

A Report on Age Cymru's 2022 Older Carers Survey



Introduction

There are more than 370,000 unpaid carers in Wales, with around 220,000 of those older than 50 years old. This figure is from the 2011 Census and is likely to have increased when factoring in the effects of the COVID-19 pandemic.

The Older Carers in Wales Survey 2022 was created to focus on the general experiences of older carers, asking them to state the number of hours per week they're caring, their opinions on support for older unpaid carers, and what three things would make their life easier.

The survey received 537 responses and respondents range from 50-89 years old. All the local authorities in Wales were represented, with the most responses from Carmarthenshire, and the least from Newport and Blaenau Gwent. Overall, the survey gives us a picture of the current situation for older unpaid carers across Wales.

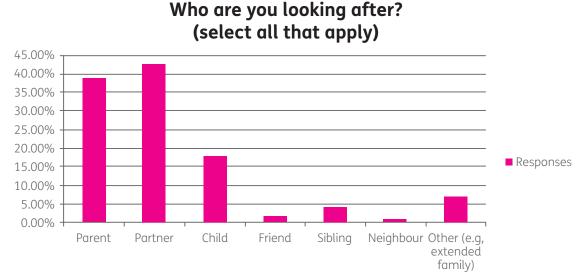
The survey is part of Age Cymru's Older Carers Project which is funded via Welsh Government's Sustainable Social Services Third Sector Grant. We work in partnership with Carers Trust Wales and the project aims to support the early identification of older carers to provide timely and person-centred information and advice, enable older carers to influence policy, service design and delivery and decision making by ensuring their voices are heard, and better meet the needs of older carers, carers of people living with dementia, and carers of people who have now moved to live in a care home. We will continue to work in partnership with the Welsh Government to address the concerns set out in this report.

To find out more about the project and how to contact the team, take a look at our website: agecymru.org.uk/carers.





Who are the respondents?



Most respondents look after their partner or a parent, with 42% and 39% selecting these options; while friend and neighbour were the least popular responses, with as little as 2% and 1% of respondents selecting these options. Furthermore, 13% said they looked after more than one person, with the parent and child, and parent and partner combinations being the most common.

The hours they're doing

We asked respondents how many hours of care they provide weekly. 54% said that they care for over 50 hours a week, and 18% up to 20 hours.

Our results show a link between the number of hours spent caring and respondents' emotional wellbeing. The self-assessed average wellbeing score of those caring for more than 50 hours a week was 36 out of 100. The average wellbeing score decreased as the number of hours of caring per week increased: the average for those caring for up to 20 hours a week was 49/100, which paints a rather bleak picture of the wellbeing of older carers in Wales.

What they do

To get a general idea of what the carers' day-to-day life is like, we asked them about their key caring tasks. Most responded that they do 'everything' or provide '24/7 care'. Other common responses included emotional and physical support, cooking and cleaning, personal care, transport to medical appointments and administrative support.



Support

We asked carers whether they were in receipt of, or had an underlying entitlement to, Carers Allowance. Bearing in mind we were asking carers aged 50 and over, 22% said they currently receive Carers Allowance, with 64% saying that they don't, and 14% stating that they have an underlying entitlement to it (this means they meet the conditions for Carers Allowance but cannot be paid the benefit because it overlaps with another benefit they're receiving). Only 76 individuals said they have an 'underlying entitlement' to Carers Allowance, which perhaps suggests there's a lack of awareness and information for carers who aren't eligible for Carers Allowance, which of course includes older carers in receipt of State Pension.

We wanted to know how accessible support is for carers and how adequate the support that's available is. When asked if they currently receive support for their role, 72% said they don't, with a follow-up question revealing that some carers are either waiting for a Carers Needs Assessment, or unaware of the support that's available and how to access it. Several respondents were under the impression that financial support is the only support that's available.

Furthermore, responses show that the wellbeing score of carers receiving support is higher than those who don't, although the difference isn't great (42% and 39% respectively).

As we received responses from every local authority in Wales, it's possible to see which area has the highest percentage of carers receiving support (41%) and which the lowest (0% was reported by respondents from one authority and 5% in another). An overwhelming 91% of respondents didn't think that older unpaid carers are adequately supported, with many respondents saying they feel forgotten and left to cope with everything by themselves. Here are examples of some of the responses:

"Slipped through the net"

"I am made to feel that it is my duty to care and not complain"

"Carers allowance is inadequate, especially now in this cost-of-living crisis"

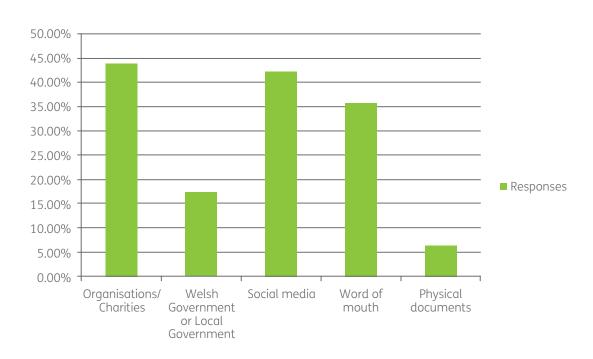
"Digital exclusion is a big issue for older carers"



The situation is inconsistent across local authorities: there were seven areas where nobody said older unpaid carers are adequately supported, while 25%, 14% and 12% of respondents from three other local authorities felt they were.

