Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Gwella mynediad at gymorth i ofalwyr di-dâl

This response was submitted to the Health and Social Care Committee consultation on Improving access to support for unpaid carers.

UC: Ymateb gan: Unigolyn | Response from: An individual

"(Respondent has asked that their contact details are not published. Identifying details including names, dates and locations have therefore been redacted from the published version of this response)"

Life as an Unpaid Carer

I have been asked to write about life as an unpaid carer. I was expecting some guidance about what is required and was looking for some sort of questionnaire with relevant questions. I shall just let you know something about myself and what has happened to me as a carer.

My husband and I are both 80 years old and have been married for 57 years, We have two sons and five grandchildren. After my husband's very successful RAF career, during which we moved homes 22 times, we returned to live in Wales in 1995. He was always very fit until diagnosed with Parkinson's in 2011, followed, a few years later, with the diagnosis of Parkinson's Dementia.

I had no previous personal experience of caring for a sick relative. It becomes a gradual learning curve as the illness progresses. We have had excellent help from my husband's Parkinson's nurse, [redacted], and his neurologist, [redacted], as well as excellent help from people like the Newport Community Connectors. As expected, the illness has deteriorated making his balance and movement worse. He has fallen many times. The dementia, particularly, has affected us both very much. My husband is troubled by confusion, delusions and hallucinations, and is often depressed. He is unaware that what he thinks is happening, or where he is living, is totally untrue. Living with that situation every day is particularly draining for me, especially as his delusions often change through the day – for instance, living on a cruise ship in the afternoon whereas when he started the day he was joining a military parade in London!

I have had some very good help and advice from various people and organisations and have also found out things as I go along. I am quite capable of looking things up to find out where to go and who to speak to. However, I have frequently been asked who is the designated Social Worker for my husband. It is only now, from a conversation about joining a day centre, for which he needed to be referred by his SW, that he has a designated person who will be seeing him next week for the first time. I am not making a complaint about anyone for this, but it does seem that the 'system' may not be foolproof. It will be so good to have a 'Go To' person when a care plan etc. has been carried out.

However, looking back on my personal path of being an Unpaid Carer, it would have been good if my situation was foreseen - after all, these illnesses are not going to improve unless there is a miracle cure!. What I

am thinking is, in an ideal world, it would have been good if I had been assessed, at an early stage, for my own ability to be a carer, our home facilities, help required etc. etc.. The fact that I am not a young woman should be a ‘flag up’ for me probably requiring help in the future? As it happens, I am fit for my age, but that is by no means usual for an 80-year-old!

My experience has often felt like being in a maze and not finding the way out easily. Having a Social Worker earlier would have helped a great deal in navigating what is available to both of us.

I often feel depressed and almost in despair about the task in front and ahead of me. I am often in tears watching him change from a very dynamic and funny man (known for his very quick wit – which still emerges amongst his confusion) into a very confused and distressed person. He reached high rank in the RAF and was involved in a great deal of important administration, and ground defence of some airfields, in his career. I feel so much for him that he is now so confused and cannot do very simple things.

What I need myself is more respite and my husband needs some day care. I currently have been part of the Bridging the Gap scheme which has given me a respite sitter once a fortnight, which has worked well. Otherwise, I am relying on friends and family to help. I really do need a day centre where I can take my dear husband regularly each week, not only to help me but also to give him some stimulation with meeting other people and not being stuck with me all the time!

I am quite sure that a lot of what I have written will be exactly what others in my situation are going through. I hope this is what you want to know about the life of an unpaid carer. It is certainly no fun and I would not wish it on anyone!!

An Unpaid Carer
September 2025