

Appendix 2

Some carers' comments from SACE 22/22, arranged by theme

Communication

"Felt like there was a lack of communication as we were often left in the dark as to what was happening. Also, every time someone left we had to start over from beginning. This seemed to be a waste of time and resources".

"Finding a care agency and negotiating a set price, a time-consuming and stressful process"

"There was definitely a lack of communication between all parties (hospital/care home/social care/family) particularly during this time. Thankfully we are all well and the person I care for came home safely, unlike a lot of others but it was an extremely worrying time, and it will take a long time for those scars to heal"

"Our s/worker was incredibly helpful. All my support came from my s/worker. Who worked so hard and communicated so well and supported us brilliantly. Our previous social workers were brilliant too"

"Difficult to know which teams to contact in S/S. Website needs to be clearer / updated. I found out about 'Move into adult team' by word of mouth. Oxfordshire Family Support Network have facilitated online information sessions which have been useful"

"I was told the Carers' Break Service no longer exists"

"The areas of activity and responsibilities of the many, many sources are just a fog. Practitioners in some of these have told me they don't understand the system either. What chances have I? A simple - if possible - multi-source list."

"Lack of communication between all parties (hospital/care home/social care/family) during the COVID lockdowns"

"We have had to 'drive' all communications. When you have a self-directed support budget, you are just 'left to get on with it' which is fine until things go wrong - then a support network is needed"

Timeliness

"Passed from one organisation to others and 3 hrs queuing on phones. Given advice with wrong problems, not got enough time to listen and understand me."

"Getting/making GP appointments was near impossible to get, long waiting time when making initial calls"

"There has been no follow-up visit from OT to help change bed height / measure for a suitable chair for his disability"

"The time that it took for a social worker to be allocated, for assessment to take place and for a Direct Payment to be put in place took 7 months"

Quality of Life

"There are massive problems in the care services. One box does not fit all. S/S give no help whatsoever to anyone needing help if they live with family. I feel alone, neglected, unworthy and unappreciated by any services. It's pointless even writing anything here because no one will read it or care. But the unpaid family carers are the unsung heroes! It's such a shame there is no recognition for them as they save the government £1000s upon £1000s every single year!"

"We do have a private carer who comes in the mornings but in the last few weeks they are also coming in the evening to help my husband to bed. This is helping me enormously

"Since looking after my husband my whole life has changed. There are days when I feel I can't cope"

"Do regular benefit and health checks to make sure the carers don't have to become cared-for"

"I have no control over my daily life - I have 2 adult sons with Autism and my husband has Parkinson's"

"I have to care for my grandchildren (usually 5 of them as well as Dad) This is something I want to do but leaves little quality time"

"This survey has made me realise the strain we are feeling and I have taken advice to reach out to the Alzheimer's society and Contacted OCC to see if her support plan can be renewed. I have also got a phone call with her GP next week which has made me feel less helpless and more in control. This survey has galvanised me into action. Thank you!"

"Taking my mum to appointments has encroached on my work time"

"The stress, strain and depression and worry from all this made me just cancel care even though my husband was newly out of hospital and incontinent. I've never felt worse"

Quality of Care

"My mother has complex needs and although we have had a live in carer, over the last 12 months, these have constantly change as carers are not used to dealing with the level of care mum needs. That either means I am constantly re-training people,

having to be on hand or concerned whether they are caring for mum in the way she needs. It is also stressful having different people in your home with you. I am grateful for the support, but it is not without its challenges for mum or I”

“2nd carer left so 8 days a month they cannot cover. They just have no one else. They had a month while the other carer worked his notice out. Did they bother to train or advertise for someone - no. that's why we're in this mess.”

“Following a week in hospital he received excellent care in an NHS Hub bed in a care home. The physio kept me fully informed and visited our home before my husband was released from the care home”

“I just think that the medical profession does not give old people any backup or support. Impossible to get a GP to visit or contact”

“My husband went to a care home from respite care and the worse decision ever made. He came out with COVID – 8 weeks of hell. I was mentally and physically exhausted, not a good experience”

Finances

“Because of my age (83) and arthritis, I find it hard to shower my husband and care prices are very high. It seems I don't qualify for a carer's allowance (I have had 1 payment of 300, but that's a one off)”

“I'm a full-time carer for my wife for 39 hrs. I get only £67.60 pw. That's all I have to live on”

“My husband is now in a care home. because of COVID-19, I had 1 hour pw for fresh air or a very quick shop. Also after caring for so long was told that I wasn't entitled to carer's allowance. The payments for carer's was not explained to us. We received, out of the blue, 4 invoices. it took every penny we had in the bank to pay them”

“I received a Social Services carers grant of £300 last winter and appreciate this, as it helped me to have a much-needed holiday in a hotel with my husband.”

“In many ways were fortunate we have insurances and so financially we have been able to convert our property and undertake works required. I do feel it's slightly insulting, I don't qualify for carer's allowance just because I go to work one morning a week (frankly, for my mental health and retain independence). I cannot earn enough money per hour to cover the cost of extra care (D has to have 2 carers at a time). As it is we are paying just under £1,000.00 pm privately for carers Mon-Fri, 1 hr in the mornings”

“We struggle financially day-to-day as we have a one wage family”

“I cannot earn enough money per hour to cover the cost of extra care”

“I shall be retiring so financial circumstances will change for the worse. We will have to review the amount of private care provision we can afford”

"I also live with mum meaning I would be without a home once mum sadly passes. I have made the decision to give up a good / well paid job in order to care for mum full-time myself. This is going to be a difficult financial period for me but feel there is little option"

"24/7 without ANY BREAK! I am 77 yrs. old caring for an 80yr old with Dementia and multiple health problems. I will continue to care for him because of the cost of any help"