State of Caring 2023

The impact of caring on health in Wales
November 2023
About this research

Carers Wales, as part of Carers UK, carried out an online survey between June and August 2023. A total of 1,325 carers and former carers responded to the survey.

This report summarises the responses from the 1,182 people who are currently providing care.

As not all respondents completed every question in the survey, a number of the figures given in this report, are based upon responses from fewer than 1,182 people.

Of respondents to the survey:

• 17% of respondents were from the Aneurin Bevan health board area, 18% from the Betsi Cadwaladr health board area, 16% were from the Cardiff & Vale health board area, 14% were from the Cwm Taf Morgannwg health board area, 16% were from the Hywel Dda health board area, 4% of respondents were from the Powys health board area, and 14% were from the Swansea Bay Health board area.
• 84% are female, 15% are male and 1% have a different gender identity than their sex registered at birth
• 33% have a disability
• 4% are lesbian, gay, bisexual or other
• 19% have childcare responsibilities for a non-disabled child under 18
• 3% are aged 0-34, 11% are aged 35-44, 23% are aged 45-54, 34% are aged 55-64, 20% are aged 65-74 and 10% are aged 75 and over.
• 34% are employees (19% are full time and 15% part time).
• 33% have been caring for over 15 years, 16% have been caring for 10-14 years, 22% have been caring for 5-9 years, 25% have been caring for 1-4 years, and 3% for less than a year
• 50% care for 90 hours a week or more, 15% care for 50-89 hours, 21% care for 20-49 hours, and 14% care for 19 hours or less.
• 72% care for 1 person, 21% care for 2 people, 6% care for 3 people and 2% care for 4 or more people

Thanks

Carers Wales would like to thank each and every carer who contributed to this survey, from those who helped us develop and test the survey to every single person who took the trouble and time to tell us about their experiences. Your experiences will be used to help build a society that recognises and supports carers more.
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Executive summary</td>
<td>04</td>
</tr>
<tr>
<td>Impact of caring on health and wellbeing</td>
<td>07</td>
</tr>
<tr>
<td>Carers’ mental health</td>
<td>12</td>
</tr>
<tr>
<td>Improving carers’ health and wellbeing</td>
<td>19</td>
</tr>
<tr>
<td>Support from the NHS for unpaid carers</td>
<td>24</td>
</tr>
<tr>
<td>Supporting carers with their caring role</td>
<td>29</td>
</tr>
<tr>
<td>Recommendations</td>
<td>38</td>
</tr>
<tr>
<td>Further support for carers</td>
<td>40</td>
</tr>
</tbody>
</table>
This year we found that carers were struggling even more with their physical and mental health, their consideration at the point of hospital discharge has not improved significantly despite new rights and they are taking more on than ever before.

Many carers are feeling stressed, depressed and lonely. A significant proportion of carers are not seeking support with health conditions due to the demands of their caring role, and many are unable to take a break from caring to do the things that might improve their wellbeing. Carers with poor mental health are continuing to care despite being at breaking point. Many carers are uncertain about the future, and anxious about the demands of their caring role, particularly if they are facing challenges such as carrying out clinical tasks, supporting the person they care for when they are discharged from hospital, or managing caring alongside their own health conditions.

This evidence from carers suggests that their health and wellbeing is being damaged as a result of caring - some of which is preventable with the right interventions, information, advice and support from the NHS, social care and the wider voluntary sector. There are clear and positive public health outcomes if unpaid carers are better supported and we set out our recommendations with that in mind.
Carers’ health and wellbeing

- 79% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year, an increase from 66% last year.

- A significant proportion of carers said their mental health has been affected by caring. Over three-quarters (79%) of carers feel stressed or anxious, half of carers (51%) feel depressed, and half of carers (49%) feel lonely.

- Over a quarter of carers (28%) said their mental health was bad or very bad.

- Over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide.

- 49% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health. Three-quarters (75%) said that they continued providing care even though they felt they were at breaking point.

- 72% of carers said they found it difficult to get a good night’s sleep. This increased to 90% for people caring for over 50 hours a week.

- 52% of carers said their physical health had suffered, and 23% said that caring had caused them injuries. 53% said they have been less active over the last 6 months.

- 56% of carers said that being able to take regular breaks from caring would be a challenge over the coming year.

- 49% of carers said that maintaining their relationships with their partner, family or friends would be a challenge - an increase from 28% last year.

At a glance...

79% of carers said the impact of caring on their physical and mental health would be a challenge.

85% of carers said that they feel stressed or anxious.

51% of carers said that they feel depressed.

49% of carers said that they feel lonely.
Supporting carers with health and wellbeing

- 58% of carers said they needed more support to be able to look after their health and wellbeing.

- Half of carers (50%) said they had put off health treatment because of their caring role.

- 54% of carers said they were receiving support with their caring roles from family and friends – a higher proportion than those receiving support from healthcare services (14%) and social care services (41%).

- 36% of carers said they needed more support from the NHS or healthcare professionals.

- Over a third (36%) of carers waiting for hospital treatment or assessment for themselves had been waiting for over a year. 6% higher than the UK average.

- 76% of carers agreed they were worried about being able to provide care in the future. Over half (53%) of carers said they weren’t sure how to plan for the future and would like more support with this.

At a glance...

58%

of carers said they needed more support to be able to look after their health and wellbeing

50%

of carers said they had put off health treatment because of their caring role

54%

of carers said they were receiving support from family and friends

76%

of carers were worried about being unable to provide care in the future
Impact of caring on health and wellbeing

We asked carers what they felt were the main challenges they might face over the coming year. The most commonly reported challenge was the impact of caring on physical and mental health: 79% of carers said this would be a challenge. This was an increase from last year, when 66% of carers said that the impact of caring on physical or mental health would be a challenge.

A significant proportion of carers said their mental health had been affected by caring. Over three-quarters (79%) of carers feel stressed or anxious, half of carers (51%) feel depressed, and half of carers (49%) feel lonely.

Carers who were struggling to make ends meet were even more likely to feel stressed or anxious (85%).

72% of carers said they found it difficult to get a good night’s sleep. This increased to 90% for people caring for over 50 hours a week.

52% of carers said their physical health had suffered, and 23% said that caring had caused them injuries.

50% of carers said they had put off health treatment because of their caring role.

“I've been diagnosed as having Burnout about 6 weeks ago and I've just been hanging in there ever since. I need to take naps most days and my CBT treatment has my Stress levels constantly at Severe.”

“Caring has ruined my health.”

Summary

- 79% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year, an increase from 66% last year.

- A significant proportion of carers said their mental health has been affected by caring. Over three-quarters (79%) of carers feel stressed or anxious, half of carers (51%) feel depressed, and half of carers (49%) feel lonely.

- Carers who were struggling to make ends meet were even more likely to feel stressed or anxious (85%).

- 72% of carers said they found it difficult to get a good night’s sleep. This increased to 90% for people caring for over 50 hours a week.

- 52% of carers said their physical health had suffered, and 23% said that caring had caused them injuries.

