Cyflwynwyd yr ymateb i ymgynghoriad y <u>Pwyllgor lechyd a Gofal Cymdeithasol</u> ar <u>Gwella mynediad at gymorth i ofalwyr di-dâl</u>

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

UC21 : Ymateb gan: Age Cymru | Response from: Age Cymru





Inquiry - Improving access to support for unpaid carers September 2025

Age Cymru is the leading national charity working to improve the lives of older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We welcome this opportunity to provide information on the experiences of older carers. In our sixth annual survey with 1700 older people across Wales¹ caring has jumped to the fifth highest challenge for older people. In 2024 it was the seventh highest challenge and in 2023 it was sixth. Of those that told us caring was a challenge, more than two thirds (72%) said they were giving more hours of care than a year ago, and only 7% said their hours of care had reduced.

Knowing the varied and wide-ranging issues carers face is vital to designing and providing the right information, advice, and range of support services that are needed to allow older unpaid people to continue their caring role.

Our analysis of older carers' responses in 2025 shows they experience a higher rate of challenges over other older people in areas of their lives including their mental health and wellbeing, employment, income and finances, transport, housing, and bereavement. Finding time for any form of activity to improve their wellbeing can be incredibly challenging.

"I'm still struggling to get my life back together after losing my husband, my mother and sister the same year. Plus, I have a son with severe mental health issues. I'm worried about my severely reduced finances, my capacity to manage my fairly large house and garden on my own. I feel I have too many things to resolve, house repairs, garden restoration, dealing with paperwork, just basically looking after myself, to find the time to join group activities."

Understanding these pressures and how they affect daily lives needs to be considered in carer support and care pathway planning.

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¹ https://www.agecymru.wales/our-work/policy/annual-survey/

Under the Social Services and Wellbeing Act (Wales) 2014, carers have the right to:

- Information, advice and assistance.
- Have their voice heard and have control over decisions about their support.
- A carers' needs assessment, and support for those assessed needs.
- Right to a Personal Wellbeing Plan when there is an assessed need.

From our survey analysis, the indication is that these rights are not always being met. Overall, 6% of older people told us exercising their rights had been a challenge over the last year but this rises to 26% for older carers. We heard from many just how hard it is to get the help they need to continue in their caring role. As one older carer said,

"Too little too late. Had to fight to be heard."

Through our engagement with older people across Wales we hear repeatedly how a lack of resourcing in social care means not only long delays in getting an assessment and the care needed for the cared for, and how little help is forthcoming,

"I have had no support as a carer, and my partner has had no support. She's just left indoors, and I'm not helped."

Providing improved support to older carers helps reduce the pressures they face and allow them to have improved quality of life alongside caring, as is their legal entitlement.

1. The main barriers faced by unpaid carers in accessing the support they need; including any specific challenges for carers based on factors such as age, ethnicity or where they live.

Identification

Despite existing awareness campaigns and continued efforts to increase identification of unpaid carers, identification remains an issue.

The Social Services and Wellbeing Act (Wales) 2014 gives carers the legal right to information, advice and assistance in recognition of how vital this to continue their caring role and lead a healthy life alongside caring.

Carers Trust Wales Track the Act report shows only 39% of carers of all ages were identified within the first year of caring, that 25% took between one and three years to be identified, and 36% took more than three years.² As such, many carers are missing out on earlier information and advice that could help them in their vital caring role and also reduce the earlier need for care and support from public services.

To access their rights under the Act, older carers need to be aware that they have the status of carer. Only three quarters of older people who had approached social

² https://www.carersuk.org/wales/policy-and-research/track-the-act/track-the-act-home-page/

services for help for someone else also identified themselves as an unpaid carer in our 2025 survey.³ Many of these indicated the long time period they had been caring alone. As many older people see their caring role as an intrinsic part of their relationship with the person needing care, it is vital that there is an increased focus on earlier identification.

In our delays in access to social care for older people report in 2024, we heard from one local authority in west Wales who had increased carer identification.⁴ They told us they had made a change to their peer review forum to include unpaid carers. We heard how having those carer voices on that panel helped staff understand the wider pressures on carers and as a result staff were more confident in offering a carers assessment. Whilst acknowledging the limited services they can offer, we heard that having that carer voice involved helps avoid planning that doesn't meet carer needs.

