

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#)  
ar [anhydraddoldebau iechyd meddwl](#)

This response was submitted to the [Health and Social Care](#)  
[Committee](#) consultation on [mental health inequalities](#)

MHI 71

Ymateb gan: | Response from: Gofalwyr Cymru | Carers Wales

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**February 2022**

Subject: Mental health inequalities consultation

Dear Health and Social Care Committee,

Thank you for the opportunity to respond to this important consultation.

Before the COVID-19 pandemic, it was estimated that there were at least 487,000<sup>1</sup> unpaid carers in Wales providing care on an unpaid basis to people who need care and support due to age, illness, disability or because of a mental health condition. At the height of the pandemic in the summer of 2020, it was estimated that this number may have risen to as many as 683,000<sup>2</sup>. The care provided by unpaid carers is diverse; from personal care such as washing to making meals, transporting loved ones to doctor's appointments, undertaking medical interventions, giving emotional support as well as organising access to formal care services.

Before the pandemic, it was estimated that unpaid carers saved the NHS and other statutory services in Wales £8.1 billion<sup>3</sup> a year, and Welsh Government data suggests 96%<sup>4</sup> of all care in Wales is delivered by unpaid carers. It was estimated in summer 2020 that unpaid carers saved Wales £33m<sup>5</sup> every year as more people had taken on caring responsibilities and services had been reduced or closed entirely. Unpaid carers are the critical third pillar of the health and care system in Wales.

Carers Wales is the national membership charity for unpaid carers in Wales. As part of Carers UK, we provide a range of information resources for carers, support carers to balance caring with employment and provide carer-focused wellbeing initiatives. We also conduct research into the experiences of carers in Wales and use our findings to respond to policy developments and campaign for better support for carers.

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<sup>1</sup> Carers Week (2020): Carers Week 2020 Research Report

<sup>2</sup> ibid

<sup>3</sup> Welsh Government (2018): Minister confirms £15m investment to support carers and adults with care needs

<sup>4</sup> Social Care Institute for Excellence (2017): Preventative support for adult carers in Wales: rapid review

<sup>5</sup> Carers UK (2020): Unseen and undervalued: The value of unpaid care provided to date during the COVID-19 pandemic

This consultation response has been informed by our existing analysis and research into the experiences of unpaid carers in Wales and has been supplemented by qualitative data from a survey based on this consultation that was completed by 44 carers in Wales from 15 local authority areas during January and February 2022. We have addressed each of the core themes of the consultation in turn.

- Which groups of people are disproportionately affected by poor mental health in Wales? What factors contribute to worse mental health within these groups?

Unpaid carers are under acute mental health pressures as a result of their caring role, and the person or people they care for may themselves be facing significant challenges with their mental health. 740 carers from across Wales completed our State of Caring in Wales survey which was open for responses between August and September 2021. Over 7 in 10 carers (71%)<sup>6</sup> said their mental health had deteriorated over the course of the pandemic, and only 26% of carers described their mental health as ‘good’ or ‘very good’. These findings are the result of a situation where unpaid carers have had to provide more care with less support during the pandemic. The vast majority of carers (80%)<sup>7</sup> have said they are having to provide more care compared to before the pandemic, with 71%<sup>8</sup> saying the health of the person they care for has deteriorated over the same period, requiring additional and often more complex care. Caring, despite its unpaid nature, has become all-consuming for many carers, with 73%<sup>9</sup> reporting in June 2021 that they had been unable to take any breaks at all from their caring role since the start of the pandemic.

Increasing attention is rightly being given to the mental health and wellbeing needs of carers, with a November 2021 research report<sup>10</sup> by Public Health Wales finding that for carers “high-intensity care is negatively associated with mental wellbeing”. Unpaid carers have increased needs for mental health support because of the exhaustion and stress many experience on a daily basis, but it should also be noted that many unpaid carers will be caring for someone who needs support with their own mental health. By both accessing services themselves, and in many cases seeking to arrange access for

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<sup>6</sup> Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

<sup>7</sup> Carers UK (2020): Caring Behind Closed Doors: 6 months on

<sup>8</sup> Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

<sup>9</sup> Carers Week (2021): Breaks or breakdown Carers Week 2021 report

<sup>10</sup> Public Health Wales (2021): Unpaid carers in Wales: The determinants of mental wellbeing

a loved one, unpaid carers are uniquely well-placed to comment on inequalities in accessing mental health support in Wales.