- 50% of carers said they had put off health treatment because of their caring role.
93% of carers who said their health was bad or very bad said the impact of caring on their health would be a challenge, and 86% of carers who were disabled said that the impact of caring on their health would be a challenge. People caring for over 50 hours a week were more likely to say that the impact of caring on health would be a challenge compared with those caring for less than 50 hours a week (90% compared with 74%).

We asked carers what, if any, impact caring had on their health and wellbeing.

Table 1: impact of caring on health and wellbeing

<table>
<thead>
<tr>
<th>Impact on health and wellbeing</th>
<th>% of carers who said this had an impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel stressed or anxious</td>
<td>79%</td>
</tr>
<tr>
<td>I find it difficult to get a good night’s sleep</td>
<td>72%</td>
</tr>
<tr>
<td>I have reduced the amount of exercise I do</td>
<td>63%</td>
</tr>
<tr>
<td>I have found it difficult to maintain a balanced diet</td>
<td>53%</td>
</tr>
<tr>
<td>My physical health has suffered</td>
<td>52%</td>
</tr>
<tr>
<td>I feel depressed</td>
<td>51%</td>
</tr>
<tr>
<td>I have put off health treatment because of my caring role</td>
<td>50%</td>
</tr>
<tr>
<td>I feel lonely</td>
<td>49%</td>
</tr>
<tr>
<td>I have experienced an injury</td>
<td>23%</td>
</tr>
<tr>
<td>Caring has no impact on health and wellbeing</td>
<td>4%</td>
</tr>
<tr>
<td>Caring has improved my health and wellbeing</td>
<td>2%</td>
</tr>
</tbody>
</table>

A significant proportion of carers told us that caring had impacted on their mental health. **79% of carers said they feel stressed or anxious.** Carers who were struggling to make ends meet were even more likely (85%) to feel stressed or anxious. People caring for two or more people were also more likely to feel stressed or anxious (82%).

Several carers told us that they worried about their ability to provide care in the future. Others said they felt anxious about the person they cared for and found it difficult to relax or switch off from their caring role. Many carers also said that issues with support services, or difficulties juggling work and care, caused them stress or anxiety.
Caring has made me feel incredibly anxious, I have had to learn to grow up fast, I have very few friends and have struggled through school and exams due to mental health problems, I struggle being in social situations as I’m so used to it just being myself and my family, I don’t confide in anyone about my problems as no one understands.”

“I am completely neglecting my own needs as my whole time is spent working full time, caring for my family and caring for my mum.”

There is a clear need for Welsh Government to deliver more sustainable long-term planning for social care, including better funding, so that carers are more able to plan their futures.

49% of carers said they feel lonely. Women were more likely to feel lonely than men (50% compared with 44%). People who were caring for over 50 hours a week were more likely to feel lonely than people caring for less than 50 hours (62% compared to 38%). 32% of carers said they feel lonely often or always. This increased to 40% of carers caring for over 10 years.

“I feel I have had to give up my former life and I feel very lonely sometimes.”

“I am on Antidepressants last two years when stress financially and 24/7 caring pushed myself to attempt overdosing.”

Isolating. Friends don’t understand. Exhausted.”

51% of carers feel depressed. People who were caring for over 50 hours a week were more likely to feel depressed than people caring for less than 50 hours (57% compared to 41%). Some carers said that they enjoyed doing activities less because they were too tired or preoccupied with caring, while others said they were unable to take time to do activities that improved their happiness.

“I am on Antidepressants last two years when stress financially and 24/7 caring pushed myself to attempt overdosing.”

“My freedom to do what I want, when I want is seriously affected. A carer has little or no freedom and for anyone who is independently minded, this has an impact on their mental health.”

72% of carers said they found it difficult to get a good night’s sleep. Those who were caring for more hours were more likely to struggle with sleep: 90% of people caring for over 50 hours a week found it difficult to get a good night’s sleep compared to 63% of those caring for less than 50 hours. Carers who were struggling financially were also more likely to struggle with sleep: 82% said this was an issue. Many carers said that they were too anxious to sleep, or that they needed to provide care during the night.

“I’m a bag of nerves, I constantly worry, I don’t sleep worrying”

“Mum has falls in the care home regularly and it’s hard to settle on a night knowing she may have a fall again.”

“I have a baby monitor for my mum at night, so I can sleep in my own bed instead of with her, but every time she moves or makes a noise it wakes me. I can’t lower the volume in case I don’t hear her.”
50% of carers said their physical health had suffered, and 23% said that caring had caused them injuries. People who had been caring for more than 10 years were even more likely to say that their physical health had suffered (59%) and that they had experienced an injury (27%). Several carers said they had experienced injuries while lifting the person they cared for, or when operating equipment.

“Constant lifting has affected my back and my daughter’s anxiety has an every day impact on my life.”

“I have inflamed tendons in my arms from lifting and holding my husband many times a day.”

Many carers said that caring had impacted on their health by making their existing health conditions worse.

“Being diagnosed with breast cancer in 2022 and having to return to caring 6 weeks after having a mastectomy. Basically as soon as I felt able to drive the 28 mile round trip post surgery and pushing to one side how I felt both mentally and physically.”

“Alopecia, skin disorders, PTSD from her sever self harm and suicide attempts.”

50% of carers said they had put off health treatment because of their caring role. People caring for over 50 hours a week were even more likely to put off health treatment (59%). Several carers told us that they didn’t have time to seek help or support with their own health issues, while others said they were unsure they would be able to find replacement care.

“I am unable to visit the GP for myself due to the way they allocate appointments. No consideration is given to carers for this. I am unable to sit for hours in the morning on the phone and then wait for a call back.”

“I do not have time to look after my own physical and mental well being.”

“Very isolating, if I’ve got a medical condition I tend to ignore the situation which makes matters worse, I hate being in a restricted situation which is very difficult every day not having time for yourself and constantly tired unable to concentrate because of the impact of caring. Not being able to have important time with family and friends its miserable.”

Many carers said that caring had impacted on their health by making their existing health conditions worse.

50% of carers said they had put off health treatment because of their caring role.
53% of carers said they found it difficult to maintain a balanced diet. Carers struggling to make ends meet were much more likely to find it difficult to maintain a balanced diet (70%).

“I don’t get enough fresh air and exercise – it’s very like being a new mum ALL THE TIME and I am stress-binge eating the treats meant for mum.

“Binge eating and drinking to cope with stress and constant demands only way to switch off.

It is clear that carers face poorer health outcomes as a result of caring. These health inequalities are particularly prominent amongst carers who are struggling financially, caring for more hours, and caring over a longer period of time.

Many carers are stressed, anxious, and depressed, and several have untreated physical health conditions of their own. It is unsustainable for these carers to continue providing high levels of care whilst struggling with their own health. The NHS must consider the needs of carers and take a preventative approach to carers’ health and wellbeing.
Carers’ mental health

Summary

• 28% of carers said their mental health was bad or very bad. This increased to 30% for carers caring for over 50 hours a week, and 32% of carers who had been caring for over 10 years.

• 90% of carers whose mental health was bad or very bad said they were experiencing increased tiredness, and 88% said they were having difficulty sleeping.

• 81% of carers whose mental health was bad or very bad said they had continuous low mood, 81% had feelings of hopelessness and 72% regularly felt tearful. Three-quarters had low self-esteem (75%).