Such good practice should be enacted across Wales to assist with increasing identification rates.

Where to go to for help and quality of information and advice available

The Track the Act report⁵ details the differences in likelihood of seeing information on caring, depending on the relationship with the person needing care. More than half (51%) of carers caring for a child have seen information, while 42% of those caring for partner have seen information. For those who care for a parent, this reduces to 39%. Given these differences, it is important that additional efforts are made to identify those less likely to see information.

Older people are more likely to be digitally excluded, and so less likely to see online information that can help them in their caring role. Only 41% of people over 75 have basic digital skills⁶ and digital access is lower in many rural areas. The Office of the Older People's Commissioner for Wales report in 2024⁷ details the additional barriers older people face in an increasingly digital world. It includes how digital exclusion has an impact on health and wellbeing, increases isolation and forces older people to be more reliant on others.

In our latest annual survey, we heard from many older people who feel left behind in a 'digital by default' society.⁸ For older people that use digital technology we also hear how rapid changes in technology are difficult to keep up with. This means some older people struggle to get the information they need as services become digital by default. As such, it is vital that campaigning and awareness raising includes a focus on those that are digitally excluded to increase identification rates.

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³ https://www.agecymru.wales/our-work/policy/annual-survey/

⁴ https://www.agecymru.wales/get-involved/campaigns/why-are-we-waiting/

⁵ <u>https://www.carersuk.org/wales/policy-and-research/track-the-act/track-the-act-home-page/</u>

⁶ https://www.digitalcommunities.gov.wales/digital-inclusion-in-wales-2/

⁷ https://olderpeople.wales/resource/access-denied-older-peoples-experiences-of-digital-exclusion-in-wales/

⁸ https://www.agecymru.wales/our-work/policy/annual-survey/

In our reports on delays in access to social care for older people in 2022, 2023 and 2024⁹, our engagement showed how many older people were not getting the range of initial information advice needed when they first approached social care services for help. Whilst local authorities all provide an initial information and advice service, how this is delivered varies and this affects the quality of service received.

We heard how some local authorities were making changes to their single point of contact services. Some were moving this in-house as they were concerned arrangements through a general contact line meant opportunities to help people earlier were being missed. Others were changing from a dedicated social care contact service to a centralised local authority version as they needed to cut costs. In such cases, additional efforts were being made to ensure telephone staff were able to ask the right questions of callers to identify them as carers and give them good quality information and advice.

Such changes should be an opportunity to make improvements to getting the right help to older people earlier through holistic information and advice that meets carers' practical needs.

Age Cymru Advice continues to receive a high volume of contacts relating to what help they can get where the caller's contact to social care departments has been unsuccessful across Wales.

Carer finances

Another key area is ensuring carers get access to information and advice on financial entitlements that can help make them more financially stable. Carers are more likely to be living in poverty, and deep poverty levels are increasing. In our latest annual survey the cost of living was a challenge for 46% of all respondents, which increases to 51% for older carers who told us caring is a challenge. 7% of all respondents told us they were getting into debt to pay their bills.

For those living on a pension, they are living on a fixed income without the ability to increase that to meet increases in the costs of living which they could not have planned for. For those living with ill health, this increases daily living costs in areas such as heating, diet, disability aid costs, increased need to use taxis to get to health appointments if they don't drive, and additional laundry costs. Those that have given up work to provide unpaid care at an earlier age are much more likely to live in poverty through lost employment opportunities.

We hear frustrations from older carers who fall between the gaps of financial support during retirement. As one told us,

"As an unpaid carer with my state pension I was not entitled to carers allowance/pension credit. I worked since I was 16 and a half and never

⁹ https://www.agecymru.wales/get-involved/campaigns/why-are-we-waiting/

 $^{^{10}\ \}underline{\text{https://www.carersuk.org/media/bvdg2fvh/poverty-and-financial-hardship-of-unpaid-carers-in-wales}\ \underline{\text{web.pdf}}$

claimed the dole in that time. When I asked for financial help, I was told that my state pension is a benefit so not entitled. I might as well have never worked, as working gave me nothing back."

