

What has been 'good' about your "Caring Role" today?

- ✓ More independence with daughter. In laws with dementia voicing appreciation of their home, first time since moving 4 hrs ago.
- ✓ I do make a real difference to my Mum's quality of life
- ✓ Seeing my caree well-dressed after dressing him
- ✓ Nothing because I cannot make contact with my son nor his CPN
- ✓ Survival
- ✓ I've had a small break
- ✓ My son was happy to be going swimming
- ✓ I have been able to add to the quality of life of those I care for by giving practical and personal care and keeping them going.
- ✓ Sitting in garden with my husband
- ✓ My Dad recognising me as his daughter. I look after him every day but most times he is not sure who I am.
- ✓ Difficult one!
- ✓ At last having a Social Worker who had a huge wealth of knowledge into the "hidden disability" of problems of living with someone who has suffered a traumatic brain injury.
- ✓ I managed to persuade my spouse to stay in bed longer this morning and thus conserve her energy,
- ✓ Knowing my parents are safe and well.
- ✓ Able to take 'N' out for a coffee. Can only go to nursery garden centre where it is level for wheelchairs.
- ✓ Encouraging Mum to be sociable by hosting a small coffee meet for a few friends and neighbours
- ✓ Nice weather so in my garden
- ✓ Getting away and having a break at work!? Being myself, in my own life instead of being an enabler for another who is critical and rarely seems appreciative (apparently unknowingly). Not being criticised and called upon when I am already in the middle of doing something else.

What has been 'not so good' about your "Caring Role" today?

- ✓ Elderly mother stressing daughter.
- ✓ I don't often get guaranteed undisturbed time to myself- I am not very well myself and do find some days really hard (daily migraines)
- ✓ Couldn't shower until this afternoon
- ✓ See above
- ✓ It is relentless
- ✓ It's been very tiring
- ✓ He was awake in the night from about 4 am, worried about the weather.
- ✓ I feel torn between the conflicting demands of the two people I care for. Each is jealous of the time I give to the other and has a huge sense of entitlement. My own retirement (I am nearly 73 years old and have been caring for my mother for 12 years) has been severely impacted and I feel quite depressed about the future.

- ✓ Coping with black moods when he's not feeling well, and is worrying.
- ✓ I've just taking a break from Dad to visit Mum in the Care Home. She can't communicate with me more than with visual expressions due to advanced dementia, but she is still lovely and still my mum.
- ✓ I am so tired.
- ✓ The battle to get the right person for the assessment.
- ✓ My wife has developed another problem and it is difficult because there is nothing that I can do to assist or relieve her discomfort.
- ✓ Exhaustion. Frustration about never having time-out.
- ✓ Ok today.
- ✓ Having to juggle the personal caring and other responsibilities.
- ✓ Had a fall.
- ✓ Feeling guilty at leaving him. Being upset and feeling that that I am trying to be patient and understanding and do my best. When he is taking out his anger on me and speaking to me in an unacceptable way I feel I am being pushed away and grieving for the person I have lost. It is difficult to discuss the changes without upsetting him and making him feel he is not doing well when actually he is doing very well given the circumstances. Feeling constantly upset and close to tears and afraid about how this will work in the long term. Feeling that I am going to burn out and that it will have an impact on my job.

How could your "Caring Role" be improved?

- ✓ More detachment skills for me.
- ✓ If my Mum was able to join a group in Ross I could have more time to myself while she was socialising.
- ✓ Free time for self.
- ✓ Knowing that his care team were making some progress.
- ✓ I have no idea.
- ✓ To have a rest.
- ✓ It would be good to be able to find some extra respite care in one of the 'Shared Lives' homes.
- ✓ I don't see any way of changing anything. My mother uses emotional blackmail to get her own way in everything.
- ✓ Health professionals don't always give the information needed. It's often difficult to get needed appointments
- ✓ Having more support for Dad. But as he won't go anywhere that's tricky!
- ✓ More help.
- ✓ Not sure, as I feel, even my friends and family do not understand how frustrating it can be supporting someone with a hidden disability, who looks fine.
- ✓ I have to learn to be more patient and tolerant, so to speak 'bite the bullet'.
- ✓ I don't think it can be. It is what it is.
- ✓ Can be a bit stressful and tiring.
- ✓ More recognition of what I am achieving as other areas have to be put to one side.
- ✓ It can't.
- ✓ Better understanding of the affect a stroke has on the brain and the changes it causes and how a stroke victim may now see life. I can only imagine. Counselling for us both together to help us work together instead of the changes pushing us apart. Him understanding the impact on me without him taking any blame. Discussions with other carers that also work full time.