



**What Matters Most
to unpaid carers**

**The Experiences of Unpaid
Carers
in Portsmouth**

Final Report February 2021

Introduction

About Healthwatch

Local Healthwatch organisations are independent champions for people who use health and social care services. We are here to find out what matters to people and help make sure their views shape the support they receive.

Project background and development

In May 2020, Healthwatch Portsmouth worked in partnership with three local Healthwatch organisations (Hampshire, Southampton, and the Isle of Wight) to find out if people had been able to access the information, services and support they needed during the Covid-19 pandemic. The survey ran until July 2020 and collected people's experiences of using health and social care services.

The responses we received about social care services, highlighted that there was a lack of support for those who were caring for adults or children. These comments indicated that unpaid Carers, felt 'abandoned' and 'left to get on with it'. The sample size for this part of the survey was small, so we decided to undertake further work to uncover the challenges that unpaid Carers faced during the pandemic.

About the survey

NHS England "An unpaid carer is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support."

We asked Carers:

- What has helped or been useful to you during this time?
- What would you like to see changed or would help you in the future?
- What is your experience of being an unpaid carer during the current Covid-19 pandemic?

Carers were able to tell us their views anonymously via an online survey, email, telephone or by letter.

The survey was also promoted by a range of stakeholders such as local councils, Carers organisations including the Carers Centre, voluntary sector organisations, Portsmouth University, further education colleges and NHS trusts.

The project was launched on the 16th November 2020 and we produced a mid-December interim report and planned a final report by February 2021. Since the survey launched, we have had 108 responses from people who have identified themselves as unpaid Carers living in Portsmouth (postcodes PO1-PO6).

Key findings

The Challenges Facing Unpaid Carers

- 90% of respondents said that they were not able to access Adult Day/Respite Services
- 71% of respondents stated that their caring duties have increased during the Covid-19 pandemic.
- 59% of unpaid Carers identified that they were not able to have a break from their caring responsibilities during the pandemic.

- “No services available to support with the suspension of all face-to-face contact.”*
- “Respite breaks were not available for dementia clients. If they had been though, 2 weeks’ isolation would have meant a worst-case scenario for clients”.*
- “There is no one else”.*
- “I’ve gone out roughly 10 times since March 23rd. Because my mum is in the shielding group, I’ve also shielded with her”.*
- “My usual respite is when my sister visits. Family being able to provide respite for Carers is not considered in the lockdown guidelines, although providing childcare is. My son has mental health difficulties and there is no provision for respite anyway.”*
- “One carer eventually had the cared for person admitted to hospital, just to get a few days’ sleep. Not the best use of NHS facilities, but they were on their knees.”*

The Impact On Carers

Family life and relationships - being a carer has put people's relationships under strain and been disruptive to their family life.

Mental health - Carers' mental health has deteriorated during the pandemic. Survey responses state people feeling **isolated, frustrated, sad, alone, worried, bored, trapped, and afraid for the future.**

Employment - Carers spoke about **struggling to fit work around the demands of caring and their family life.**

Financial pressures - Carers highlighted the **additional financial pressure** they have faced. An example of this includes **reduced working hours** due to full-time caring.

Physical Health - Carers have stated that caring during the pandemic has had a negative impact on their physical health. They have said it has been **harder to get out of the house to exercise** due to the risk of leaving the person they are caring for alone.

What help or support were they looking for?

-  46% of respondents said they were looking for help with a health problem (person they care for).
-  38% of respondents were looking for help with **getting medication and respite/or a break.**
-  72% said they could not access the **NHS Responder scheme.**

The other options people were looking for support were:

- *“Help with home learning”.*
- *“Help with internet and devices for home learning.”*
- *“Help with keeping my child active and helping him get outside.”*
- *“Moving to care home.”*
- *“It would be nice to have assistance with shopping and essentials as I do not like shopping at all during this pandemic”.*
- *“Carers assessment (Awful capacity assessment which kept changing)”.*

What did Carers find helpful?

- 54% said that their GPs were helpful.
- That ASDA has increased the number of deliveries they can do.
- Mental health support via primary care.
- Online services, food boxes, church, library services, local groups, school.
- Being able to access medical appointments by video link or phone has been helpful.

What Carers said they needed for the future?

- Recognition and Support.
- Getting a chance to speak to a doctor.
- Financial and emotional support to help us recover from this pandemic.
- I would like the Government to see respite as an essential service whether provided by family/friends or the local authority.
- More help for unpaid Carers, more understanding that it is not humanly possible for the carer to be a superhero all the time and they need a break too.
- Easier access to social services and a more joined up approach.