Our engagement shows instances where carer identification is missing, and how carers who are already under immense pressure from caring don't get the right help when they can no longer cope. One older person who did not identify as a carer told us.

"Asked Social Services for help when friend was discharged from hospital and wasn't managing with personal care and I was exhausted trying to care for myself and friend. Answer to request was given by way of a printed sheet with lists of private care agencies."

In this case, there has been no opportunity to ensure that they have the finances to pay for private care, and no carers assessment has been offered. Under the Social Services and Wellbeing Act (Wales) 2014, fairer charging arrangements are intended as a safety net to ensure that no one pays more for care than is affordable on their income. This safety net isn't there when carers aren't identified and are instead directed towards private arrangements.

Employment

Staying in work when care hours are increasing is difficult. In our annual survey, of the unpaid carers who told us that caring had been a challenge over the last year, 52% were aged 50-64 and 48% were aged 64 and over. From this it seems working aged carers are finding it difficult to juggle work and care,

"Anxiety and depression, caring responsibilities which impact on workable hours availability and cash flow."

It is vital that care assessments can consider the impact on working carers and respond accordingly.

2. The current availability of respite care across Wales, including levels of variation across regions.

The State of Caring report from Carers Wales in 2024 shows 67% of all carers are caring for more than 50 hours a week. In our 2025 annual survey nearly three quarters (72%) of older carers told us their hours of caring had increased over the last year. For those that also needed care themselves, more than half (53%) said the hours of care they give had gone up. This indicates the need for respite is increasing.

¹¹ https://www.carersuk.org/media/eljlpini/carers-wales-state-of-caring-2024-the-impact-of-caring-on-carers-health-and-wellbeing.pdf

The evaluation of the Short Breaks Service shows that only 14% of adult carers had accessed a short break from elsewhere in the last year and 80.5% of carers taking a short break were caring for at least 50 hours a week.¹²

Proving unpaid care makes carers more likely to have reduced physical health,¹³ poorer mental health and finances,¹⁴ and increased levels of isolation and loneliness.¹⁵ Given the hugely negative effect high hours of caring are having on older unpaid carers, it is vital that there is a renewed commitment to resourcing respite care options.

ADSS Cymru's rapid review in 2023 found that respite care is a significant unmet need¹⁶ and our ongoing engagement with older people across Wales demonstrates this has continued. This has a detrimental impact on their health and wellbeing and compromises their ability to continue in their caring role.

Respite care should be designed as a way to support families in maintaining important relationships, maintaining and developing new skills, and should underpin and sustain the overall wellbeing of both individuals and families. The range of respite need is wide, and it is important that respite options are designed with the flexibility in-built to meet the wide and fluctuating needs of carers.

Our engagement shows how difficult it can be to get enough respite hours, that what is offered isn't what has been asked for. Further, respite availability seems to be reducing. One older carer said,

"There has been lots of confusion around respite for my son, meaning that he has no respite at all at the moment."

Another person told us how both their physical and mental health was poor and had deteriorated over the last year as a direct result of a lack of respite care,

"Much of our respite has recently disappeared making everything much harder."

We heard how even in instances where a care assessment had been completed, the offer of support was well below the level of help needed.

"I needed residential respite care for my partner while I had major abdominal surgery due to my cancer diagnosis. My partner had dementia, was doubly incontinent, and could not stand unaided. We had no outside care help at the time. It was suggested that I go to a care home for three weeks, while my partner

¹² https://www.shortbreaksscheme.wales/downloads/evaluation-of-short-breaks-scheme-interim-port.pdf

https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/unpaidcareexpectancyandhealthoutcomesofunpaidcarersengland/april2024

¹⁴ https://carers.org/campaigning-for-change/new-research-finds-unpaid-care-has-huge-impact-on-mental-health-and-affects-low-income-households

¹⁵ https://olderpeople.wales/resource/briefing-tackling-loneliness-and-isolation-in-wales-december-2023/

 $[\]frac{16}{\rm https://www.adss.cymru/en/blog/post/rapid-review-of-how-unpaid-carers-rights-have-been-upheld-during-and-after-the-covid-19-response}$

remained at home with three visits a day. Then I could return home to care for him. I would not be able to lift him for at least 12 weeks. I had to have a screaming meltdown in order to get the help I needed. I am thus never hopeful about apparent offers of help. It also appears that the worse you behave the better you get treated. This was the first time I had asked for help. It was not forthcoming without a fight that I did not need after a shock diagnosis of stage 3 bowel cancer."