On the Welsh language version of the survey, we asked carers about their experiences of accessing services in Welsh. These often weren't positive. Many responses included carers saying there aren't any Welsh services available locally, with one carer writing that it's "heart-breaking" and "impossible to get support in Welsh". They went on to say that when their father was in hospital, staff kept insisting he speak English, even though he was in his 90s, blind, living with dementia and unable to feed himself. Responses such as this highlight the need for improved access to services in Welsh across Wales so that people's preferences and needs are accommodated.

How do you receive information and current updates about caring? (Select all that apply)





Information

Access to information is one of the rights for unpaid carers set out in the Social Services and Well-being (Wales) Act 2014. We therefore asked carers whether they thought information for unpaid carers is easily accessible. Only 17% thought that it was. Further, 89% of the oldest respondents group (80-89 years old) said that information isn't easily accessible, compared to 80% of those aged 50-59 years old.

How are unpaid carers receiving information and current updates about caring?

The previous graph shows that organisations/charities and social media are the most popular sources of information and updates about caring. Respondents were also far more likely to receive updates via word of mouth than physical documents (5%), or Welsh Government or Local Government sources (17%).

The highest percentage of respondents saying that information isn't easily accessible for carers were in the 80-89 year old bracket, who were also the group who are most likely to use physical documents as a source for information and updates about caring.15% of those between 80-89 years old reported physical documents as being one of their sources, while 1% of 60-69-year-olds, and 7% of 70-79-year-olds and 50-59-year-olds use physical documents.

Similarly, there's a clear difference between age groups when it comes to those who use social media to get information and updates about caring. The use of social media by 80–89-year-olds, at 11%, is significantly less than reported by those aged 50-59 years old, at 53%.

Carers Needs Assessment

Only 54% of carers are aware they're entitled to a Carers Needs Assessment from their local authority, making it clear that although all carers should be aware of this right many are not.

The level of awareness of the right to a Carers Needs Assessment varies across local authorities, from 50% of carers aware in one area to 32% in another. There's a lack of consistency across local authorities, suggesting there needs to be a focus across Wales to make people aware of this right.





What carers would've liked to have known

One of the other questions we asked was what respondents would've liked to have known when they started caring. They said:

"Clear information on financial/legal situation"

"My rights as a carer"

"How emotionally challenging it can be"

"What to do when something goes wrong"

"Training on how to care, and help with complex needs after diagnosis"

"How to access help from social services"

"Support with paperwork – form filling etc"





Listening to the Voices of Older Carers

One of the starkest findings of the survey was that 85% of older unpaid carers reported that they feel their voice isn't being heard as a carer. 13% of respondents aged 50-59, and 7% of those aged 80-89, believe their voices are being heard as carers. Overall, 18% of those currently receiving support for their role feel that their voice is being heard, and 7% of those who don't currently receive support, alarmingly low figures which shouldn't be ignored.

It was noted that 100% of respondents living in one local authority believe their voice isn't being heard, but at the other end of the spectrum, there are two areas where 63% and 67% believe their voice is being heard. Overall, it's still very clear that across Wales the majority of carers don't feel they're being adequately listened to.

Three things that would make their life easier

Finally, we asked respondents to share three things that would make their lives easier. Much of what they stated relates to the issues highlighted already, such as the lack of support, access to information. But without a doubt, the theme that came up most was respite, as it was mentioned in 162 of the 479 responses to this question. This means that 34% of carers who responded to the survey called for more respite, many saying they "just want a break" and time to themselves. Financial help was the next most common response, mentioned in 27% of the responses.

Other frequent answers included employers to be more understanding of people's caring responsibilities, and for unpaid carers to have easy access to information.

Many of the answers to this question correspond with what respondents stated were their concerns for the future. The instability of the future in relation to finances, particularly as the cost-of-living crisis continues, was one of the most common responses. However, unpaid carers were most concerned about their own health in the future. Not only are they concerned about getting older and their ability to continue caring, but they are also concerned about what will happen to the person/people they care for should they fall ill. With the toll on their mental and physical health increasing, many respondents highlighted the need for respite and the lack of access to it, as they "still have to do things for ourselves."



Welsh Government is funding a range of projects to address the issues set out in this report:

- The Deputy Minister for Social Services has allocated £4.5million to continue the successful Carers Support Fund over three years. Since the fund was set up in 2020, more than 10,000 unpaid carers have accessed a small grant or information and advice from this fund. Nearly a third of carers who benefited from the fund were previously unknown to services. Reopening the fund year will allow more carers to get immediate financial help or ongoing support to manage their caring role. The fund is now open and details on how to apply are on the Carers Trust Wales webpage.
- Welsh Government is investing £9million over three years to set up a new national Short Breaks Scheme for unpaid carers. Carers Trust Wales is the national coordinating body and, in this financial year, is working with Regional Partnership Boards to create new services that support unpaid carers to take a short break that suits their individual needs.
- Welsh Government also continues to provide funding to national third sector organisations, Carers Wales, Carers Trust Wales, the All Wales Forum and Age Cymru, through our Sustainable Social Services Third Sector Grant. This scheme was extended and will now run until 2025. In total, we are allocating £4.4m to four carer specific projects over the five years.
- In 2022-23, £75,000 is being invested in helping unpaid carers of all ages to have their voices heard by Welsh Government. £1million is also being allocated to health boards to support unpaid carers when the person they care for is admitted to or discharged from hospital.
- The funding listed above is in addition to the annual funding settlement for local authorities (the Revenue Support Grant) to meet their statutory duties to support unpaid carers.





Age Cymru and Carers Trust Wales are working in partnership to develop person-centred service models to identify, and better meet the needs of older carers and carers of people living with dementia, funded by the Welsh Government Sustainable Social Services Third Sector Grant



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