- For the groups identified, what are the barriers to accessing mental health services? How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

For many unpaid carers, their caring responsibilities can become all-encompassing. A carer who responded to our consultation survey described feeling how they are *“Having to do everything and to be available 24/7. Everything is on me, making appointments, doing forms, getting medicines, reminding about appointments, helping with dressing, helping with shower, drying, help with getting dressed. Help keeping the person calm in certain situations (anger issues). Not being able to go to bed at a reasonable time as the person you care for is in pain or ill and you have to sleep on the sofa.”*

Worries about leaving the person they care for alone, exacerbated by difficulties in sourcing replacement care (such as sitting services provided by care workers), results in many carers feeling unable to take even a small amount of time away from caring to access mental health services. One carer said *“help is unreachable as you can't leave the person you care for”*, while another described how *“Social Services repeatedly point out various services I “could” access but don't respond when I tell them I can't because there's nobody to support my Cared For [person]”*. Feelings of guilt can also dissuade a carer from accessing mental health services as they may feel they are neglecting the needs of the person they care for by taking time for themselves, while other carers have said their own needs are sometimes overlooked and not asked about with all the attention from health professionals focused on the person being cared for.

Our State of Caring research<sup>11</sup> reinforced a picture of continuing service reductions, with only 8% of carers saying day services for the person they look after had fully re-opened, and only 20% said NHS funded care was fully operational over the period of August to September 2021, over a year and a half on from the start of the pandemic. As well as increasing stress and exhaustion for carers, and impeding their ability to take time to look after their mental health, insufficient services for carers risks a further deterioration in the condition of the person they look after, including worsening mental health conditions. A carer explained how *“Inadequate packages available to carers or to anyone requiring help”* can lead to waits of *“a couple of months’ time when their*

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<sup>11</sup> Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales

*condition has deteriorated and becomes advanced mental health. In the long run this is worse than if it was dealt with head on when they made a cry for help”.*

Carers have endured increased isolation during the pandemic, even when neither they nor the person they care for were in the shielding category, as carers sought to limit the risk of infection to those they care for and also to themselves due to widespread worries of what would happen to the cared for person if the carer fell ill and was unable to care. One carer explained how they are “*still having to limit what we do/where we go. Life is still in limbo for us*” while another spoke of a “*stark decrease in respite services and socialising opportunities*”. This situation both increases the likelihood of a deterioration in wellbeing for a carer while also placing a barrier in front of accessing mental health services. As carers approach the removal of many COVID measures with unease and worry, services must consider how they can reach out to isolated people and provide the necessary reassurance to help carers engage.

- To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?

The Delivery Plan<sup>12</sup> for the Welsh Government’s Strategy for Unpaid Carers contains welcome mentions of extending access to psychological support for carers as a theme within the third national priority around supporting life alongside caring. It says the Welsh Government will consider the needs of carers within wider policy development and implementation relating to mental health, though we would welcome further detail on how this aspiration will be taken forward. The delivery plan also pledges to “raise practitioner awareness of the local psychological support available”. Improvements in the quality of signposting that professionals across health, social care and local government offer to carers are long overdue. Alongside the strategy’s aspiration to increase access to respite for carers, the delivery plan contains welcome aspirations in areas relating to the mental health of carers but is likely to need greater ambition and strong Welsh Government monitoring to ensure meaningful improvements can be achieved regarding the mental health of carers in Wales.

The Welsh Government’s revised 2019-2022 Mental Health Delivery Plan<sup>13</sup> sets out ambitions to strengthen co-production with carers, with the Welsh Government and the Mental Health Forum creating national guidance on co-production. This is to be

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<sup>12</sup> Welsh Government (2021): Strategy for unpaid carers: delivery plan 2021

<sup>13</sup> Welsh Government (2020): Review of the Together for Mental Health Delivery Plan 2019-2022 in response to Covid 19

welcomed but, unfortunately, we are frequently told by carers who engage with service design processes, such as through Regional Partnership Boards, that they feel their involvement generally has no impact on decisions and that senior managers at local and regional levels do not embrace an ethos and culture of co-production in keeping with the Welsh Government's requirements around co-production.

