

# COVID19 BRIEFING:

## Impact on Unpaid Carers in Wales

### Purpose of the briefing:

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To summarise evidence collected by Carers Wales on the impact of the COVID19 pandemic on unpaid carers. The briefing combines information from

- Carers UK's Caring Behind Closed Doors report (April 2020) and Caring Behind Closed Doors: Six months on (October 2020)
- Anecdotal evidence and feedback collected from unpaid carers contacting Carers Wales or accessing our support services (March to October 2020)
- Carers Wales' information request to local authorities and local health boards (June 2020)

### Overview:

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2020 has been a challenging year for us all. The Covid-19 pandemic has had a major impact on health and social care and changed how society views and values those working in these professions.

Research showed that since the start of the pandemic, the number of unpaid carers rose from 1 in 6 to more than one fifth of the population in Wales<sup>1</sup>. Their selfless commitment to provide care for someone who is older, seriously ill or has a disability has been vital to ensure the sustainability of our health and social care system. Despite their huge

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<sup>1</sup> <https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report>

contribution however, they have remained largely unrecognised and undervalued by society.

This briefing outlines research completed by Carers UK and Carers Wales since the beginning of the pandemic and provides evidence of the unsustainable pressure and exhaustion carers are facing.

**Urgent action is required to support unpaid carers now.** Carers UK research has found that more than a quarter no longer feel they can cope with their caring role as a result of the pandemic. Many unpaid carers are at breaking point. They have told us that during lockdown they have felt “abandoned”, “set adrift” and expected to “get on with it” with little or no support. This has highlighted the deficiencies in the social care system and the failure of the Social Services and Well-being (Wales Act) 2014 to achieve its vision for carers. This is more alarming given the upswell of 200,000 new carers caring in Wales since Covid-19 emerged<sup>2</sup>.

Carers UK previously found that carers were already seven times more likely to be lonely than the average person, and restrictions and shielding have stripped away carers support networks leaving many feeling isolated. This has led to half of carers feeling lonely and isolated during the pandemic.

With winter coming and the number of Covid19 cases increasing across Wales, there is significant concern that more pressure is going to be put on unpaid carers. Carers are already anxious about the impact of this and what this will mean for them, with 68% being concerned about whether they will be able to cope in further lockdowns. Carers need to be confident now that there are the systems and services are in place to support them to continue to care for our most vulnerable during this next phase of Covid-19 and into the future.

Unpaid care must be given the respect and acknowledgement as the third pillar of our health and social care system alongside health and social care services. This means carers

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<sup>2</sup> Carers Week (2019) ‘Getting carers connected’

being treated as equal partners in care, meaningful financial and structural reform to ensure carers are adequately valued and included in planning for the short, medium and long term.

## Key findings:

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- The number of unpaid carers rose from one in six to over a one fifth of the population in Wales during the pandemic, which is an estimated 683,000 carers. Many of these will be 'hidden' carers, not have identified themselves as such, potentially missing out on information, advice and support. This is likely to continue as we deal with the challenges around Covid-19 combined with the pressures in the winter months. Many who have taken on caring responsibilities during the pandemic have not been able to relinquish them.
- There has been a lack of systematic recognition for unpaid carers and their vital role during lockdown, which has meant that they were not able to routinely access support designed to help those such as key workers during Covid e.g. unpaid carers unable to receive priority access for food shopping.
- The challenge of dealing with the pandemic meant that many carers teams in Local Authorities were redeployed to other areas of activity and many carers found it difficult to speak to anyone about their situation. Their ability to provide information, advice and needs assessment during lockdown was severely impacted.
- The restrictions imposed due to Covid-19 have been particularly challenging for unpaid carers who have seen a reduction or complete closure of services available, at a time when this was more important than ever.
- Local Authorities and Health Boards did develop and introduce new services for carers during lockdown which were targeted at the most vulnerable and most in need, but in many cases this did not happen quickly enough, services were not universal and only reached a minority of carers.

