you go (like cat naps rather than a full night's sleep and some finger foods to snack on throughout the day rather than sitting down to a 7 course meal). You can't be your best for someone else if you are burned out physically, mentally, emotionally and spiritually.

At what point have I suffered enough?

I think that the healing from the effects of suffering starts when you think of that question but in order to find your answer you need to ask and answer some deeper questions like:

- Who will be the judge? Will it be you or someone else around you like your family and if not you then what gives someone else the right to decide for you?
- How much can you stand? What is your breaking point and how close are you?
- How are you suffering? What distinguishes an honest burden from self-imposed anguish to offset some sense of guilt or failure?
- Do you feel worthy of release? Does the "punishment fit the crime"? Is the suffering proportional to the need that it serves?

In truth then, I think you have suffered enough when you feel you have suffered enough and decide to stop - when you feel the debt has been paid and it is time to share the burden ~~and~~ and get help sharing that load.

Should I feel guilty about being happy?

Do I deserve any happiness while my wife slides away into the fog of dementia?

I think I do deserve what comfort/joy/happiness I can find in my life in spite of this tragedy. As all consuming as the disease has become in our relationship, life goes on. I feel I need to search for positive things in the midst of the disappointment, otherwise ~~that~~ life becomes a black-hole of depression, gloom and despair. Good things continue to happen to our children and grandchildren, the world continues to turn and the sun still comes up every morning. Life has not stopped and neither should we.

As long as those things that bring joy and comfort do not take away from the care I give to her I find no reason to feel guilty. As a matter of fact, if my finding some happiness improves my state of mind then I am probably going to be a better caregiver as a result.

Being less depressed is better, not only for her and myself but for everyone around me.