



For the Moment

Summary of findings
from older carers

Introduction

Prior to the Covid-19 outbreak, it was estimated that there are more than 370,000 unpaid carers in Wales. More recent estimates by Carers Wales suggest that over 680,000 have been providing unpaid care during the pandemic.

Unpaid carers provide support to relatives, friends or neighbours who have a disability, physical or mental health needs, or who are affected by addiction. Support they give can include cooking and cleaning, administering medication, providing personal and intimate care, or emotional support. These responsibilities can vary greatly, taking less than a couple of hours to more than 50 hours per week.

While unpaid carers can be any age, a growing number of older people are providing care. Wales has the highest proportion of older carers in the UK, each of whom have needs that are specific to their situation, and which are not necessarily being met by current service arrangements. Too many carers and those they care for do not receive help until they are at crisis point, at which point their health, both physical and mental, and their financial situation can become compromised. The intervention required can be more intensive and costly than preventative or early intervention may have been.

To support older carers, Age Cymru and Carers Trust Wales are working in partnership on a national project, funded by the Welsh Government. It aims to: support the early identification of older carers; to provide timely and person-

centred information and advice; to enable older carers to influence policy, service design and delivery, and decision making by ensuring their voices are heard; and to better meet the needs of older carers and carers of people living with dementia.

On Carers Rights Day 2020, we launched a survey for older carers who were not accessing support. More than 300 people have responded either online or by post, sharing their experiences and opinions with us. We also held several follow up sessions with carers who had indicated they would like to remain involved, giving us the opportunity to outline some of the survey findings, get their thoughts on the emerging key themes, and gain greater insight into their own situations

The survey paints a picture of older carers who are just about managing, coping now, but worried about the future.

51% of respondents said they have not tried to access support either because they don't know what's available, are reluctant to seek external help for either themselves or the person they care for, or don't have the time. Many also said that they felt the care they provide was an extension of traditional family support and therefore their responsibility.

For those who said they needed support, respite opportunities and emotional support for themselves and those they care for was their top priority. A majority of respondents wanted easily accessible information to help them in their role, with 73% wanting to receive this information online.

A concerning number of older carers said they were worried about the future of the person for whom they provided care. More than two thirds said they had concerns about their own personal financial situation, but said they were able to cope at present.

This survey provided a snapshot of the contribution, challenges, and needs of older carers and provides a solid foundation to explore how communities, the third sector and public sector can work together to reach and support more older carers before they reach crisis point.

Following the publication of this report, we will engage with older carers, carers organisations and other stakeholders from across the sector to disseminate and discuss findings, and to identify shared opportunities to make a positive difference.



Background

In 2014, the [Social Services and Well-being \(Wales\) Act](#) provided a new framework for social care provision, repealing and consolidating existing carers legislation to address key challenges facing public services, such as changing communities, changing expectations and a changing economic reality. It aimed to promote consistent, high quality services across Wales and empower service users through giving them a stronger voice, choice, and control in the services they receive.

The Act defines an unpaid carer as “a [person who provides or intends to provide care for an adult or disabled child](#)” and removes previous requirements that carers must provide substantial amounts of care on a regular basis.

Underpinned by four core principles ([voice and control](#), [prevention and early intervention](#), [well-being](#), and [co-production](#)), the Act enshrines in law the rights of carers and the duties that public bodies must adhere to, such as the right to information and advice, the right to an assessment of their needs where the local authority believes there to be unmet need, the right to have control over decisions made and support received, and the right to advocacy – so that the carers views, wishes and feelings are fully expressed.

The Act also established the creation of [Regional Partnership Boards \(RPBs\)](#), bringing together local authorities and health boards to provide a more integrated approach to the delivery of health and



social care services. Among their duties, the seven RPBs must produce population needs assessments – including the needs of carers - and corresponding regional plans.

In 2018, the [Health, Social Care and Sport Committee](#) of the Senedd opened an inquiry into the impact of the [Social Services and Well-being Act](#) in relation to carers. The report [Caring for our future](#), published in November 2019, recognised the advancement of carers rights since the Act came into effect but also concerns, including those raised by Age Cymru and Carers Trust Wales, that the needs of carers were not being fully met. Out of the 31 recommendations made by the committee, the majority were accepted by Welsh Government in their response. The committee revisited this in their report, published March 2021 on the impact of the pandemic on unpaid carers, highlighting the additional challenges facing carers as a result of the Covid-19 outbreak and re-emphasising the need to find creative ways of funding and delivering support.

Also in 2018, the Deputy Minister for Health and Social Services announced her intention to develop a new national plan for carers and in late 2020 a draft plan was opened for consultation. The draft plan, the result of engagement with unpaid carers and carers organisations through the Ministerial Advisory Group for Unpaid Carers and its supporting engagement group, outlined four national priorities: [identifying and valuing unpaid carers](#); [providing information, advice and](#)

[assistance](#); [supporting life alongside caring](#); [and supporting unpaid carers in education and the workplace](#); as well as a commitment to create a charter for unpaid carers that will clearly define roles and responsibilities of Welsh Government, local authorities and health boards, third sector organisations and carers themselves.