Most worrying is that even in a crisis, social care can't always immediately respond. Pressures on social care mean increased reliance on families to provide care in an emergency. The disruption to the lives of distance carers can be immense, and the unpredictability of when a health condition may flare up makes it vital that social care is able to respond in crisis situations immediately.

In our 2024 annual survey, we heard from older carers who have had to give up work, reduce hours worked, or change their working pattern to be able to provide the care their loved one needed. This year in our survey, older carers told us how stressed they are with fears of redundancy, insecure work contracts and how they can juggle these with their caring role. We regularly hear from older people who need urgent care for their loved ones, but it is not immediately available. Not providing that care is damaging the employment prospects of carers and the Welsh economy.

Lived experience example:

A caller to Age Cymru Advice enquired about application of fairer charging for his circumstances. He provides unpaid care to both his mother and mother-in-law at considerable distance and his father had to be admitted to hospital suddenly. He told us his dad has been neglecting his health as he was concentrating so much on his mum's care needs.

His dad had been assured that care would be provided for his wife whilst he was in hospital. However, the area in which his parents lived had significant delays in accessing domiciliary care and no help was available for his mum.

With no help available immediately, our caller had to take two weeks off work, source a telecare wristband, arrange shopping deliveries, provide all care his mum needed, visit his dad and then travel home each evening. He was keen to stress to us that he is happy to help his loved ones, but this one incident has meant a huge increase in his car's mileage (and so has reduced its value) as well of costs of around £1000 for that fortnight.

He told us that money is far less important than his parents' wellbeing, but many other people may not be financially secure enough to provide this help, or have such a sympathetic employer.

Social care departments need to ensure that they have sufficient resources dedicated to those in immediate need.

Living with dementia

Having respite services designed to meet the needs of carers of people living with dementia is vital given the projected demographic increases in people living with dementia. The Older People's Commissioner for Wales 2018 report showed the respite 'offer' and timing of that offer need to be embedded early in dementia care pathway planning. The respite offer was also not in line with 'what matters' care planning. The report evidenced how routes to respite aren't clear to the public, and how the language used around respite care can be a hindrance to getting meaningful options that achieve better outcomes. ¹⁷

Whilst some movement has been made nationally since this report, (such as the Amser scheme that is exploring tailored respite options), much still needs to be done to give carers meaningful breaks from their caring role.

One person told us of their frustrations at getting help via social care for extra help with their partner who was living with dementia.

"I have 26 hours a week under direct payments, the other 142 hours in the week I am alone caring. My nighttime rest is totally destroyed. I'm super tired. How can I recover from a knee replacement when I'm on the go non-stop."

It is important that commissioners and service planners consider the needs of people living with dementia in respite planning.

The evaluation of the former Dementia Action Plan highlighted challenges in implementation and monitoring, limitations in partnership working and how poorly coordinated communication limit positive outcomes.¹⁸ Our engagement with older carers of people living with dementia shows that offers of help are delayed, are limited and often not based on what matters to the carer and the person living with dementia.

At the time of writing, the new Dementia Action Plan to replace its former version has yet to be consulted on. It is important that it includes an increased focus on accountability in service planning to reduce the barriers people living with dementia and their carers face in getting access to the vital care needed.

3. The extent to which the demand for carers support services is being assessed and addressed, and current levels of unmet needs

We detail above the increasing stresses on older carers. It is vital that there is a renewed focus on sustainable, longer-term funding for carer services. Investing in carer services that have carers involved in their design from the outset contributes

¹⁷ https://olderpeople.wales/wp-content/uploads/2022/05/Rethinking-Respite-for-People-Affected-by-Dementia.pdf

¹⁸ https://www.gov.wales/sites/default/files/statistics-and-research/2025-03/evaluation-of-the-dementia-action-plan-2018-to-2022-main-findings-and-recommendations-for-future-strategies.pdf

enormously to meeting Welsh Government's commitment to earlier intervention and preventative services.