## **Carers UK Caring Behind Closed Doors Reports April and October 2020: Responses from Wales**

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Throughout the Covid19 pandemic Carers Wales, in partnership with Carers UK, have monitored the effect of societal change in this period on unpaid carers in Wales. This has been achieved by running two wide-ranging surveys, collecting anonymised data from information and advice enquiries and our project work and through our support networks and social media.

### Key statistics

- The number of carers in Wales has grown from 370,000 to as many as 683,000<sup>3</sup>
- 4 in 5 (80%) of carers report that they are providing more care now than before the pandemic began<sup>4</sup>
- More than three quarters (76%) say the person they care for needs more support since the pandemic began<sup>5</sup>
- More than three quarters (76%) are reporting to be exhausted and worn out by their caring role during the pandemic<sup>6</sup>
- Two thirds (68%) are worried how they will cope with further lockdowns and restrictions<sup>7</sup>
- More than half (54%) are more stressed than before the pandemic<sup>8</sup>
- More than a quarter (29%) are struggling to make ends meet due to the extra financial pressure of the pandemic<sup>9</sup>

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<sup>3</sup> Carers Week 2020 Research Report The rise in the number of unpaid carers during the coronavirus (COVID-19) outbreak (June 2020)

<sup>4</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>5</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>6</sup> Caring Behind Closed Doors: 6 months on (October 2020)

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

<sup>8</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>9</sup> Caring Behind Closed Doors: 6 months on (October 2020)

## What carers have told us

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During the early stages of the national lockdown, the primary concern for carers was how to protect themselves and their loved ones. The most common questions centred on ‘where can I access Personal Protective Equipment (PPE)?’, ‘how do I use or know if the social care provider is using PPE correctly?’ and ‘Can I go into the home of the person I care for to provide care if I am wearing PPE?’<sup>10</sup>This was encapsulated by one carer who simply stated “I have to keep him safe.”<sup>11</sup> Six months on concerns about better access to PPE is still a high priority for a quarter (25%) of carers<sup>12</sup>.

A general lack of clear communications from UK and Welsh government, local authorities and care providers is another consistent theme spoken about by carers throughout the pandemic. Early on one carer told us “Information is not easy to obtain and is ambiguous”<sup>13</sup> and another “I’m just not sure if I am breaking the law but my mother needs my help”<sup>14</sup>. Other carers spoke about services being pulled without significant communication with one saying “I have no respite from my children's high needs and challenging behaviour”<sup>15</sup>. Our helpline had a large upsurge in calls from carers trying to find out what their rights were to regain services and the reinstatement since has seen many with support plans reduced with one carer saying “My support plan has been reduced by 10 hours. I’m expected to do the rest”<sup>16</sup>. Another simply stated “Two periods of respite care have been cancelled and I don’t know why”<sup>17</sup>

The continued lack of communication has turned to anger for some with comments like “Unpaid carers have been totally forgotten by our governments over last 6 months”<sup>18</sup> and

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<sup>10</sup> Carers Wales enquiry statistics ‘April-May 2020’

<sup>11</sup> Caring Behind Closed Doors (April 2020)

<sup>12</sup> Caring Behind Closed Doors (April 2020)

<sup>13</sup> Caring Behind Closed Doors (April 2020)

<sup>14</sup> Social media May 2020

<sup>15</sup> Caring Behind Closed Doors April 2020)

<sup>16</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>17</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>18</sup> Caring Behind Closed Doors: 6 months on (October 2020)

“The complete lack of recognition in daily bulletins from government to the millions of us who do it 24/7 was shameful”<sup>19</sup>.

There is no doubt that unpaid carers have been critical to enable health and social care services to function in this time of crisis. 80% of carers have stated they are caring longer per week and more than three quarters (76%) acknowledging that the person they care for needs more support at this uncertain time.