Following consultation, the [Strategy for Unpaid Carers](#) was published in March 2021 with a delivery plan to follow in the autumn.

Profile of respondents

The survey was live between November 2020 and March 2021, it received more than 300 responses with the majority being submitted online. Covid restrictions meant that face to face engagement couldn't take place, which meant that groups who are digitally excluded are likely to be underrepresented in the results. We believe this may account for the comparatively low number of people aged 70+ who responded.

We asked a series of questions to develop a profile of our respondents, with the key data outlined below.

- 57% were aged between 50-59, with 29% aged 60-69 and 14% aged 70+
- 44% live in the same household, with 56% living elsewhere
- 77% of respondents were female, 23% male
- 91% were looking after someone 50+
- 41% caring for a parent, 25% a spouse, 17% caring for a child, 17% looking after another relative/friend/neighbour
- 47% were providing up to 19 hours support each week, 31% providing between 20-49 hours, 22% providing more than 50 hours per week
- Reasons for providing support were; 59% issues associated with older age, 49% physical disability, 29% long term condition, 17% dementia, and 11% drug/alcohol dependency
- Key caring tasks undertaken were: 95% making meals/housework and support,

83% said keeping company, 80% said paperwork (inc. benefits), 71% said "getting out of the house," and 54% said managing medication.

We also asked carers to rate their general satisfaction on a scale of 1-5 (with 5 being very satisfied). A third of respondents said they felt average (3) while 39% indicated low levels of satisfaction (1,2) and 29% indicated a high level of satisfaction (4,5). When asked how this compared to their normal state of satisfaction, the majority (65%) said this was typical, with almost a third indicating that this was worse than normal and only 4% indicating that it was better than normal.

Respondents by Health Board

Aneurin Bevan – 19%

Betsi Cadwaladr – 20%

Cardiff and the Vale – 10%

Cwm Taf Morgannwg – 7%

Hywel Dda – 16%

Powys – 14%

Swansea Bay – 14%

Identified needs

The contribution carers make to the lives of those they care for are enormous, but they are often in need of support themselves. All unpaid carers have a legal entitlement to an assessment of their needs by their local authority, if it is believed that they have support needs that are not being met by preventative services. When asked if they have been offered a carers needs assessment, 89% said they had not.

Almost half of respondents (48%) said that they needed support, and when asked what support would help in their caring role, top responses included:

- 25% said accessible advice and information
- 25% said services at home (help with meals, shopping, gardening, cleaning and intimate care)
- 22% said respite
- 7% said emotional support
- 5% said socialising and companionship
- 3% said financial support

The remaining 13% made various comments on presence (or not) of family support, transport difficulties, or unspecified support needs.

When we asked those who indicated that they did not need support to give more information they made the following comments:

- They were managing/coping at the moment
- The person they care for not interested/reluctant to seek support

- They're currently sharing caring responsibilities with family/friends
- They feel it is their duty as a parent/child/sibling/partner to provide care
- They've previously had difficulties accessing support

It's interesting to note that some of the comments given above describe barriers to accessing support rather than reasons why they don't need support. This could indicate confusion over the question asked, or that some of the respondents to this question do have support needs.





“Someone to give me respite for a few hours would be amazing.”

“Covid has taken the social activities we had taken ages to find...As well as supporting and encouraging him this gave me an hour or two’s break which I just don’t get anymore. I don’t need a lot but we both need a break from each other occasionally.”

“Information online that’s accessible, in one place, easy to understand.”

“I am physically/mentally exhausted. Learning about dementia as I go along – it’s difficult, frustrating.”

“She’s my wife and I should help her.”

“I have supportive friends and family, other organisations want you to fit into boxes for support.”

“It would upset my wife to have outsiders ‘taking over’.”

“I feel I can manage at the moment.”

Accessing support

A clear majority of respondents (86%) were comfortable with the term “unpaid carer”, while 14% said they were not. Reasons for feeling uncomfortable with this term varied, but many centred around a sense of family duty.

Despite having a right to support if they need it, just over half (51%) of all respondents indicated that they had not tried to access support. While this figure may seem high, it should be noted that a similar figure had previously said that they didn't need support. When asked why they had not accessed support, 52% indicated that they did not know what was available, 36% said that the person they care for did not want them to access support and 24% indicated that they have no time.

When asked for more information, 22% of those who wrote a comment mentioned that Covid has limited the availability of services, 19% said they were currently managing and didn't need support, 15% said that they are worried about getting external help or the person they care for doesn't want it, while other comments focused on not knowing where to get help or access support.

32% of respondents said that it was either very or fairly difficult to access support, with only 16% finding it very or fairly easy to access support.

