

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.](#)

UC37: Ymateb gan: Susan M Rendell | Response from: Susan M Rendell

I wish to submit my personal experience of being a carer for my husband for consideration by your inquiry, particularly the respite work as follows:



Background

I am 73 years old living in Caernarfon, Gwynedd. My husband first showed signs of ill health in 2008 culminating in a diagnosis of stroke and vascular Parkinsonism at Christmas 2012. I had previously watched the destruction that being a carer inflicted on my mother.

It gave me an idea about what was to come so I prepared. I moved us from a 'heart' house to a 'head' house, spent savings adapting it to future needs, did courses to improve my resilience, kept saving for when it would really be needed and did all the caring alone.

After my husband's burst appendix in 2023 I asked for help when he came home from hospital. After a few teething problems the home care morning and evening has been very good.

However, the work is still relentless. I worked fulltime throughout my life about 37 hours a week with weekends off and about 4 weeks holiday a year. Now I work over 80 hours a week, 7 days a week and 52 weeks a year. I could not plan for the attrition of this on my own wellbeing.

I have tried to get respite. For me that means a week to myself while he is in a care home about every 8 weeks. There is next to nothing available and certainly nothing on a regular planned basis. I don't know how to keep going as the work gets harder as his health declines. I know what I need to keep going - time to recharge mind and body - but it is not available.

Issues

1. *Lack of supply of respite beds, both residential and nursing homes.*

I approached my local authority (LA) last year (2024) but nothing happened apart from a discussion with the social worker. In spring this year, I tried again. We were promised a respite week on 7th April in a LA care home with

follow-up weeks in the summer and autumn. This was later cancelled at short notice due to lack of staff. I was told that the only care homes with a dedicated respite room which can be booked in advance are those run by the LA. We are not eligible for two other local LA homes as we are not in the right doctor's catchment area and the fourth said T's needs were too great. I also rang round or visited all private care homes in this area. I only found one room which was completely unsuitable. Other homes took details to contact me if a room became available, but I have heard nothing

I have since been told that my husband is no longer suitable for an LA care home and that there are no nursing respite beds available in this county or the adjoining one. As T deteriorates and my work gets harder, the chances of getting respite diminish as well.

2. *Poor analysis of need/demand and supply*

Perhaps I am not looking in the right place, perhaps the Senedd statistical service has figures but policy documents do *not* suggest that there is a good understanding of the demand for and supply of respite care beds, both residential and nursing or the distribution across Wales, Are there deserts like Gwynedd elsewhere in the country? There is no disaggregation by types of carer such as young, working, parents, young retired and old retired people. Future trends are not readily available.

3. *'Fine words butter no parsnips'*

Current legislation contains the right for carers to have a Carer's Assessment and for LAs to 'ensure that these needs are met'. In my experience a discussion of my needs has been undertaken fairly readily. I have been given two 2hour sessions per week to leave the house and this has helped as I have carefully guarded it for my own wellbeing - namely swimming.

However, my key priority, regular respite, has not been met. Is that and a line in my husband's care plan that I need regular respite several times a year what is supposed to be a Carers Assessment?

A Right to Respite for unpaid carers of a defined length and flexible enough to meet different needs would be a great idea but unless it was backed with improved supply it would be just lip service.

4. *Short Breaks Scheme*

In a similar vein the Senedd sings its own praises of its Short Breaks Scheme but as far as I have been able to ascertain the scheme helps with locations, activities and grants but does not provide care for the 'cared for' person whilst the carer is having the break.

5. *Fee structure*

I have managed to find two separate weeks of respite from my own research so far.

T has just returned from a week in Llandudno Hospice arranged through a specialist Parkinson's Nurse who I called in the spring. It was free! (We donated)

Had the week in the LA home taken place in April we would have paid £100, the same as we pay each week for 7 and now 11 hours of homecare as our savings are over the LA limits. A bargain!

I managed to get a week in a Dementia Centre at the end of May. It is not ideal as T does not have dementia. Very quickly and just before T went there a Decision Support Tool form was completed by District Nurse, Social Worker with me responding to the questions. I now understand that this was a Continuing Health Care assessment. As I paid the bill of £1481 on picking him up, I received a call saying T had been granted Funded Nursing Care of £224 per week. This goes to the care home, a private business. This is only available if he is in a care home but not the charitable Hospice. It is not available to me, the unpaid, untrained nurse who does it for the other 50 weeks of the year!

This disparity of fee structure seems utterly random, unintelligible and inequitable. We have modest savings and could contribute. Back in the spring I naively thought if the council can't help I will go round the private care homes, choose one that I thought would suit him and book him in for several regular visits in a year. It just doesn't work like that. The rooms are not available, and if there was a room it would be ad hoc, short notice.

6. *Opportunities to draw in more money to the system*

What schemes has the Senedd considered to bring more money into the sector? Private businesses like to 'do their bit' what about a 'sponsor a respite bed' scheme. A fairer, more comprehensive fee structure might help. A requirement for private care homes to maintain a dedicated respite room for every so many permanent residents. A secure scheme akin to timeshare where an annual fee gives a defined number of slots per year. There must be many more ideas.

7. *Preventative approach to health care fails without respite*

The change of emphasis in health planning towards preventing ill health before it happens flies directly in the face of the lack of support for carers.

Three different ministers, Health, Social Care and Wellbeing in charge suggests that there is no joined up thinking.

The move towards more community health and care services just puts more pressure on to those who co-ordinate these 'helicopter' health care people, namely the unpaid carer army.

8. *Negative attitudes to carers by 'government' in all its forms*

There's a number of small tweaks that could show that unpaid carers are actually valued.

The Social Care issue is continually pushed further and further into the future for others to tackle, no-one seems willing to tackle it properly.

The FNC issue above is like a slap in the face

Many times, I get my husband out for vaccinations only to be told that I am not eligible even though I am the one most at risk.

As I had an occupational pension, I thought I would defer my State Pension to allow it to accrue interest but claiming Carers allowance stops that happening.

Carers allowance stops when your State pension age is reached. The work doesn't change, you're just getting older and finding it harder. I worked and contributed to get my pension. It is not a benefit in my eyes.

A while ago it was suggested that as I was carer we might be eligible for a Council tax rebate. The official went through the form with me until we got to the end. Are you married it said - yes- oh you don't count then.