Carers Assessment

- 45% said they were not able to get a Carers Assessment during the pandemic.
- 43% did not know what a Carers Assessment was.
- 65% of Carers who answered the survey have registered as a Carer with their GP.
- 34% of Carers in this survey have not registered as a Carer with their GP.

What are your experiences of being an unpaid Carer during the Coronavirus pandemic?

- *“Traumatic, as it was unclear where to get support from, I was not sure who to approach, were GP Surgeries open?”.*
- *“During the pandemic, my child has deteriorated. This has meant that my caring role has been even more work. The physical and emotional strain that it has taken on has been hard”.*
- *“Working from home helped, but I felt isolated juggling work, caring, frustrations at poor communications of changed processes, getting things fixed indoors etc”.*
- *“Worried about what will happen to the person I care for if I become unwell. Feeling very lonely”.*
- *“Overwhelming feelings of guilt that there is only so much I can do”.*
- *“It is too painful to look back and fully comment on it all. It was a very difficult time and extremely hard; mentally emotionally and physically. It is an experience that I hope we do not have to do again. We were left alone to fend for ourselves just the two of us. Four days after lockdown I was diagnosed with cancer. I had to hide this from my child and carry on as if nothing had happened. It is not acknowledged that I am a carer for my son because I am his mother.*
- *“During the pandemic, my child has deteriorated quite a lot which means the caring role has been even more work. The physical and emotional strain that it has taken on has been hard”.*
- *“Stuck - no matter how much I understand about the necessary limits caused by the pandemic in general, there are much more complex limitations and difficulties surrounding unpaid Carers like myself who live with mentally an ill person”.*
- *“Feeling unsupported as services were prioritised, we were not a priority and were only interested in crisis situations. Loneliness because I had to work from home, juggling the need to give attention and keeping vigilant whilst being home. Privacy and confidentiality is more difficult”.*

Why did you become a Carer?

- *“Family member. My duty as a mother. By choice as a human being”.*
- *“My mother had a stroke in January and father has onset undiagnosed dementia”.*
- *“Partner struck down with a functional neurological illness and MH issues - impossible to continue working”.*
- *There is no fixed point when someone becomes a Carer. Anyone who has relationships will care for others, but the needs of others fluctuate and sometimes deteriorate, and the caring role becomes more intense and more one-sided.*
- *“Circumstance”.*
- *“Mother became ill, father passed away and other children unwilling to help”.*
- *“Had no option after my son attempted suicide and was diagnosed with a serious mental health illness, that now we know is chronic”.*
- *“It started off with just helping out on a few things, but quickly dependency increased”.*
- *“I am her only relative and she is physically disabled and has learning disabilities. She lived with my mother and when she died 25 years ago, I have been the only person she has to help with day to day living and help with paperwork etc.
Before she was 'locked down' although she has many problems including mobility, she was able to go out most days with the use of a walking aid and also to eat out, now I am the only way she can get out”.*

Demographic



40% identified as ages 55-64
33% are 35-54
26% are 65+



78% identified as female
16% male
1% prefer not to say



85% identified as white British
5% white other
3% stated "any other ethnic group."



88% identified as Heterosexual/Straight
3% identified as Gay
5% preferred not to say



65% identified that they do not have impairment or disability
27% stated they do.



Areas covered PO1 - PO6



55% identified that they have been a carer for 10+ years
20% have been a carer for 1-4 years.

Healthwatch Portsmouth Recommendations

These are our recommendations which we will discuss with partners and key stakeholders to help ensure the voices of Carers are heard, to understand what has been helpful and what they need from services they rely upon.

- **Greater access to short breaks** including breaks that family members can offer should be made available to Carers at short notice to **relieve the pressures** Carers are facing.
- **Better signposting for Carers** (via GP-referred social prescribing services) to primary care based mental health and financial support packages **tailored to their stated needs**.
- A **'carer pathway to access social care services'** to be mapped out (and produced as an explainer via hard copy or URL). **To help carers to better navigate services**.
- The **'Carer pathway explainer'** to be provided to Carers when registering with a GP practice or contacting Portsmouth Councils City Help Desk.
- To review and comment on public **access points to the NHS Responders Scheme** to help address the **access difficulties** experienced by Carers.
- **Information on the Carers Assessment** to be included on each Portsmouth GP surgery website to **raise awareness** and encourage more Carers to register.
- **Prioritise GP appointments in Portsmouth for Carers** to help them access care when they need it to **maintain their own health and wellbeing**.
- To work with the Carers Centre to review why **45% of respondents** said they could not get a Carers Assessment.
- To provide survey respondents **who identified they needed further information** with the email address of the Carers Centre in Portsmouth.
- More support to be offered to Carers, such as **extending 'support bubbles' from family members** to carers during the COVID-19 pandemic to **address their emotional needs**.

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