From summer through to winter 2021, 6 out of 7 health boards in Wales<sup>14</sup> (all except Powys), along with their associated local authorities, announced that they would be asking families and unpaid carers to take on yet more caring tasks due to disruption in the social care workforce, including by caring for people who require a package of care but have been discharged from hospital without one. At a time of well-evidenced stress, exhaustion and declining mental health among carers who have struggled since early 2020 with reduced support, moves by authorities to expect unpaid carers to take on yet more responsibilities undervalues the importance of maintaining the mental and physical health of carers. The Welsh Government must not let this situation continue and should tackle this as a matter of urgency, funding and monitoring service providers to ensure services for carers are reinstated to the greatest extent possible without delay.

- What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

The financial cost of caring is a recurring source of anxiety for unpaid carers. Our State of Caring research<sup>15</sup> found that carers in Wales were having to pay around £1,300 on average out of their own pocket to ensure their loved one received the care they need and, for some carers, this figure will be much higher. Financial stress was raised by carers in our consultation survey, with one saying "*Worrying about money is adding to the stress. I often pay for caring supplies myself*" and another reflected a common sentiment when saying "*Government should provide a living wage for carers*". Though the benefits system is a reserved policy matter, the Welsh Government should take steps to ease the financial burden on carers, for example by making Carers Allowance a qualifying benefit to receive the £200 Winter Fuel Support Scheme payment when it is repeated, and giving unpaid carers a recognition payment similar to those one-off

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<sup>14</sup> Carers Wales (2021): Struggling unpaid carers face bleak Christmas as health boards and local authorities ask them to provide more care

<sup>15</sup> Carers Wales (2021): State of Caring 2021: Wales Briefing A snapshot of unpaid care in Wales



payments given to paid care workers who do many of the tasks undertaken by unpaid carers.

Public Health Wales has stated, “Continued action to support unpaid carers to prevent worsening mental health is needed, including respite care, breaks from caring, and extending access to psychological support”<sup>16</sup>. As mentioned previously in this response, the Welsh Government, local authorities and local health boards must act with urgency to restore services for unpaid carers without delay. Doing so would go a long way to preventing further deterioration in the mental health of carers. The Welsh Government announced £3m of funding for respite opportunities for carers in June 2021<sup>17</sup>, but this amount goes only a small distance towards the level of funding needed to noticeably increase access to respite and short breaks. As mentioned previously in this response, investment is needed in psychological support for carers to increase service capacity alongside existing efforts to improve signposting.

Many carers value opportunities to attend support groups with other carers. Local authorities and health boards should ensure their staff who interact with carers are knowledgeable about local services and support groups so they can signpost carers to them effectively, and the Welsh Government and local authorities need to prioritise such groups for funding. Consideration must also be given to the preference of many carers to attend support groups and other wellbeing services face to face, with some having felt the online nature of recent support made it impersonal and less effective.

GPs and staff in GP practices should ensure that their registration processes and record-keeping guarantees that carers are identified and that their caring responsibilities are recorded. A carer told us how they were “*Not sure my GP even knew I was a carer until last year, after a charity told me to register. Should be a question asked of all patients*”. Sufficient training and resources for GPs to understand the needs of carers would increase the likelihood that the mental and physical health needs of carers will be identified and supported effectively. A carer explained how they felt all health staff should be informed “*about who is a carer so carers don’t have to repeat themselves during various telephone calls*”, while another called for “*training to understand the effects long term caring has on a person’s overall health*”. GPs should further be knowledgeable about local services and support groups for carers to aid signposting. Against a backdrop of feelings of isolation and struggling to find time for their own needs, a further theme raised by carers has been the benefits of regular

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<sup>16</sup> Public Health Wales (2021): Unpaid carers in Wales: The determinants of mental wellbeing

<sup>17</sup> Welsh Government (2021): New £3m respite fund launched to give unpaid carers a well-earned break

check-ins. A carer explained how GPs should check up on unpaid carers more often and arrange for carers to be visited at home because *“they can’t leave their home most of the time and feel lonely and cut off”*.

Yours faithfully,

Jake Smith

Carers Wales Policy Officer

On behalf of Carers Wales