“I'm always rushed off my feet and don't have time to research.”

“Sometimes my mother refuses help she desperately needs.”

“I don't drive so depending where support is based, I wouldn't be able to get there.”

“Forms are too long and complicated just to get nothing in the end.”

“Before Covid [I had] four hours a week respite, now none.”

“My father wouldn't want strangers in the housing caring for him...would reinforce his lack of independence and affect him adversely mentally and emotionally.”

“I wouldn't know where to begin.”

Information needed

The [Social Services and Well-being Act](#) places duties on local authorities and other public bodies, including the promotion of well-being. Part of fulfilling this duty is the provision of information to unpaid carers – about their rights, the support available and how support can be accessed.

When asked what type of information would be helpful to carers, respondents answered with the following (carers could tick as many as applicable)

- 51% said contingency/emergency planning
- 41% said accessing benefits
- 38% said health/welfare support
- 37% information about regular breaks
- 35% communicating with social services
- 31% wanted information on future planning needs

Future planning also came out quite strongly when carers were asked to expand on their answers.

“I feel more help would be useful as the situation gets worse as the dementia progresses.”

“Access to experts and more importantly advocates that can help on an individual basis.”

“I want to be able to go to one information point and learn about all the options available, rather than having to run around trying to find out about different services. It’s too confusing and time consuming.”

When asked how they would like to receive information and advice:

- 73% said online
- 43% said via their GP
- 39% said via post
- 32% said one-to-one services.

When asked about where they would prefer to access information, 60% said they access information online, 54% through their GP surgery, 24% said libraries, 22% said pharmacies and 21% said carers centres.

Current circumstances

Caring can increase demand on an individual's finances, as well as affecting their employment and limiting their earnings. We asked about this and 51% of respondents said their finances had not been adversely affected by the caring role, with 49% saying they had (34% said it had to a small extent, 16% said it had by a lot)

More than two thirds (69%) said they have concerns, but are able to cope at present, with 18% saying they're worried about finances in the future, 9% said they were struggling financially and 4% said they are in debt as a result of their caring role.

When it comes to the relationship between employment and caring, 34% were not in employment, 18% said caring made their job more difficult, 12% gave up work, and 11% reduced their hours.

Caring for someone can have an adverse impact on an individual's health and wellbeing, and we found this to be the case amongst our respondents as 63% reported feeling more tired, 66% a general feeling of stress and 52% had disturbed sleep over the last 12 months.

Finally, we asked if there was anything else they wanted to say about their experiences being a carer. Many respondents said they were worried about the future, that they were exhausted, some felt lucky to have support while others felt abandoned and isolated. The pandemic has had an impact on the mood of many carers as well as their ability to provide care or access services. This had led to a feeling of loss of control, while others said they felt unappreciated.

"I worry that I am not doing enough, or not noticing signs that Dad is not coping as it's the first time I've had to do this."

"Others are so much worse off than me and I shouldn't complain but I do despair sometimes and it's going to get worse I fear."

"I am part of a team, we laugh together, problem solve together and plan together. I understand what my husband needs to cope with daily life and we have adjusted well."

"Very difficult to think about yourself and to take care of your needs. You put yourself at the bottom of the pile."

"Feel invisible to the outside world and have to fight to get information."

"It's just the feeling I have no control."

"I have willingly given up my life to look after my son, but during the last 9+ months I have never felt so unappreciated."

"He won't talk, he won't share his feelings, he won't let any of the family know. Due to covid restrictions it has been impossible for me to talk to anyone about it."

Looking forward

Unpaid carers are an essential part of our communities, providing 96% of care in Wales (Social Care Wales). At some point in our lives, many of us will undertake a caring role. As they provide support, so too do they have a right to support if they need it.

This survey has provided us with a broad overview of some of the current challenges and needs of older carers. Following the publication of this report we will disseminate and discuss our findings with stakeholders across the sector.

Our next steps:

- We will map out systems of support as they currently exist across Wales, understanding local differences in provision and identify areas of best practice
- In full collaboration with carers, we want to understand better the barriers related to accessing information, advice and support and how they may be overcome
- We want to engage with groups underrepresented within these survey results, such as older LGBTQ+ carers, carers who are digitally excluded, older carers within the Black, Asian and minority ethnic communities, carers over the age of 70, and male carers generally

- We will work with Welsh Government and other stakeholders to ensure that the delivery of recently published strategies – such as the Strategy for Older People, and Strategy for Unpaid Carers – and their delivery plans take account of and address issues highlighted by unpaid carers through the survey.

Over the course of this survey we have had an opportunity to hear from carers across Wales, many of whom have been very open and generous with their responses.

We want to thank everyone who has given time to participate, especially given the additional pressures many are facing at the moment.

If you want further information about this report or want to be involved in the next stages of the project, please contact us using the following contact information.

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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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