• Over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide.

• 49% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health. The most commonly reported barrier to seeking support with mental health was being too busy caring (55%).

• Three-quarters (75%) of carers whose mental health was bad or very bad said that they continued providing care even though they felt they were at breaking point.
We asked carers how they would describe their mental health. Only 5% of carers said their mental health was very good, while 21% said it was good. 46% of carers said their mental health was fair, while 28% said it was bad or very bad. This replicates the results of the 2021 Census in England and Wales, in which 28% of carers said their health was not good.

**Carers who were struggling to make ends meet were much more likely to say their mental health was bad or very bad (45%).** Carers who have been caring for over 10 years were also more likely to say their mental health was bad or very bad than those caring for less than 10 years (30% compared to 25%). People caring for over 50 hours a week were more likely to say their mental health was bad or very bad compared to people caring for less than 50 hours (32% compared to 24%).

We asked carers who reported their mental health as bad or very bad to tell us whether they had experienced certain symptoms.

### Table 2: symptoms experienced by carers with ‘bad’ or ‘very bad’ mental health

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>% of carers affected</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased tiredness</td>
<td>92%</td>
</tr>
<tr>
<td>Difficulty sleeping</td>
<td>89%</td>
</tr>
<tr>
<td>Inability to switch off from worrying about caring</td>
<td>83%</td>
</tr>
<tr>
<td>Feelings of hopelessness</td>
<td>82%</td>
</tr>
<tr>
<td>Continuous low mood</td>
<td>82%</td>
</tr>
<tr>
<td>Irritability and mood swings</td>
<td>79%</td>
</tr>
<tr>
<td>Eating too much or too little</td>
<td>77%</td>
</tr>
<tr>
<td>Low self esteem</td>
<td>76%</td>
</tr>
<tr>
<td>Restlessness and difficulty concentrating</td>
<td>73%</td>
</tr>
<tr>
<td>Regularly feeling tearful</td>
<td>73%</td>
</tr>
<tr>
<td>A sense of fear or dread</td>
<td>73%</td>
</tr>
<tr>
<td>Thoughts related to self-harm or suicide</td>
<td>36%</td>
</tr>
</tbody>
</table>
The most commonly reported symptom was increased tiredness (92%), followed by difficulty sleeping (88%).

“Isolating. Friends don’t understand. Exhausted.”

81% of carers who said their health was bad or very bad said that they had continuous low mood, and 81% experienced feelings of hopelessness.

“I feel like I am existing and not reaching my full potential. I don’t feel valued. Life with ALN children is a constant battle.”

“Days just merge into one and there is no sign of light at the end of the tunnel.”

81% of carers with bad or very bad mental health said they had an inability to switch off from worrying about caring. Many carers said they were worried about their ability to care in the future, or anxious about the condition of the person getting worse over time.

“I feel that I sometimes need to make decisions which the individuals I care for should make but cannot always. These often leaves me feeling as though I risk making wrong decisions. This is very stressful.”

Concerningly, many carers said they felt overwhelmed, and at breaking point. 36% of carers who said their mental health was bad or very bad said they had experienced thoughts related to self-harm or suicide. It is vital that carers struggling with their mental health are able to speak to their GP, yet our results show that many carers are concerned about long waiting times and delays in accessing services.

Many carers told us that they felt they had lost their sense of identity as a result of the demands of their caring role, which affected their self-esteem, confidence and wellbeing.

“Completely taken away my confidence and independence and self esteem.”

“I feel my life is running away from me and I am unable to take full advantage of my time because of my caring responsibilities.”

“I feel like my life is repetitive and pointless. I am just here for others.”
Supporting carers with their mental health

We asked carers who said their mental health was bad or very bad whether they were receiving support to help manage their mental health. Less than a fifth (18%) said they were receiving help from NHS health services. 4% were receiving help from local mental health services or charities, and 2% were receiving private mental health care. However, 38% of carers said they were not receiving any support with their mental health.

In addition, many carers (28%) were receiving support from a partner, friend or relative rather than a health service.

“Online friends as it’s all words and no real support, waiting lists are ridiculous.”

“I initially received support from my GP and my employers counselling service but this only last for 6 to 8 weeks. Since then I only get support from friends and family.”

Many carers said that they had struggled to access support for their mental health, due to long waiting times for counselling, or services not meeting their needs.

“I had some therapy sessions funded by social services. My therapist identified I needed more - they refused further funding.”

“I’m on medication for anxiety. I was offered CBT by the Primary Mental Health Support Service, but the options were not at a time/place I was able to attend due to caring and work.”
Barriers to seeking help

We asked carers who had bad or very bad mental health whether there were any barriers to seeking help with their mental health.

Table 3: Barriers to seeking help experienced by carers with ‘bad’ or ‘very bad’ mental health

<table>
<thead>
<tr>
<th>Symptoms</th>
<th>% of carers who felt this was a barrier</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am too busy caring</td>
<td>58%</td>
</tr>
<tr>
<td>I am concerned about long waiting times for support services</td>
<td>29%</td>
</tr>
<tr>
<td>I don’t think support services would meet my needs</td>
<td>28%</td>
</tr>
<tr>
<td>I don’t feel comfortable talking about my mental health</td>
<td>28%</td>
</tr>
<tr>
<td>I’m too embarrassed to ask for help</td>
<td>19%</td>
</tr>
<tr>
<td>I don’t think my problems are serious enough</td>
<td>18%</td>
</tr>
<tr>
<td>I don’t know where to go to access help or support</td>
<td>17%</td>
</tr>
</tbody>
</table>

The most commonly reported barrier was being too busy caring (58%). People who were caring for over 50 hours a week were more likely to say that being too busy caring was a barrier to seeking help than those caring for less than 50 hours (62% compared with 38%).

“...The help offered has been inadequate (try mindfulness in the face of regular violent meltdowns) or I’ve been unable to access it due to location or time.”

“I do not have time to look after my own physical and mental well-being.”

The other most commonly reported barriers were concerns over long waiting times (29%) and carers feeling that services would not meet their needs (28%).

“I know I could ask for counselling, which I’ve had several times over the years through my GP and other organisations. But the waiting lists are very long.”

58% of carers said they were ‘too busy caring’ to seek help with their mental health.
Over a quarter of carers (28%) whose health was bad or very bad said they didn’t feel comfortable talking about their mental health and 18% said they didn’t think their problems were serious enough. 19% said they were too embarrassed to ask for help.

Men were more likely feel embarrassed about asking for help than women (31% compared to 19%), and more likely to say they didn’t feel comfortable talking about their mental health (36% compared to 23%).

17% of carers said they didn’t know where to go to access help or support.

Some carers also told us that they felt too anxious about seeking help with their mental health because they were worried about the consequences, or because asking for help was pathologised rather than being seen as a responsible thing to do. Carers are entitled to an assessment of their needs, especially if they feel these are worsening.

“ I thought my children would be taken off me if I had been put on medication because I really thought it made you like a zombie.”
Capacity to care when experiencing poor mental health

We asked carers whose health was bad or very bad whether any issues related to their mental health may have affected their capacity to care. Three quarters (75%) said that they continued providing care even though they felt they were at breaking point.

