

CARERS STORY RE: MEMORY SERVICE AUG 23

My name is Ros and I care for my husband who has dementia.

My husband is on Rivastigmine patches, and I was not sure they were having any good effects. (Rivastigmine transdermal patches are used to treat dementia in people with Alzheimer's disease)

I asked the Admiral nurse for help, and they contacted M at the Memory service, who said my husband had been discharged from the Memory Service and that I should contact our GP.

The GP's response was 'We don't deal with medication for Dementia sufferers, go back to the memory service'.

At present I am working through this process!! and have yet to see what will transpire.

I would say that we are very grateful for all the help we receive but mystified as to why my husband is "off" the memory service books.

The change I have seen is:

Carers IW contacted Memory Service on our behalf, and they have arranged an appointment to review the medication, I feel supported, thank you.

It would be great if GP surgeries could offer the support we need when we need it or keep us to the Memory Service.

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My name is Gretl and I care for my husband who has dementia.

In September 2022 FP, the Memory Service made a visit to our home for Post Diagnostic Support. FP sent a report of the session, via letter on 22nd September. I responded to the letter correcting some errors, knowing that a copy had gone to my husband's doctor, and unless corrected was giving a false impression - but never had a reply from FP.
(I can show you the correspondence if you wish to see it)

When I next saw FP at the memory club on the 10th January 2023 and asked her if she had received my letter in response to her report that wasn't factually correct. She told me she had. I asked her why I didn't have a reply and she told me 'She wasn't allowed to write back to me'. The CST was a group of elderly men and two women. We felt for the three sessions we went on, that the quizzes were geared at the wrong age group. The organisers hummed various tunes for the group to guess what the tune was, but the combination of hum and tune was not successful. Both my husband and I agreed that the sessions were patronizing, and he felt niggled to be part of it.

We thought it was a very expensive way for the NHS to be providing two hours of babysitting for people who were not babies. As well as the heating on full blast with sometimes the door wide open. On the third visit on 24th January, I told the Organiser that we felt it wasn't for him, and she insisted 'that John was getting a lot out of it' but my observation was that he was irritated by the frustration of a missed opportunity.

The change I would like to see is:

I would like correct information to be sent to us and the GP. We would like good quality sessions for the CST.

CARERS STORY RE: MEMORY SERVICE AUG 23

My name is Ann and I care for my husband who has early onset dementia

I've not had too much involvement over the last 12 months, but the support I've had has been positive.

Dementia Outreach Team signed us off at the end of August 2022 but it provided a point of contact sitting in the background in case of a crisis situation. We have received visits from the team on a few occasions and support was absolutely vital when I needed a quick response.

I've attended a few meetings of The Circle Group for people who had come to the attention of the DOT but once again it's finding somebody to look after my husband whilst I attend that is a problem.

We received support from JS and TS which was helpful and useful and provided a link back to the services for a meds review which was needed by Memory Services level.

Times of out of hours telephone support from Carers IW thank you for that is really useful.

CARERS STORY RE: MEMORY SERVICE AUG 23

My name is Issy and I care for my husband who has dementia

Personally, I have been disappointed with the limited service I have received regarding my husband.

The first consultation last September by an agency nurse was somewhat upsetting and not handled with the professionalism I expected.

Initially my husband was offered an 11-week cognitive course and I understood he was put on the waiting list. After a few months I enquired when the next course would start, I was informed the course was full and he would have to wait for the next course.

Eventually I was informed he would not be suitable for the course. We were informed he was Cluster 19!!!! We have no idea what that is!!!!

The only support and advice I have received thus far is from Carer's Isle of Wight who have been absolutely amazing.

The change I would like to see is:

As a carer I can only live in hope that the Isle of Wight memory service can be vastly improved to meet the needs of our Island aging population.

Please send letters that show empathy and state what things mean not just medical speak. Send the gobbled gook to the GP not me!

Please do not promise then to withdraw your offer.

CARERS STORY RE: MEMORY SERVICE AUG 23

My name is Ann and I care for my husband who has dementia

We paid privately for a Memory assessment as there was a year waiting list, I could not wait over 12 months to start this journey with the medical professionals as our journey started some years ago.

We had 3 nice visits from M which helped my husband to be accepted onto the Cognitive Stimulation Therapy Tuesday afternoon sessions from January through to April. He also arranged for a handrail to be installed in our shower.

My husband has not deteriorated a great deal as yet, but he needs a little more help from me for day-to-day care.

We also have a carer who visits him too, that we arranged ourselves after talking to Carers IW.

Carers IW training has been a lifesaver.

The change I would like to see is:

More contact or visits from the Memory Service would be good, if possible.

I hope that they do not close us after the CST sessions.

CARERS STORY RE: MEMORY SERVICE AUG 23

My name is Ann and I care for my husband who has cognitive issues and has suffered from mental health issues and OCD for many years.

We were referred to the Memory Service as my husband's memory appeared to be worse. The workers we saw were disrespectful to his anxieties and OCD and would zoom up to him on their wheeled chairs. He received a scribbled change of medication with instructions to stop his lithium and to start a new drug. I asked for them to write down a menu of dates of starting and reducing his three different drugs as I am in my 70s and struggle to remember it. We did not understand the scribbled notes on a piece of scrap paper and asked that we could have it typed up and sent to us as I was very aware of the dangers of getting his medication wrong. Everyone stated we don't do that why don't you ask..... (Memory Service/GP/Pharmacy) we went round in circles.

Carers IW arranged for a meeting with Memory Service, and I was able to explain my concerns about the behaviours of staff and the lack of written instructions of reducing and increasing the different medications. I felt a great weight of responsibility and worry about how my husband's health could suffer if I had misunderstood. Initially I felt listened to, it lifted me, and I was expecting to receive written communication through the post – I didn't understand it!

The change I would like to see is:

Everyone in a professional capacity to stop passing the buck!

Understand and show us respect, we are the experts in our cared for. When there is a change in medication then have it typed up in a clear and easy way to understand and send a copy to the carer and the GP.

Do what you say you are going to do and if you get it wrong –
– admit – apologise - review - implement change – stop sending carers round the block please!