

..... there is something I have to tell you, I am having to give you my one months notice". Words that a person who receives care can dread. I have had these words said to me, by carers, over the 5 years that I have employed my own staff, some effected me emotionally, some not. But this month three of my care team have said these words; not because they don't like the job here with me because they do, but their lives have moved on and so must they. A sad fact that I must accept but as this article will show, easy to say but hard to do. So who are the three I am talking about? All three of them are, were, part of my care team for a very long time, J 1 year, MH 5 years and MF who is only reducing her nights from 2 nights to 1, 15 years. Over the 25 years I have received care, mainly through social services and care companies, the leaving/changing of staff has never been an issue, why? Because you very rarely saw the same carer more than twice in a row, if you were lucky. As I did not like this state of affairs, and because the government brought in Direct Payments giving service users a greater control over their care, five years ago I decided to take the Direct Payment/Personal Budget route and employ my own staff, some 9 in all, - Due to the extent of my disability, I have severe Rheumatoid Arthritis meaning I have great human and wheelchair dependency hence the number of part time staff I employ - while I would never admit it, staff changes did and do effect me but no more than it is right now. While I and my carers always try to keep a professional line between us, that line when someone has been with you a long time, tends to get fudged and try as I do, I still find myself seeing them as a carer cum friend and not just a carer. With this in mind and the fact that two carers are leaving and one reducing her hours I would like to share with you the mental and emotional journey I am now on.

Talking to anyone about ones true emotions on any subject is not always easy, especially to strangers on a Talking Health Matters web site, but I will give it a try; perhaps some of you have had similar experiences.

I was expecting MH who has worked with me for 5 years this month, to say she was giving in her notice because for the past year MH and her hubby have been going through all the hoops, and believe me the authorities leave no stone unturned so there are many, many hoops to jump through, to become foster parents and last week it was confirmed that they had been accepted. I was thrilled for them both and was already emotionally ready for her to leave. Her job along with MF, who is dropping a night, was put in the job section of the local newspaper, and I am, as I write, waiting for returned application forms. A situation I have found myself in a few times since 2006 so why are things different this time, the answer is J and her dog Sally.

J has been with me, as I said just over a year, and does my weekend shift 10 am to 6 pm. I really thought that we would grow old together, but that now will not be happening. J is a great cook, she used to be a chef on the rigs but left to get married and bring up her family. Her other job is working with people with learning difficulties which she loves, and the organisation that she works for has offered her a position which includes her love of cooking that J just will and could not turn down. If all the plans in regards to this position fall into place today, I will be getting her months notice on Saturday. J, along with her dog and mine, often go out at weekends for long walks along our coastline. This I will miss terribly so will Jack and Molly my two Jack Russell's. There are lots of other things I shall miss about J, her very dry sense of humour, nipping to the bottom of my garden for a quick 'tab', her Scottish accent, and most of all J and Sally, who has a unique bark to get your attention and their being themselves.

J told me about her decision and the reasons for it on the Saturday and on the Sunday while I was in church, I found myself fighting back tears as the reality hit me that my friend cum carer was leaving. That fact made me realise that no matter how hard I try not to get close to my care team, in some cases I just fail, as in the case with J. I now have to face the prospect of trying to fill her post, easy to fill the post but hard to find anyone like her and Sally. So why this narrative?

I realised that I may not be alone in feeling as I do when a member of my care team leaves. It also appears no one in authority has ever given it a thought about how some who are dependent on the people who care for them feels when that person leaves. My care team are the most important people in my life; I have no immediate family, and friends not connected with my care you could count on one hand. My care team share with me my good and bad days. They share with me and make it possible for me to live my life as I wish to, whether that is driving my power chair from Lands End to John o'Groats, working as a volunteer with McMillian Cancer Support, feeding me, or even taking me to the loo, someone from my care team is there with me. I slowly build up a trust with them, I hear about their lives and they share mine. I share with them, some more than others, my secrets, fears and joys, then that person is no longer there as in the case of J and a few others. To me this whole situation is like living through bereavement but without the emotional support you need. I am lucky this time as there is one particular carer who is a third year counselling student and whom I can talk to, but I have just learned that due to an accident she is off sick for 6 weeks. I feel a lot of phone calls will be going in her direction as this time I work my way through how I feel.

I have been asked, for this narrative, to log what happens to me over the next few weeks, this I will be doing. At this precise moment I am waiting for a text that will say if or when J is leaving. I should know early evening. Who knows I may be lucky it may not be until the New Year.

It is 5.30, time for Neighbours on Channel 5 and I am waiting for J's text. I am feeling unsettled and every time I get a text I jump because I think it is J... Must be like waiting for any verdict especially when that verdict will have an impact on your life.

At 7 pm my text went off, no it was not J it was someone answering my add in the paper sending me her postal address. Details will be put in the post tomorrow. My waiting goes on.