“ I know I am low but I just have to keep going, there is no other option.”

“I’m so low at the moment that only one of the above makes a difference, because you always have your caring role to go back to. Even my faith has been shaken in recent weeks.”

Just under a quarter (23%) of carers said that they weren’t able to provide the same quality of care due to issues with their mental health.

22% said they had to leave their job or reduce their working hours because of poor mental health affecting their ability to care, while 17% said they had to take time off paid employment.

73% of carers said they continued caring when they were at breaking point.

27% of carers said mental health issues affected the care they could provide.

“I’m so low at the moment that only one of the above makes a difference, because you always have your caring role to go back to. Even my faith has been shaken in recent weeks.”

“I have reduced my social life to cope as I work fulltime which makes me more lonely.”

Many carers are struggling with their mental health. While caring can be rewarding, it can also be stressful and unpredictable, and many carers feel they have lost their own identity as a result of providing high levels of care. Carers providing high levels of care and carers who are struggling financially are even more likely to have poor mental health, and some are providing care despite being at breaking point.

Concerningly, although many carers feel they have poor mental health, only a small proportion are seeking help: many feel unable to look after their own wellbeing due to the demands of caring, or reluctant to seek help due to concerns over long waiting times. It is vital that the health service treats carers’ needs as a priority.
Improving carers’ health and wellbeing

We asked carers what their main needs are at the moment. **58% of carers said they needed more support to be able to look after their health and wellbeing.** 78% of carers who said their health was bad or very bad said they needed more support to look after their health and wellbeing, and 69% of carers with a disability said they needed more support to look after their health and wellbeing.

People caring for more than 50 hours were more likely to say they needed support to help with their health and wellbeing than those caring for less than 50 hours (65% compared with 55%). Carers who had been caring for over 10 years were more likely to say they needed support with health and wellbeing than those caring for less than 10 years (64% compared with 58%). Carers who were caring for more than one person were also more likely to say they needed help with their health and wellbeing than those caring for one person (70% compared with 56%).

Summary

- 58% of carers said they needed more support to be able to look after their health and wellbeing
- 66% of carers said that spending time with family and friends improves their wellbeing
- 69% of carers said that getting a good night’s sleep improves their wellbeing
- 41% of carers said they needed more breaks or time off from caring.
What helps to improve carers’ wellbeing

We asked all carers whether there were certain things they felt improved their wellbeing.

Table 4: What improves carers’ wellbeing

<table>
<thead>
<tr>
<th>What improves wellbeing</th>
<th>% of carers who said this improved wellbeing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting a good night’s sleep</td>
<td>69%</td>
</tr>
<tr>
<td>Spending time with family or friends</td>
<td>66%</td>
</tr>
<tr>
<td>Being valued as a carer</td>
<td>56%</td>
</tr>
<tr>
<td>Taking a break from caring</td>
<td>55%</td>
</tr>
<tr>
<td>Engaging in my hobbies or interests</td>
<td>54%</td>
</tr>
<tr>
<td>Being physically active</td>
<td>47%</td>
</tr>
<tr>
<td>Having a pet</td>
<td>45%</td>
</tr>
<tr>
<td>Having good quality care services for the person I care for</td>
<td>43%</td>
</tr>
<tr>
<td>Eating a balanced diet</td>
<td>37%</td>
</tr>
<tr>
<td>Being in paid employment</td>
<td>29%</td>
</tr>
<tr>
<td>Speaking to other carers</td>
<td>28%</td>
</tr>
<tr>
<td>Counselling, therapy or listening support services</td>
<td>20%</td>
</tr>
<tr>
<td>Taking part in education/training opportunities</td>
<td>16%</td>
</tr>
<tr>
<td>Having a faith or religion</td>
<td>14%</td>
</tr>
</tbody>
</table>
The most common response was getting a good night’s sleep (69%), followed by spending time with family and friends (66%), being valued as a carer (55%), taking a break from caring (58%) and engaging in hobbies and interests (54%).

However, many carers felt they did not have the time, energy or motivation to do the things they knew would improve their wellbeing. Several carers also said they felt guilty about looking after themselves.

“It is morally difficult and practically impossible to put my own needs ahead of others.”

“I have severe anxiety. Unable to fulfill paid role or family responsibilities i.e. childcare well. Feel like I am dying and my life is over.”

Some carers said they found it difficult to relax, while others said they were too exhausted from caring. Many carers told us they were unable to find replacement care to enable them to take a break.

“There is no time for me to participate in any activities outside of the home as I’m still waiting for adult social care to provide appropriate care and support for the person I care for.”

“I cannot get any respite care so far this year for me to have a break. The nursing homes no longer have respite beds apparently and can’t take short term bookings as they have waiting lists for long term clients.”

“I force myself to do good things for me, but its difficult to switch off and I often feel rushed.”

Recognition

Some carers said that a lack of recognition about their caring roles affected their wellbeing: some felt invisible or forgotten about. 55% of carers said they needed better understanding and recognition of unpaid carers from the general public.

“To just be recognised as an unpaid carer that’s all I want.”

“I was called scum and drain on society and that a person pays for my existence as don’t have a real job so people to understand our role in society.”

Recognition

69% of carers said getting a good night’s sleep would improve their wellbeing

55% of carers said that being valued as a carer would improve their wellbeing

41% of carers said they needed more breaks or time off from caring

We also know that financial wellbeing has a direct impact on carers’ overall wellbeing. In our State of Caring finances report, we set out carers’ responses to our survey questions about finances, as well as recommendations that would improve carers’ lives such as increases in the levels of carers benefits, better access to financial support and lower costs of care.
Breaks

41% of carers said they needed more breaks or time off from caring. This increased to 57% for carers who said their health was bad or very bad. People who were caring for over 50 hours a week were more likely to say they needed a break from caring compared to those caring for less than 50 hours (52% compared with 37%).

Some carers who had received support from respite services or paid care workers had found this helpful in improving their wellbeing.

“Carers come twice a day. They vary in quality and experience but the majority are great and supportive.”

“Just a few hours respite a week can make a big difference to my mental and physical wellbeing.”

However, many carers said that support services that would enable them to take a break were often unavailable or unsuitable. Just over a quarter (28%) of carers have relied on family or friends to provide replacement care, and only 10% received replacement care from a health or social care service.

“I would love to take a break, to reset my emotions but there is no respite available unless in an emergency ie if I die (and I quote that from the social worker).”

“I am fortunate to have supportive relatives to spread the load - whilst our own health holds up!”
56% of carers said that being able to take regular breaks from caring would be a challenge over the coming year. Over a third of carers (37%) haven’t tried taking a break because they think it’s too difficult. This increased to 72% for carers who said their mental health was bad or very bad, and 74% of those who are often or always lonely.

“I would love to engage in classes at the gym and to follow a healthy diet. Yet I do not feel I have the time or the energy to do either.”

“I need some respite care but am finding it very hard to get. Was visited last week and told my situation had been escalated and a social worker will be contacting me. I’m still waiting.”

People caring for 50 or more hours a week were more likely to say that taking a break from caring would be a challenge compared with people caring for less than 50 hours a week (66% compared with 50%).

