

Examples of stories shared with MtM

Stress management

"I attended a stress management course for carers a little while ago - I didn't think I was stressed and didn't think there was any point going but went along anyway. It was amazing. I realised how stressed I was and that the only reason I hadn't noticed was because of how busy I was caring for my mum. I'm so glad it was recommended to me - I've now qualified to deliver the course myself."

Life-line

"I attend a group for people with the same health condition as me - it's a lifeline. The group gives me emotional support as well as providing me with invaluable information... Finding the group and getting involved has dramatically improved how I feel about myself and how I feel about living with a chronic condition."

A piece of my life

"My support worker is very important to me because she takes me to self-advocacy group meetings and picks me up. She also takes me to other social meetings which gives my mum and dad a break as they are retired now. If it wasn't for her support it would be too much for my mum and dad to do."

Family support worker

"...The service provided Dad with some support and harm reduction approaches to help his health, and vitally they assigned me a family support worker, who I think probably saved my life. Having someone who was an ally, who I could talk to and feel was there for me, was invaluable."

Frustrated with social care

"...Asked about a stair lift - told I was on a list, had to shuffle up and down the stairs on my bottom. Went out to buy one myself in the end. Cannot get into the bath and contacted [a third sector organisation] for support to get handrail, etc. Carers coming in but only able to have a wash not a shower. Waiting for a hip replacement - had 2 knee replacements. Husband and daughter both need caring for - I need to get support for my own needs as well as making sure they have what they need. I'm disappointed that I'm finding it so hard to get a response from social care."

Guilt

"I hate phoning up for anything - now that I have to ring a central number I don't know who's going to answer or what they're going to ask me. They often ask quite intrusive questions and the whole process makes me feel guilty for even getting in touch."

Good social worker

"My older daughter got a new social worker and he's really good - both my daughter's needs and mine are now being looked at much better. He takes a properly collaborative approach to supporting us - he discusses when and where is best for us to meet, and supported me to complete my own carers' assessment, ensuring my needs were fully identified."

Large print prescription

"My pharmacy provide my prescriptions and the all the dosage info to me in large print - they do this every time without me needing to ask. It's very helpful."

Nice things

"I live with my mum and dad. I have a PA (personal assistant) and go out with him twice a week. We go to wherever I'd like. My favourite place is [on the coast] I like the breeze by the sea. And there is a cafe in nearby where I like to have hot chocolate. Sometimes I go out for dinner with my PA. When I'm at home I like to listen to music and watch football."

Good family placement

"I go to a family for adult placement to provide my granny with some respite. I go to the same family each time and we have gradually built up how much time I spend with them. I went for tea a few times, then had an overnight stay and a weekend stay. Throughout the process it was made clear to me that if I wasn't happy that was fine and the placement could be stop or adjusted. The matching seemed to work very well and I like the family a lot."

Ever-changing carers

"I have carers come to my home every day. I have no idea who they will be - sometimes I have the same person a few times in a row but not always. And although they have set times to come, they don't stick to them. I feel very unsettled all of the time."

Always changing

"Social workers and social care staff change regularly – five social workers in two and a half years, for example. This leads to breakdowns in communication, poor handovers, disappearing paperwork and, more significantly, disruption and instability for us and our children. Building relationships takes time and my children don't want to meet new workers, increasingly now that's because they say there's no point, the worker will have moved on soon anyway."

In the know

"My son has mental health problems and care for him when needed. Supporting someone who is suicidal is really difficult and distressing. I knew who to get in touch with for help because I work in the sector and I know people. If that weren't the case then I don't know what I would have done. The services I contacted were a lifeline and I'm grateful they were there and I knew about them."

Carers' strategy group

"I am part of carers' strategy group which is tackling some of these issues and has produced an information book with lots of contact details and info about services people can access locally. And I'm involved in various pieces of work and activities that enable me, and others, to share our experiences with those that work in the sector and those that are new to being carers..."

People who listen

"Having people (services) on the end of the phone that I can ring for advice, information and support has been so important. I am so grateful to them for everything they do for me, and for helping me and my husband. Being listened to and being able to speak is a lifeline..."

Different pads

"When she became incontinent, for example, I didn't know that there were different kinds of pads, and I didn't know how to put them on properly. I wasn't told about this, or shown what to do, I was just expected to get on with it, and you do. Because we had the wrong sort of pad though, we had to change them five times a day and they often leaked so I was needing to wash my wife throughout the day, make sure she was clean and launder her clothing repeatedly."