

Caring for my daughter

After 20 years of caring, I wondered if the equivalent of a telegram from the Queen might come through the post to celebrate the fact that I'm still standing. Standing, and with my sense of humour generally intact. I haven't acted on my sometimes almost murderous thoughts directed towards a thoughtless friend or insensitive professional and feel that that too should be worthy of a round of applause.

Early on in this caring journey, I was told by a professional with little or no people skills that people 'in my position' often have their children adopted and he offered to put me in touch with someone to arrange that. He was lucky his remark had put me into some sort of shock, or I may have lost the bragging rights mentioned above straight away. Instead of taking him up on his unpleasant offer, I started to lurch through a series of upsets, challenges, hurdles and long term sleep deprivation. It was hard but I came to understand it, develop ways of coping and more often than not, to predict the next crisis.

However, I didn't predict the good stuff. I was braced ready for emergencies, and found that when good things happened they often took me by surprise. On a practical level, I eventually learned how to work with social workers, nurses, consultants, therapists, support workers, education specialists etc. I accepted having strangers in my house asking questions about my family, invading my privacy and making a normal way of life a thing of the past. Life didn't change, I did.

My new attitude helped me to deal with the hurt of insensitive remarks or thoughtless letters or emails. I got to know some amazing carers and found Carers Outreach to be a sanctuary in a mad world. I appreciated genuine efforts by individuals and saw how much happiness my daughter was able to bring to so many people. I didn't tolerate professionals who couldn't put my daughter at the centre of any process, ignoring her and talking to me over her head. I have told more than one consultant that I didn't want them working with her any more and found a different one.

Most of all, I didn't know just how much my daughter would bring to my life. What she has generously given me on a daily basis cannot be measured in monetary terms. I delight in her loud and happy announcement when she goes to the local (quiet) library of 'Here I am', throwing her arms out wide and charming the library staff. I am

impressed by her kindness, giving away her last sweet. I remember with amazement that when she only had three words, one of them was please. When I am down, I see her face and get up again. I may not have had that telegram from the Queen but I've had much more.

~ Delyth Lloyd Williams