Some carers were also concerned about COVID-19 and were still shielding or reducing their activities to keep the person they care for safe. 27% said that keeping the person they care for safe when there are fewer public health measures to reduce COVID-19 would be a challenge over the coming year.

“We are still shielding, the covid pandemic hasn’t ended for us, there is no recognition of this or how difficult it is.”

49% of carers said that maintaining their relationships with their partner, family or friends would be a challenge. This was an increase from last year, when 32% felt this would be a challenge. 24% of carers said they needed more support so they can build and maintain relationships with others.

“Loneliness in marriage caring for husband with Dementia

“I feel I am neglecting the needs of my teenage sons as I care for my mum.

“Caring puts a big strain on your marriage

Many carers are providing high levels of care without taking a break, sacrificing their own health and wellbeing to support their loved ones. While there are things that carers can do to improve their wellbeing, such as spending time with family and friends, our recent report on carers and poverty found that carers are often having to cut back on the things that might be beneficial for their health.

Our research suggests that taking a break can be beneficial for wellbeing, yet carers often feel unable to do so because they can’t find suitable replacement care services. It is vital that we have a fit-for-purpose social care system that protects the health and wellbeing of unpaid carers across the UK. It is unsustainable for carers to continue to provide hours of care each week with little support in return.
Support from the NHS for unpaid carers

Summary

• 75% of carers said they would like systems that make managing appointments and speaking to health professionals easier.

• Over a third of carers (36%) of carers waiting for hospital treatment or assessment for themselves had been waiting for over a year, only a slight decrease in the last year. More carers were waiting for treatment compared with the person being cared for.

• The lack of carer involvement at hospital discharge remains high and has not significantly changed in the last year. 59% of carers disagreed they were asked about their ability and willingness to care during the hospital discharge of the person they cared for.

• 36% of carers said they needed more support from the NHS or healthcare professionals, and 37% said they needed better recognition from the NHS of their needs as a carer.

• A majority of unpaid carers felt virtual wards would mean providing more care but 59% of carers agreed that virtual wards would give them and the person they care for more ownership of care being provided.
We asked carers what their main needs are at the moment. **36% of carers said they needed more support from the NHS or healthcare professionals** and **37% said they needed better recognition from the NHS of their needs as a carer.** Some carers said they would appreciate more flexibility when making appointments, allowing them to balance their own health needs with their caring role.

“Being able to book appointments at times that suit. Taking complex autism children out of school for appointments is disruptive and challenging.”

“More availability for "zoom" appointments. Some appointments are difficult to access in person, due to limited disabled parking, limited parking, limited accessibility. More information on accessibility on the website.”

Some carers also said they needed more support and guidance from healthcare professionals on how to manage their own health conditions alongside caring.

“A data base which would quickly identify me as a carer if I am away from home and would immediately access a record of my address and that would activate an emergency care plan for my daughter. I currently wear a wristband identifying me as a carer but can only hope that emergency responders would check my mobile phone for the necessary information. A system like medic alert bracelet linked to a data base would be good and give me greater peace of mind.”
Online patient records and identifying carers

We asked carers whether they were accessing online medical records. 89% of carers said they hadn’t thought about accessing medical records online for themselves, and 95% said they hadn’t thought about doing so for the person they care for. 88% said they didn’t know how to access medical records online for themselves, and 95% said they didn’t know how to access medical records online for the person they care for.

This reflects the lack of awareness of the NHS app in Wales as these numbers are distinctly different to the UK average where only 37% of carers hadn’t thought about accessing their own medical records online for themselves, and 95% said they hadn’t thought about doing so for the person they care for. 88% said they didn’t know how to access medical records online for themselves, and 95% said they didn’t know how to access medical records online for the person they care for.

Similarly, only 31% said they didn’t know how to access medical records online for themselves, and 34% said they didn’t know how to access medical records online for the person they care for.

This strongly suggests that more work needs to be done in raising awareness of how carers can use online technology to help their caring journey.

We also asked carers whether other forms of online support would be helpful. 77% said that they would like systems that identify them as an unpaid carer on the record of the person they care for. 75% said they would like systems that make managing appointments and speaking to health professionals easier. 63% said they would like systems in which information about them or the person they cared for was shared across services.

"Thinking about the amount of repeating stuff that my Mum has to do (she does the bulk of the phoning up!) actually having some sort of system in place so that you don’t find yourself repeating over and over again would be great."

"Being able to input symptoms and readings knowing they can be assessed without the need to call and speak to someone."

"Patient records. So sick of different NHS hospital departments not talking to each other when multiple issues overlap. It takes an age and things get missed."

Table 5: Carers’ experiences of online medical records

<table>
<thead>
<tr>
<th>Type of help</th>
<th>% of carers who agreed (re themselves)</th>
<th>% of carers who agreed (re the person cared for)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accessing medical records online was helpful</td>
<td>8%</td>
<td>7%</td>
</tr>
<tr>
<td>It was difficult to access or understand medical records</td>
<td>3%</td>
<td>3%</td>
</tr>
<tr>
<td>I wasn’t able to access the record as I didn’t have permission</td>
<td>5%</td>
<td>7%</td>
</tr>
<tr>
<td>I haven’t thought about accessing medical records online</td>
<td>43%</td>
<td>42%</td>
</tr>
<tr>
<td>I don’t know how to access medical records online</td>
<td>41%</td>
<td>41%</td>
</tr>
</tbody>
</table>
Hospital treatment/assessment

We asked carers whether they or the person they care for were waiting for specialist treatment or assessment (e.g., a scan or consultation) in the hospital. The maximum waiting time for non-urgent out-patient treatments is for 95% of patients to be seen by 26 weeks and all patients to be seen by 36 weeks from when the hospital or service receives the referral letter. However, it is clear carers have been waiting much longer than this.

29% of carers said they were waiting for specialist treatment or assessment, either for themselves or the person they care for. **Over a third (36%) of carers waiting for treatment or assessment for themselves had been waiting for over a year.** This is a slight decrease from 2022, when we found that 41% of carers waiting for treatment or assessment for themselves had been waiting for over a year.

31% of carers said the person they care for had been waiting for over a year for specialist treatment or assessment—a decrease from 43% last year.

>“Recognition that carer’s own health issues are also important.”

Emergency treatment

We asked carers whether the person they care for needed to attend A&E in the last 12 months. Some carers had experienced long waiting times for ambulances to arrive, for handovers with A&E staff to take place, and to see qualified doctors.

**30% of carers had waited over an hour for an ambulance to arrive, with 7% waiting for over 8 hours.** A fifth (20%) had waited over an hour for the ambulance to hand over care to A&E staff, and 45% had waited over an hour for an initial examination by a doctor or nurse.

The role of Urgent and Emergency Care planning is essential in ensuring that unpaid carers are integral.

>“Many carers disagreed that they were involved in the hospital discharge process with 62% disagreeing that they were asked about their ability and willingness to care, and 60% disagreed that they received sufficient support to protect the health and wellbeing of the person they cared for.”

Hospital discharge

We asked carers whether they had experienced hospital discharge for the person they care for. Last year, many carers had told us that hospital discharge could be a stressful experience, particularly if they felt unprepared or unsupported to provide care at home.