It's Thursday 3 pm and this morning I received the text from J, I will not reveal the contents but will tell you that it is official, on Saturday J will be formally handing in her notice. I have so many emotions churning around in my mind that half of me wants to cry, the other half is excited that a new era is about to start in my life. New carer staff, new who knows?

Everyone is telling me that everything happens for a reason. How many times have we heard that old cliché? How many times has it proven to be true? When one door closed another opens. We have all heard that one. I think I am getting to old for changes in my life, but saying that, I have three new volunteering projects that I am hoping to get involved in. I have attended training sessions for two of the project and the third I will attend in December. Yet another case of opening a door and seeing what is the other side, but you know what I had started to open these doors before J told me her news. I just want things to stay as they are but I have no control over the situation. I am feeling helpless and if I dare say the D word, Disabled.

My staff are free to leave when ever they want, and do. But with employment law as it stands, I cannot ask someone after one year of working with me, to leave just because we do not get on or I don't like them.

I feel very lonely at the moment. I feel I have lost control of my life. Changes are being made that I don't want to happen. J, I know you will read this narrative and I want you to know that you and Sally will be missed terrible. I know we all say we can keep in touch, stay friends but that will very probably not happen.

Right now I just need a very big hugggggggg. So not going to happen. Maybe my next piece should be on the subject of touch and what it feels like not to have it, unless of course someone is doing my personal care. A different touch to what I am talking about, but I think you know that.

So what next.. Before Saturday, when J returns to work, I will put the add in the carer required column of the job section of the local newspaper for J job, that will go out next Thursday. I will get about 25 replies and information packs will be sent out. If I am lucky 20 will be returned and I will offer them an interview but only about 6 will turn up. 2 will make it to my home and one will be offered the job on a trial of 4 months.

As regards J I know what the next four weeks are going to be like with J. We will both try and carry on as if all things are normal. This Saturday J will come into work. I shall tell her that I am happy for her, we shall talk about her new job and the dogs will chase each other around the house. The kettle will be put on coffee. I will then be taken in the garden if it is not raining, coffee and tabs for J. I have this Saturday a plan, best to get out and about. Why, for me to get away from the reality I am now in. We are going down to the beach, meet up with B, run the dogs, have lunch of fish and chips and talk. I need some talk time with B by myself, but I am not too sure when that will happen on Saturday, if it happens.

As I am been honest with this web site, it is times like these that I just wish it would all stop. That I could just say enough is enough. No more social services, no more fear of my care package been cut. I have this fear at the back of my head all of the time. No more dependency on others to enable me to do things from opening my gate to let me out, to feeding me, and to wiping my bottom. I think you know what I mean.

I know that I am very lucky. I have a nice house, people around me that care for me. I am in very good health, but I am not free. I would give this all up to be able to put a pack on my back, Jack and Molly on their leads, just close my door and go where the wind blows. To be free again from my dependency on people. But that is not going to happen unless there is such a person as a Fairy Good Mother.

7.00 pm Thursday. T has also given her notice. T only did 3 hours per week for me and has now found a full time job. T will be missed very much. This all goes to show me how reliant I am, a reliance I hate, on total strangers to run my life. Total strangers whom I have only meet because of an advert in the newspaper. If I was disabled as I am with a hubby and family around I am sure I would feel a lot different. Love of a fellow human being must help someone in my position to feel wanted and valued as a human being. This is a feeling I am not getting right now.

Monday, I need a hug. I can tell you, I am in an emotional mess with J leaving. This forming a relationship and trust with someone and their dog just to have it broken is a killer. From the short list (the two jobs were advertised) only 2 said they were still interested. The two I would think could take J place have said no. It is like having any relationship broken up; it is like having a friend saying they do not want to play with you anymore. It is a bereavement. I must try harder not too get close to my carers, Keep that professional line. How long can I keep this up time after time?

I know that I will work my way though all the feelings, good and bad, my care team will see to that. I know that tears will be shed when J and Sally leave for the last time, but there is still a lot to do before then. I know that a suitable person will take their place in my care team, but that will take time.

Final update, 3 weeks later (Christmas approaching), J has now left the building. We are to stay in contact, just hope that is so. We said no goodbyes, no tears, but I was fighting back the tears all day. The final lift in the hoist, the final coffee, meal, that sort of thing. I shall miss J and her dog immensely but have the New Year to look forward in a few days. I have signed on 2 new staff, and there are a number of new projects for me to be involved with but these are all material things, it is the relationship that we have with people that is the most important thing, well I think so.

All good narratives should finish on a positive note and this one is no exception. So to finish this narrative, I would just like to raise my glass to the New Year and bring on all that it holds no matter what it is. Main thing is to stay positive, stay focus and enjoy the moment. This I fully intend to do.