This has affected carers whoever they care for. One person who cares for a loved one with autism said “Lack of routine has had the biggest impact on my son. The changes have upset and confused him”<sup>20</sup> while another said “4 broken TV’s and extensive holes in the walls because my son was angry and frustrated about being stuck at home day in and day out”<sup>21</sup>

Those caring for people with dementia have also highlighted the circumstances adversely effecting the loved ones’ health as one carer put it, “My husband’s condition is worsening. I provide all care since he has recently been in hospital and the load has got heavier.”<sup>22</sup> Anxiety amongst those who require care has also been a big impact on carers. One carer stated “My wife becomes anxious if I leave her for more than 5 mins. She can look after herself but she has to told/advised what to do from getting dressed to reminding her where the kitchen is etc”<sup>23</sup> while another said “The two I care for as a result of lock in, now fear the outside. Their health has deteriorated and the level of local authority support has gone.”<sup>24</sup>

More recently, the primary concern for many carers has been the ongoing effect of stress caused by the long periods of caring without any support and the exhaustion this has caused. More than half of carers in Wales (54%)<sup>25</sup> have said that they are more stressed

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<sup>19</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>20</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>21</sup> Caring Behind Closed Doors (April 2020)

<sup>22</sup> Caring Behind Closed Doors (April 2020)

<sup>23</sup> Caring Behind Closed Doors (April 2020)

<sup>24</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>25</sup> Caring Behind Closed Doors: 6 months on (October 2020)

than before the start of the pandemic and more than three quarters (76%)<sup>26</sup> have indicated that they are worn out or exhausted.

This combination of higher levels of tension and tiredness has had a wide-ranging effect on carers. Many carers are worried this is effecting their ability to care with one carer saying “High stress levels impacting sleep. Minor accidents and errors due to tiredness.”<sup>27</sup> Others are feeling the isolation of not being with other people due to tiredness “I was meeting up with friends, this has stopped due to additional strain of Covid”<sup>28</sup>

Others are feeling an emotional impact as emphasised by this carer who said “It’s like Groundhog Day! I’m tired but keep on pushing myself to continue looking after mum who has dementia. I’ve felt particularly isolated because I want to keep mum safe from the virus. I’m tearful at times and get frustrated with mum”<sup>29</sup> Another said “I am exhausted and stressed as a result of having no break whatsoever”<sup>30</sup>

Carers are also feeling the financial strain of caring with 29%<sup>31</sup> struggling to make ends meet and many others have had to reduce to few luxuries they could afford previously. This unilaterally effected carers whether they were in employment or not. Unlike benefits under the umbrella of universal credit, carers who rely on carers allowance did not receive a subsidy during the pandemic period. Many carers on carers allowance were vocal on this point, with one saying “I work full time, 24/7 caring but I don’t get any more help despite the cost of having my partner at home all the time. Why am I different from everyone else who got help [during the pandemic]”<sup>32</sup>

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<sup>26</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>27</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>28</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>29</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>30</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>31</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>32</sup> Social media – August 2020

Another carer said “More time at home, more bills!”<sup>33</sup> which mirrored what many have said, with one carer explaining further “Due to being home and using more of our utilities. Due to having to pay for things to cheer up/entertain/amuse my son. Due to his anxiety, washing things more, as well as the government’s guidelines.”<sup>34</sup>

Those balancing paid employment and caring responsibilities are experiencing different financial pressures. One carer stated “My heating and technology bills have increased dramatically”<sup>35</sup> while another said “I can not access the services I need to continue to work so have had to give it [employment] up”<sup>36</sup> An increasing number of carers are also being put in the difficult position of deciding between paid work and their caring responsibilities. As one carer put it “I need to give up work to care for family but there is no financial support to enable me to do this.”<sup>37</sup>

Another notable theme that has affected carers is the number of women who have become significantly less independent due to the need for increased care. Multiple women have told us “My partner has to support my financial position”<sup>38</sup> and more have gone on to say “I am totally reliant on my husband's income, not financially independent. My son, for whom I care has a greater weekly income than me.”<sup>39</sup>

As we look towards an uncertain winter, many carers are increasingly nervous what this will mean for them and the people they care for. More than two thirds (68%)<sup>40</sup> are worried how they will cope with future restrictions.