This year, 35% of carers agreed they were involved in the decisions about the discharge from hospital and what care and treatment they needed. Less than one-fifth (17%) said they were asked about their willingness and ability to care, and 13% felt listened to about their ability and willingness to provide care. 14% said they received sufficient support to protect the health and wellbeing of the person they care for as well as their own health, and 11% said they were under no pressure to care and felt fully prepared and supported.

This is particularly concerning as it indicates that the majority of families are being given assumed responsibilities without consideration to their rights under the Social Services and Wellbeing Act.
Virtual wards

This year, for the first time, we asked carers about their experiences of virtual wards. A virtual ward is online care, monitoring and treatment offered in someone’s own home, and is provided, when appropriate, as an alternative to NHS in-patient care, to relieve pressure on healthcare systems. It can also include more intensive support at home with care for a short period of time.

We found that very few carers have experienced virtual wards (3%). This low proportion is because the numbers overall still remain small in relation to the numbers of NHS patients with treatments. The NHS has been shifting towards using the term ‘hospital at home’ which may be easier to understand.

Although few carers had experienced virtual wards, we asked all carers what they thought about the idea of providing care, monitoring and treatment at home. The majority of carers (51%) felt that virtual wards would result in them having to provide more care. This increased slightly to 59% for carers in paid employment. However, many carers felt there would be benefits to virtual wards: 51%, for example, agreed that the person they care would receive care in a more comfortable environment, and 45% agreed it would prevent the person they care for going into hospital unnecessarily.

“I could see Virtual Wards being very helpful for the person I care for who finds it extremely difficult to get out the house. Hospital appointments are always very difficult for the person I care for; they’re extremely painful due to physical conditions and it ends up where recovery for a ‘simple’ appointment takes days, if not weeks.”

“I feel this would help tremendously as my son never leaves the house due to sensory overload.”

42% of carers agreed that virtual wards would allow them to provide personalised care, and 41% agreed that virtual wards would give them and the person they care for more ownership of care being provided.

While many carers felt that virtual wards could be beneficial, some carers disagreed this was the case. 16% of carers disagreed that virtual wards would provide more personalised care, and 16% disagreed that virtual wards would give the person they care for more ownership of care being provided. Some carers also felt that the extra responsibilities for them would be difficult to deal with. Those who had already experienced virtual wards felt that it had created more work for them.

Some carers were also concerned about using technology.

“Internet connection in parts of North Wales is poor. I don’t think it will work.”

“None but I think hopefully they could answer any questions, I don’t think virtually would really work depends on how the Carer would feel when he was if they had any confidence.”

“Lessons for me in using all this. Older carers are not as web enabled as younger people”

Whilst there are benefits to virtual wards or hospital at home, there are also clear risks for families in providing more care. This may not be possible for many reasons, including paid work, other family responsibilities, cost, and health reasons. Carers need to be an integral part of any virtual ward care pathway, and given a clear choice about providing care. Any attempt to reduce support for virtual wards would be potentially catastrophic for unpaid carers.

Our health and care services are facing unprecedented challenges, and it is unpaid carers across the UK who are bearing the brunt of this crisis. The recent ONS Census in England and Wales found that the proportion of carers providing over 50 hours of care per week has increased over the last 10 years, and carers’ health and wellbeing is suffering as a result. Many carers are concerned about their health but unable to get help due to concerns over long waiting times.

Carers have also told us how difficult it can be to find help for the person they care for, particularly when services are not joined-up, and they are not recognised as a carer. Many carers find it challenging to provide care when their loved one has been discharged from hospital, and it is vital that carers are given the support they need with this. While virtual wards may enable people to receive the care they need at home, in a more comfortable environment, carers must be given a choice about how care is provided.
Supporting carers with their caring role

Summary

• The most common source of support for carers was family and friends. 54% of carers said they were receiving support with their caring roles from family and friends.

• 36% of carers disagreed that the social care support met their needs and the needs of the person they care for.

• A fifth of carers (20%) said they received support from a local carers organisation, with many carers telling us how beneficial this support had been.

• However, nearly half (48%) of carers said they needed to know what support might be available for them and how to access it.

• 76% of carers agreed they were worried about being able to provide care in the future.

• Over half (53%) of carers said they weren’t sure how to plan for the future and would like more support with this.

• 74% of carers said they don’t like thinking about the future as it makes them feel anxious or stressed.
A huge proportion of carers told us that caring can be stressful. For some carers, issues with health and social care services can create additional stress. This can result in carers providing more care themselves and not prioritising their own health and wellbeing. For other carers, a lack of knowledge about where to go for help and advice means they may not be getting the support they need to take a break.

We asked carers whether where they were receiving support with their caring roles.

Table 7: Where carers are receiving support with caring

<table>
<thead>
<tr>
<th>Where carers are receiving support</th>
<th>% of carers receiving support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, friends or neighbours</td>
<td>54%</td>
</tr>
<tr>
<td>Social care services (eg residential care, day/drop in centres,</td>
<td>41%</td>
</tr>
<tr>
<td>A local carers organisation (eg a carers group)</td>
<td>20%</td>
</tr>
<tr>
<td>Healthcare services (eg NHS funded services)</td>
<td>14%</td>
</tr>
<tr>
<td>A national charity for unpaid carers (eg Carers UK)</td>
<td>7%</td>
</tr>
<tr>
<td>A local charity or community organisation</td>
<td>7%</td>
</tr>
<tr>
<td>A faith organisation or place of worship</td>
<td>2%</td>
</tr>
</tbody>
</table>

The most commonly reported source of help and support was family, friends or neighbours (54%). More carers said they received support from family, friends or neighbours than health or social care services.

“I’m 43 and haven’t been in a relationship for 17 years, as I just see myself as someone with so much baggage and have to ensure my son is looked after 24/7. I’ve joined two fitness classes but find it so awkward to have to depend.”

“Friends are wonderful. Local CC provides payment for Respite but it is always on the same day and all hours assessed as essential to be taken in one block.”

Carers who said they were often/always lonely were less likely to receive support from family, friends or neighbours (36%). In addition, although 54% of carers said they were receiving support from family, friends or neighbours, a fifth of carers (20%) said they needed more support from family and friends.

“*I am a support for the family to help fill gaps in the care provided by social services and night care.*”
41% of carers were receiving support from social care services. We asked those carers whether they were satisfied with the support they were receiving from social care services. Over half (52%) agreed they were satisfied with the quality of care provided, and over half (52%) agreed that the support was consistent. However, a quarter (25%) disagreed that they were satisfied with the quality of care, and over a third (38%) disagreed that the support met their needs and the needs of the person they care for. 33% disagreed that they would be listened to if they had any concerns about the quality of care.

“The people that come out to us clearly haven’t looked at our files which inevitably means our precious time off caring for our daughter is taken up answering questions that wouldn’t need asking if they’d done their homework. Very occasionally we get someone who does read our file prior to visiting but they rarely stay in post very long.”

“The [paid]carers who come to do the leg washing and dressings are very variable in experience and some have caused problems/ small wounds when apply compression stockings. There are some that seem to have been taken on with no health care experience and I wonder how much training they get. They also are under so much time pressure, new systems of appointments put in place that seem to cause them stress.”

