

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](#).

UC01 : Ymateb gan: | Response from: Ceri Higgins

Please find my response below as an unpaid carer of 32 yrs experience.

In 11 yrs I had 11 days off due to illness, due to being refused respite or support to finish my degree I had waited 28 yrs to do due to my 20 plus hour caring role. I cared for my dad with mixed dementia and my mum with organ failure and small vessel disease.

I genuinely believe my role started when I was a teenager. With complex needs and 10 social workers in 7 yrs, the system did its best to prevent me achieving my rights. Human and other. Respite for myself was refused because my mum was a co carer and my dad required 2 at all times. They refused to acknowledge that my mum had care needs and that I was caring for 2.

I coproduced a report with a public body and shared with social services, only to be told 'oh we don't do that'. Nothing but ignorance and failure to prioritise person centred needs.

The sswb act talks of voice and control. Rct local adult services social workers stopped me from having control in my life, due to lack of expertise, knowledge and awareness.

In complaining, a manager turns up and says - 'oh just tell us what you want and we ll see what we can do'. This approach was intimidating.

When my dad and mum were in hospital, social services often considered that respite- because we are not caring. It's the opposite, without me the hospital could not care for my dad and my role was intensified, travelling and maintaining his house etc and mine.

Failure to provide respite altered my family set up and connections. Friends had disappeared and so had certain family members.

When we asked for direct payments and support to go on an adapted holiday, social services said ' it's not an excuse for you to have money'. Appauling treatment bordering on bullying. The social worker got time off due to the stress, I got no respite at all.

When a person is in advanced condition and needs equipment and palliative care, the services ignore you saying, oh you don't want to go there. I was early 30 and offered a care home or put my dad in one.

In the more modern realms of respite and carers support funds and respite schemes, I got a SEWING MACHINE. I didn't have time to shower or eat and the options were the cinema, gardens or hobbycraft.

Good for some but I was a 24 hr a day unpaid carer struggling for oxygen during the day, and the inability to sleep without one eye and ear open.

The recent funds have reached 50,000 people. Great but we know the census altered data and I'm still convinced we have over 600,000 unpaid carers in Wales. Welsh gov discriminated against unpaid carers who couldn't receive the £1000 due to following UK rules. Shame on you Wales.

The issues are in my opinion...

Model if respite are unclear and run by so many different organisations no one knows what's happening.

Long term carers are in poor or impacted health and respite can impact your wellbeing too. It should be a respite wellbeing model approach.

Postcode lottery of old school models.

Funding has been Chaotic.

The focus on holistic respite such as hols etc has hidden the deep crisis in social care and that unpaid carers are taking the brunt.

The sswb act evaluation recommendations upheld have not been mandated strongly enough.

Local authorities are not sufficiently held to account, despite meetings with ministers because the continuation to fail unpaid carers is still happening.

Bodies such as CIW and ombudsman have raised concerns and still we see the same thing happening.

Why? Failure to acknowledge true coproduction and the rights that are not being upheld in law.

I'm happy to share my details, give verbal evidence, anything that will encourage action.

Enough is enough, inside as unpaid carers we are dying, at high risk of infection and to other conditions. This is a legal and health failure.