

Stories from Carers

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 and I've now qualified to deliver the course"

Amazing financial advisor

"At the outset of the care needs assessment process as a carer with power of attorney for both my parents, I was able to arrange a financial assessment with the local authority. I have had the need to be reassessed 3 more times as my parents' circumstances have changed. Each time I have seen the same financial officer, and each time been treated with kindness, dignity and respect. Each occasion the advisor has left me with a list of things to do - benefits to apply for, for my parents who both have dementia...without the financial support [facilitated by the advisor] the quality of life for my father, mother, husband and myself would have been dramatically affected...without those additional funds we may not have coped."

Being a carer is hard

"I am a carer and had a carers' assessment for my husband who has dementia. My daughter and son in law arranged it and whilst I was fearful at first, it turned out to be a really positive experience and provided a great deal of assistance that I would not have otherwise accessed."

Poor support for carers

"I had a carers' assessment - I look after my parents both of whom have dementia. All I was offered was a massage which when I tried to change the date of I lost. And training I had requested and booked as a carer was cancelled through lack of interest."

Carers' assessment

"Since their introduction I have made enquiries about a carers' assessment. I've been told that if I had a carers' assessment it would only be in relation to my caring for 2 of my 6 children, which makes no sense to me. On top of that, it feels to me that it's being approached as a safeguarding or child protection issue and the language associated with it is quite distressing."

I should do more

"I asked for help from the social services team and was told that I needed to do more, that that 'is my job as a parent'. I have had no training on how to support children with autism, or how to provide the level of parenting this team seem to think I should be providing. I am told again and again by social care professionals that I should be doing more, trying harder, that I should know more, be better somehow. It feels really unfair but coming from people that I am inclined to believe because of their roles it starts to take its toll."

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."

Good team support

"I get regular visits from [local organisation] to help support with my wife. I pay for some extra hours on top which I'm very happy to do. The District Nurse visits regularly to look for pressure points and sores. [Organisation] have been very good - well set up with slings and hoists. Their team system works well e.g. contact helped with finance information, good advice given. OT visit was good - they change slings that were worn, provided a ramp and a commode. I'm really pleased I can still look after my wife at home even though she has high care needs."

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..."

Excellent support

"Respite was arranged for my husband when I went into hospital and for when I came out as my operation meant I wouldn't have been able to take care of him. good bond with social worker and got the respite sorted which worked well - concern that if this needed to happen again the social worker could have been a different one and that relationship is so important. Respite was good and put in place in good time."

Respite

"Both my husband and I would benefit from respite and when I have asked about this I've been told that when my children are at their activities, youth club, for example, that is my respite time. I have several children who attend a variety of activities at different times and all requiring me to drive them to/from them and that drive may be too far from my home for me to just drop them off. There is no opportunity for respite..."

No respite options

"There are no respite services for people with learning disabilities, the only option is adult family placement. Staying in a group environment, like a respite home, gives my son a peer group, people to socialise with, do activities with and gives me confidence that his routine, safety and well-being will be well taken care of. My son has had successful family placements previously but changes within the family meant they could no longer host anyone; finding a new family and building a relationship with them takes time and there is the constant knowledge and worry that something may happen to affect the placement. It doesn't offer a sustainable, long-term option for us as a family."

Beauty and the Beast

"My son is 2 months away from transitioning from children's to adult services. He has good and appropriate support up to now, although it was a struggle to get that sorted initially. We are now facing a cliff-edge with provision as there is nothing in place for when he's deemed an adult. I was warned 6 years ago by other parent-carers that this would happen so I've been looking for solutions, services, and establishing what the law says. We're now really close to D-day, when all children's services will stop and nothing new is scheduled to start/take over. My son currently has 6 or 8 people support him every day, providing a range of services and in two months there'll be nothing. I've run parent-carer groups, I'm involved in lots of networks and am very active with local groups giving 70 hours a week volunteering to them. In 2 months, this will all have to stop."