“[The paid] carers cannot seem to read the notes around the house to help care for my relative. Every time I go in there is something not done properly. They do not follow the care plans in place. They do not put my relative on the commode so when I go in I have to hoist my relative on my own to toilet. I have spoken to the manager on more than one occasion but nothing changes. I have to hoist my relative after a 12 hour shift when I am really tired. My relative has been left with food on her face, teeth not brushed, put back on a soiled chair. The list is endless.”

40% of carers receiving support from social care services said the support enabled them to take a break from caring. However, 38% disagreed that they can rely on social care services and 29% disagreed that the support is consistent.

“A dementia patient would be much better helped with the same [paid] carer coming in every day. Even 2 to share the week. So far it is very random and we are lucky if the same one appears more than once.”

“They are under pressure with recruitment and retention and that occasionally translates into no shows or timings that don’t fit into the contract we have.”

“Care worker always in a hurry and don’t stay the full time allocated. Consistency of care workers varies.”

Over a quarter of carers (20%) said they received support from a local carers organisation and 7% said they received support from a local charity. Many carers said they had taken part in health and wellbeing activities organised by local groups or charities, while others had benefited from listening support and counselling.

“I have been on several activities with Carer’s charity Neath which have been lovely to make time for me.”

“Support and activities organised by wonderful staff at Bridgend Carers and amazing mutual help from fellow carers.”
Other carers said that local carers groups or local charities had helped them to identify and obtain support by signposting to other services.

“Carers Outreach, Bangor, have been very helpful over the years with general advice on navigating the system of benefits.”

“There is a carers’ association in NPT, but I am usually unable to attend their activities as my partner attends physio 4 days per week at various times.”

Some carers said that local carers groups enabled them to speak to other carers about issues and challenges.

“Community groups for one of the people I care for have been a lifeline for the person and also respite for myself.”

“Meeting other carers once a month is a lifeline. Swimming subsidy to help me relax too.”

While some carers were already receiving support in helping them connect with others, 32% said they would like support to prevent or reduce their loneliness/social isolation, and 32% said they would find it helpful to have online support groups and activities for carers.

Carers UK runs a number of different groups for carers as do many local carers organisations who have a combination of online and in-person activities since the pandemic.
Information and advice

48% of carers said they needed to know what support might be available and how to access it. This increased to 61% for carers who had been caring for 2 years or less. 22% of carers said they needed more information and advice about caring. Some carers said that information and advice about financial support and the benefits system would be helpful, while others said they needed more guidance on what practical support with caring might be available.

“I feel support is hidden unless you ask for it.... I don't know what I'm entitled to and now I have ill health.”

“We need a one stop shop to access support and grants available.”

We asked carers where they got information and advice from about caring.

Table 8: Where carers get advice about caring

<table>
<thead>
<tr>
<th>Where carers get information and advice from</th>
<th>% of carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internet search</td>
<td>44%</td>
</tr>
<tr>
<td>A local carers organisation (eg a carers centre or carers group)</td>
<td>27%</td>
</tr>
<tr>
<td>GP or health professional</td>
<td>22%</td>
</tr>
<tr>
<td>A national carers charity (eg Carers UK)</td>
<td>18%</td>
</tr>
<tr>
<td>Other carers</td>
<td>17%</td>
</tr>
<tr>
<td>Family or friends</td>
<td>17%</td>
</tr>
<tr>
<td>A charity specialising in a particular illness, condition or age group (eg Age UK, MS Society, Mind)</td>
<td>16%</td>
</tr>
<tr>
<td>I don’t know where to get advice or information</td>
<td>16%</td>
</tr>
<tr>
<td>Local authority</td>
<td>9%</td>
</tr>
<tr>
<td>Pharmacy</td>
<td>6%</td>
</tr>
</tbody>
</table>
The most commonly reported source of information and advice was the internet (44%), followed by a local carers’ organisation (27%) and GP or health professional (22%).

Although 54% of carers said in a previous question that they received support from family and friends, only 17% said they got information or advice about caring from family and friends. This suggests that the support provided by family is emotional support, or practical support (such as providing replacement care).

17% of carers said they received information and advice from other carers. This increased to 38% for carers who were receiving support from a local carers’ organisation, suggesting that local carers centres or groups can play an important role in bringing carers together and allowing them to share information and advice.

Concerningly, only 9% of carers have received information from their local authorities despite the legal mandate in the Social Services and Wellbeing Act. However, it should also be noted that the local authorities do fund many of the local carers organisations which is a mitigating factor.

Several carers said they found it hard to access information and advice.

“I find that information isn’t specific enough for my situation and often English policy is different to Welsh policy.”

“As it is simply "helping an elderly relative" it is very difficult to obtain any advice because he’s "just" old.”

“Just signed up to local carers support group, but not sure how helpful they will be or what resources there will be in the rural location I’m in.”

31% of carers said they weren’t sure how to plan for an emergency

Planning for the future

We asked carers whether they considered what might happen if an emergency prevented them from being able to support the person they care for. 43% said they had identified people to provide care in their absence, and 21% said they had a plan in place if they were unable to provide care in an emergency. However, a third (31%) said they weren’t sure how to plan for an emergency and would like more support with this, and 29% had never considered planning for an emergency. Some carers said they were too busy to plan for an emergency, while others said they didn’t want to think about the future as it caused them anxiety.

“I do not have another option in an emergency. Thinking about it makes me panic”

“This thought has now worried me as I have not prepared for the eventuality of me being unable to care.”

“I desperately need to plan for an emergency and have requested support with this many times! I am so, so worried about what would happen if there was an emergency, I am a single mother.”

Many carers expressed anxiety about what would happen to the person they care for if an emergency prevented them from providing care. Some carers felt that other family members would be too busy or live too far away to provide care. Others felt that health and social care professionals wouldn’t understand the needs of the person they cared for, or the person they cared for wouldn’t accept support from someone else.

“What happens if I become ill?”

“Will all good intentions, plans are not always practical or worked out!”
We asked carers whether they had considered what might happen if they were unable to provide care in the future, or had to cut back on the amount of care provided. **76% of carers said they were worried about being unable to provide care in the future.** Many carers felt their ability to care might change over time as they got older.

“**I have the form from social services to set up an alternative plan, but do not know enough people in and who would be able to step up and help. He seriously believes that without me his life would be so diminished that for him under those circumstances, suicide would be the only logical plan.”**

“**I am 91 years old and can no longer cope but I feel no one believes me.”**

A quarter of carers (24%) agreed they had a plan in place if they were unable to provide care in the future. However, **74% said they don’t like thinking about the future as it makes them feel anxious or stressed, and 48% said they don’t have time to think about the future. Over half (53%) of carers said they weren’t sure how to plan for the future and would like more support with this.** 21% said they had tried to put a plan in place but didn’t receive support from health and social care services.

“As the sole carer for my husband my biggest worry is having a contingency plan if I was ill and unable to care for him. Without my input he would be unable to get in/out of bed, shower chair, manage his bowel care etc.”