In our reports on delays in access to social care, we detail how resource pressures on social care departments that are struggling to meet the most urgent needs of their increasingly unhealthy population post-pandemic. This means carers support can be further down the priority list, despite the long-term impact they know this has on carers own health. ¹⁹ Social care leads are frustrated that they can't do more than they are doing without sustainable longer term funding streams for carer services.

It is clear from our conversations with local authorities that there is an appetite to make improvements, but plans they wish to take forward can stall. We heard how local authorities have dedicated time and resourcing to develop improved care models, including extensive engagement with carers.

Another local authority told us how they no longer tendered for regional funding via the Regional Partnership Board as the resourcing for tendering, service development if successful and resourcing required on reporting was so resource intensive it had been deemed a poor use of time for short term funding pots where good outcomes could not be met. They felt their time was better spent concentrating efforts on ensuring core funding can provide the 'basics' of support.

Without increased and dedicated resourcing for carers needs, service planners desire to produce improved outcomes is diminished and carers needs continue to be unmet.

Pressures on social care increase reliance on telephone assessments. Though this may be the preferred option for some older people, for those with sensory loss this inhibits good communication through that assessment process. Our local partner feedback shows instances where face to face assessments have not been offered for people living with sensory loss and how detrimental this is to good care planning.

It is important that care planning offers include face to face assessments and ongoing communication through the medium of their choice.

4. The role of Regional Partnership Boards in the provision of support for unpaid carers, and the effectiveness of current commissioning practices for services.

The Social Service and Wellbeing (Wales) Act 2014 recognises the key role played by carers, giving them the rights to support which are equivalent to the rights of those they care for.

Section 14 of the Act places a joint requirement on Local Authorities and Health Boards to work together to assess:

• The extent of the care and support needs of the local population;

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¹⁹ https://www.agecymru.wales/get-involved/campaigns/why-are-we-waiting/

- The extent of support needs for carers.
- The extent to which those needs are being met.
- The range & level of services needed to meet the care and support needs identified.
- The range and level of preventative services needed.

Carers needs in most instances require a multi-agency response to meet their holistic needs. As such Regional Partnership Boards (RPBs) have a vital role to play in ensuring services that meet carers need are commissioned and deliver. We have detailed above local authority's frustrations with short term funding tenders for services that should be sustainably funded in the long term. It is vital that RPBs make concerted efforts to improve commissioning processes to ensure that services for carers are there to meet their needs and that tendering processes are not a barrier.

5. The actions required to improve the implementation of the Social Services and Well-being (Wales) Act 2014 provisions for unpaid carers (including Carers Assessments and support plans).

Welsh Government must commit to long term, sustainable funding for carer services.

We have detailed above where implementation of the Act is failing despite the will of local authorities to do better. We have detailed above how many carers are not getting the information and advice they need early enough in their caring journey, how once identified what is offered is often what is needed, or enough; and how pressures mean an increase the breakdown of the carer relationship. Without increased, dedicated resourcing for carer services, this situation will not improve.

Resourcing for carer identification must continue

We have detailed above the low identification rates of carers. An increased focus is needed on earlier identification of carers. Welsh Government provide national resourcing to increase carer identification and the Older Carers Project funded by Welsh Government and delivered by Age Cymru and Carers Trust Wales continues to work to meet this aim.²⁰ With carer identification levels still low, it is vital that work in this area continues.

Importance of improved data collection

We have detailed above some sources of evidence on where carers are being supported. There is no singular data set available that allows an understanding of

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²⁰ https://www.agecymru.wales/our-work/carers/older-carers-project/

levels of need, what is and is not being met, and whether services are producing positive outcomes.

Improved monitoring of carer support provision is vital to ensure the Social Services and Wellbeing (Wales) Act 2014 aim of allowing people to live at home for longer is met so that plans can be made to meet the levels of carers needs.

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