Many carers are worried about how they will be able to get essentials as one carer said “I already struggle to get a food order, it will only get worse”<sup>41</sup>. This general concern often

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<sup>33</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>34</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>35</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>36</sup> Social media – August 2020

<sup>37</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>38</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>39</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>40</sup> Caring Behind Closed Doors: 6 months on (October 2020)

<sup>41</sup> Caring Behind Closed Doors: 6 months on (October 2020)



tempers many carers expectation for the future as most carers refuse to engage beyond the near future as one carer commented “I just care each day. Tomorrow is tomorrow”.<sup>42</sup>

## **Information from Local Authorities and Local Health Boards, June 2020**

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As part of our information request to local authorities and local health boards for our Track The Act 5 briefing [citation], we requested information on what they had done in the first three months of the pandemic to support carers. We would like to thank the local authorities for responding at a time when they were under additional pressure.

Whilst we understand that the pandemic has been unprecedented, we believe that in many cases the actions outlined below were not actioned quickly enough. Feedback we received from carers from the start of the pandemic clearly showed that following lockdown many services were withdrawn completely and that for a period of time, carers were expected to cope with little or no support.

We are also concerned that there was a low-level operational response by public authorities, rather than a clear strategic approach to supporting unpaid carers as part of the overall pandemic response. Instead health and social services were prioritized which left many unpaid carers feeling marginalised and set adrift, despite the huge responsibilities placed on them to care for the most vulnerable.

The person-centred approach outlined in the Act was also forgotten, with unpaid carers finding that carers needs assessments couldn't be accessed despite the huge change in caring responsibilities and they were expected to fit in to any surviving support. Carers also contacted us to raise concerns that carers teams had been redeployed to other areas of activity within the council and it had been difficult to speak to anyone about their situation. It is hard to fathom why this was, given the obvious implications of the lockdown on unpaid

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<sup>42</sup> Social Media – September 2020

There was confusion and concern amongst carers initially regarding the availability of PPE which has now been resolved. Even though carers can now access PPE for free from their Local Authority, the vast majority of carers are unaware of this. Going forward, we believe unpaid carers should be given priority access along with other key workers to Covid19 testing and in the vaccination rollout. An information campaign to ensure carers are aware of their rights should accompany this.

### **Communicating with carers during lockdown**

The majority of services provided by local authorities and health boards for carers, and those being cared for had to be cancelled during the lockdown period. Most local authorities stated that where possible, they (or their service delivery organisation) had remodelled delivery to telephone, email, social media and video calls such as skype. It is clear that use of technology increased in delivery of services across Wales. This has included remote delivery of What Matters Conversations and carers assessments. A small number noted that services continued to be provided face to face, particularly where carers were in crisis e.g. Bridgend. Many local authorities worked to improve access to information during the pandemic e.g. the Cardiff and Vale Carers Gateway, Pembrokeshire Community Hub. In Carmarthenshire, an interim position was been established in partnership with care managers and the third sector to support unpaid carers to continue their caring role and to maintain wellbeing. In Newport, 540 Emergency Carer Packs were sent out (via post and email) to all known carers and Newport Carers Forum at the start of the pandemic. Many of the local authorities continued to send out carers newsletters and increased communication via email and social media.

In Betsi Cadwaladr, Practice Managers and Carers Leads have liaised with GP Carer Facilitators via telephone and e-mail and referrals have been received via the phone and directly through NEWCIS' website. They also reassigned funding for planned carer engagement events direct to three third sector carer organisations, AVOW, Carers Outreach and NEWCIS to provide additional support to carers affected by the virus.

To ensure that families and carers had a point of contact not only in the week, but also on the weekend, the Cardiff and the Vale Health Board Patient Experience & Concerns teams

implemented a 7-day service from March 2020. They also launched a volunteer led Chatter Line. Carers could request a call from one of their volunteers as a one off or as a regular call. Volunteers were provided with information on services to support in the community should they identify that the person they are calling has further needs to just a 'chat'.

Swansea Bay noted that all providers funded through the Carers Partnership Board had adapted their services to be able to deliver online and telephone support.