76% of carers said they were worried about being unable to care in the future

53% of carers said they would like more support with planning for the future
Clinical tasks

We asked carers whether they carry out any clinical tasks as part of their unpaid caring role. The most common clinical task was monitoring health and wellbeing, with 62% of carers saying they performed this task. A quarter (25%) of carers said they monitored blood pressure or blood sugar, 23% made decisions about whether to give emergency or specialist medication, and 23% dressed a wound.

Table 9: Carers’ experiences of clinical tasks

<table>
<thead>
<tr>
<th>Clinical task</th>
<th>% of carers who do this</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monitoring mental health and wellbeing</td>
<td>62%</td>
</tr>
<tr>
<td>Monitoring blood pressure or blood sugar</td>
<td>25%</td>
</tr>
<tr>
<td>Making decisions about whether to give emergency or specialist medication</td>
<td>23%</td>
</tr>
<tr>
<td>Dressing a wound</td>
<td>23%</td>
</tr>
<tr>
<td>Using equipment such as hoists to lift someone</td>
<td>11%</td>
</tr>
<tr>
<td>Giving injections as medicine</td>
<td>7%</td>
</tr>
<tr>
<td>Using an oxygen or CPAP machine</td>
<td>6%</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>3%</td>
</tr>
<tr>
<td>Suctioning</td>
<td>1%</td>
</tr>
<tr>
<td>Helping someone on dialysis</td>
<td>1%</td>
</tr>
</tbody>
</table>
Carers providing 50 or more hours of care were more likely to carry out clinical tasks. 31% of carers caring for 50 or more hours made decisions about whether to give emergency or specialist medication compared with 16% of carers caring for less than 50 hours. Carers who lived with the person they cared for were also more likely to carry out clinical tasks. 23% of carers who lived with the person they cared for were involved in monitoring blood pressure or blood sugar, compared with 23% of those not living with the person they cared for.

Many carers felt that they lacked any training to do clinical tasks and were anxious about whether they were performing these tasks correctly.

“Colostomy, virtually no support, trial and error and NO choice about having to do it.”

“I am not medically qualified to carry out such tasks but have to in order to help those I care for.”

“No training given, no choice about taking on tasks.”

“Getting new tubes for ACE procedure is difficult and there is no specialist nurse to liaise with and trying to see the consultant is difficult because understandably he is very busy with nobody available to deal with routine problems.”

Of those who had received training, many had had this through prior employment in health and care services. Some carers had received support from healthcare professionals or local charities. Others had taught themselves, through the internet. However, many carers said that more training and support would be helpful. Over a quarter (27%) said that vital signs monitoring such as blood pressure monitor, blood glucose monitor and heart rate monitor would be helpful.

62% of carers said they were involved in monitoring mental health and wellbeing.

Some carers highlighted a lack of support for this.

“No support or training for mental health and wellbeing. I just get along and meet problems from day to day and try not to worry about the long term.”

Carers often need practical support to enable them to carry out their caring role and to look after their own health and wellbeing. However, many carers are not getting the support they need, particularly with complex caring tasks like clinical tasks and support with medication. Many carers are also unsure about how to plan for the future in the event of an emergency, or if their own health declines, particularly as they get older.

Carers charities, carers centres and carer support groups can provide much-needed support for carers, reducing loneliness and isolation. But carers can only take advantage of these services if they receive appropriate and affordable replacement care. It is vital that carers get the help they need with their caring roles, to help reduce carers’ stress and improve wellbeing.
Recommendations

This report makes it evident that large numbers of carers in Wales are struggling with their health and many are teetering on the edge of their ability to continue to provide care. A significant proportion of carers have life-altering mental health concerns while many others are putting off or waiting for health treatment that would improve their physical health. This strongly tallies with carers having a high level of concern for what the future holds for them.

With recent analysis by Sheffield University and Carers UK finding that unpaid carers saved Wales £10.6 billion over a 12 month period, investment in the health of carers and their ability to continue to provide care is investment in the very foundations of the health and care system. Failure to protect and improve the health of unpaid carers will lead to significant further strain on the health and care system.

Caring should be a part of every public health programme. There are clear opportunities to identify unpaid carers and support them through their healthcare journey which could transform carers and the lives of the people they care for.

Protecting carers’ health could be transformed with reasonable changes to systems and processes from early identification within health, to documentation of their status as a carer on medical documents and establishing unpaid care as a clinical prioritisation factor.

Tackling the immense health challenges facing unpaid carers requires action from the UK Government as well as the Welsh Government. Carers Wales therefore fully supports Carers UK’s recommendations found in the UK State of Caring report.
Carers Wales recommends the Welsh Government:

- Allocate at least £1m to Health Boards in the 2024/25 financial year to improve the experience of unpaid carers when the person they care for is admitted to or during hospital discharge, based on the £1m funding allocated in 2023/24.
- Establish unpaid care as a clinical prioritisation factor
- Ensure funding for information and advice services provided by local authorities is adequate
- Work with NHS Wales to review the current state of carer identification and recognition in health settings and explore how these can be enhanced. Create a unique fund for mental health support for unpaid carers including access to counselling and independent well-being services
- Use carer feedback gathering through the monitoring of the national short breaks scheme 2022-25 to revise and improve the scheme as it rolls out. Further investment in short breaks is needed to ensure carers beyond the 30,000 targeted by the scheme can access the breaks they need.

Carers Wales recommends the NHS:

- Incorporates unpaid care into mandatory training in all disciplines so that identification and understanding of carers rights are ingrained into the health service
- Produce guidance for staff to help them identify when an unpaid carer may benefit from mental health support with advice on utilising referral routes to enable the carer to access support as soon as possible.
- Ensure all patient records, including forms used during hospital admission/discharge and GP records, include whether someone is an unpaid carer or has an unpaid carer
- Create safe and secure methods of sharing carers’ health and care information between different components of the NHS and social care system
- Ensure all teams involved in hospital discharge are aware of carers rights under the Social Services and Well-being (Wales) Act 2014 and incorporate carers into discharge processes accordingly

Carers Wales recommends local authorities:

- Increase resourcing to information and advice services for carers so more carers are aware of their rights under the Social Services and Well-being (Wales) Act 2014
- Work with national and local charities to create more health and well-being opportunities for carers in the community
Further support for carers

If you are a carer whose mental health is affected by their caring situation, there are sources of support for your mental health. The first person to talk to is your GP. The NHS website also has lots of helpful information on it. If you are in a crisis, you can ask for an urgent appointment with your GP, or call your local NHS urgent mental health helpline. It is okay to go to A&E or call 999 if you can’t keep yourself safe. The Samaritans have a listening service on 116 123, or you can text “SHOUT” to 85258 to contact the Shout Crisis Text Line.

There is also further information relating to mental health on the Carers Wales website. Our local directory also has details of local organisations which support carers in each area.

For carers in England, the Mind website and the Rethink Mental Illness website both have information and contacts relating to mental health problems.

Carers in Scotland can contact Breathing Space or the SAMH information service.

For carers in Wales, the charity Adferiad supports people with mental health problems.

Carers in Northern Ireland can contact Action Mental Health Mindful Carers Project or MindWise carer support.

This is the first of a series of reports based on data from State of Caring in Wales

Across the UK today 5.7 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We’re here to make life better for carers.

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