

In respect and admiration for all the informal carers who've invited me into their lives

Dear Elspeth

You called me - a stranger to you - because you recognised that you needed help in your caregiver role. I'd love you to give yourself a pat on the back for doing that, and for acknowledging that need. Too many people feel it's a failure to ask for help, embarrassed, sometimes angry, at feeling as though they could break under the strain. It's a strength, not a weakness, to seek support. Too few people really understand the role of caregiver, the relentlessness and the loneliness, the helplessness and the exhaustion.

Resentment, fear, love, hate, disappointment, exhaustion - you don't need to feel guilty about any of these, your strength comes from recognising not only that you need help but being brave enough to seek it.

I didn't come into your lives with a magic wand; in getting to know you both, together we've found some ways forward. Sometimes it's the little things; recognising that seeing the person, not reacting to misunderstood behaviour, can calm a storm. Your ability still to find the joy in each other is a celebration - though I see your tears even as I hear you laugh together. I see the discreet support you give, not drawing attention to unexpected behaviours or conversation, just carrying on, mindful of the importance of the comfort zone.

Being able to chat together about continence concerns, difficulties with food and drink, disturbed nights - you're so grateful for the ideas we pull together. Sometimes, they work; sometimes, they don't - and even when some ideas only work some of the time, you recognise the success in that. Your ability to celebrate these discoveries and successes together is so rewarding and makes my role, small though it is, so worthwhile.

I know how often you waken up in the morning, unsure what your day will bring or how you'll get through it. You work so hard to create a comfortable routine, whilst that routine may well go out of the window within minutes. Everything can take so long, and time takes on a shape of its own. Appointments and plans create extra pressures - how much time do you allow when you don't know if it's going to be a good day or a bad day? And yet, you make plans, you allow time - and you manage to take in your stride that the plans don't always work.

I see with admiration how you "gird your loins"; you cherish those moments to yourself when you can enjoy a cup of coffee and read the paper, recognising the value of that, over trying to "stay on top of" the housework. You've created a routine which can, albeit not always, give you repair time. You have learned that you need to take care of yourself, to achieve what you strive to achieve each day. You work at that self-care and I applaud you for it.

Your approach is inclusive, chatting about the plans for the day, not overloading but nevertheless respecting the importance of communication between you, even if it's sometimes one-way, or misunderstood. I don't think you recognise what amazing skills you bring into the lives you now lead.

Your lives now are not the way you want or envisaged and I know you feel that the way ahead looms over you like a shadow, but the love, the normality, the tears, fears and hopes which you bring into every day, show the remarkable person you are.

Yours,

*Jackie*