Recognising that this was a critical time to share information, Cwm Taf Morgannwg Carers Champion Network was utilised across GP Practices to disseminate timely and relevant information for Carers as well as informing Carer Champions across the region.

Aneurin Bevan also provided specific support to young carers, including a letter being sent out to support them while shopping during the pandemic and activities have been delivered via Zoom and TikTok.

### **Financial support for carers**

Others have made financial support available via emergency grant schemes in partnership with third sector providers such as Carers Trust South East Wales, CREDU. Related to this some local authorities have switched carers support to Direct Payments to give carers more freedom to manage their own support services.

Some Health Boards joined local authorities by contributing funding to carers emergency grants e.g. Cwm Taf Morgannwg contributed to the Carers Trust South East Wales fund.

We also note that Welsh Government has also recently announced a £1million Carer Support Fund (Ref), which will be distributed by Carers Trust Wales and its network partners.

### **Welfare checks**

The majority of local authorities and/or their service delivery organisation have delivered welfare/ check-in/ companion calls to carers. In Denbighshire, 19 carers affected by COVID 19 have been supported to access to counselling services and the Neath Port Talbot Carers Service secured Voluntary Sector Emergency Funding to provide First Aid Wellbeing phone calls by a trained counsellor. The Pembrokeshire Carers Information and Support Service

(PCISS) expanded its telephone support service, extending its hours and providing weekend support.

### **PPE**

In some areas PPE was made available to unpaid carers e.g. Swansea, Carmarthenshire and Denbighshire noted that they introduced a process for unpaid carers to acquire PPE. In some areas, processes were put in place regionally for carers to access Covid19 testing e.g. Ceredigion.

### **Testing for Covid-19**

The approach to testing changed as the pandemic progressed and a key theme for Hywel Dda University Health Board were concerns from Carers about their entitlement to Covid-19 testing. In response to this, a process was established for Carers to have a discussion with their local carer information service explaining the options available to them including access to a home testing (via web or telephone booking) or as an alternative, travelling to a local testing centre.

### **Support in accessing food & medication**

Some local authorities noted how they had supported carers to access food and medication through the lockdown. Conwy Council received Morgan Foundation funding to provide £5000 worth of food parcels to carers and also received funding to provide tablets and Amazon Echos to families who were socially isolated and support carers to care e.g. medication reminders to the cared for person.

In Flintshire, service provider NEWCIS developed 'Keep busy, keep well' boxes for the most vulnerable carers which were delivered to their door. These boxes included basic fresh food such as vegetables, fruit, salad, bread, eggs and milk. They also provided unpaid carers with resources and activities to keep them well whilst at home and included puzzles, books and games.

In Newport, those who were experiencing food poverty due to financial hardship, were referred to the Newport Hubs for Welsh Government food parcels or food bank boxes. These hubs were operated by Community Regeneration, Investment and Housing and worked

Ynys Mon Council established the Neges Community meals programme, a free of charge meals service.

### Respite

In some areas emergency respite provision has been developed which has been bespoke to the situation and carers/ cared for needs and primarily provided in the person's own home. For example, Blaenau Gwent noted that they had provided wrap around care and support packages to support carers and avoid emergency situations / carer breakdown and in particular avoid admissions to care home or hospital settings.

In Neath Port Talbot, it was ensured that PPE was provided to volunteers so they could resume their "sitting service", to enable carers to get some much-needed respite.

It was noted by Ceredigion that after an initial reluctance there has been a steady take up of respite and care services over the last month.

The Flintshire Carers Strategy Group is looking into the other ways in which respite can be delivered over the coming months for carers, which is compliant with national guidance but gives carers a real break/time off.

In Powys, Credu's Co-Production of Respite Project has taken off where in some cases traditional methods of respite care have been reduced or stopped, people have come up with different ideas that will support their lives at home. These include items that have been purchased such as laptops, garden equipment etc. and will last beyond the pandemic.

We recognise that the information provided above was given in June and since then further action has been delivered to support unpaid carers.

## For more information

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