healthwatch Hampshire

Caring during Covid-19

The experiences of unpaid carers in Hampshire

December 2020

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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 Hampshire worked in partnership with three local Healthwatch organisations (Portsmouth, 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

"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."

NHS England

The survey was developed in partnership with local carer organisations, Carers Together and Hampshire Parent Carer Network. We asked carers:

- **What is your experience of being an unpaid carer during the current**

Covid-19 pandemic?

- **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?**

Carers were able to tell us their views anonymously via an online survey, email, telephone or by letter. We also spoke to carers via online workshop sessions organised by the Hampshire Parent Carer Network and the Princess Royal Trust for Carers.

We engaged with young carers groups via the Young Carers Alliance and through sessions run by youth projects at Elson Junior School and the New Forest Young Carers Project. The survey was also promoted by a range of stakeholders such as local councils, voluntary sector organisations and NHS trusts.

Key findings

179 Adult Carers
spoke to us via email, telephone and zoom workshops.

10 Young Carers' Groups

provided us with feedback from young people.

The challenges facing carers

- Unable to get a break
- Problems getting essentials like food and medication
- The closure of day services and schools
- An increase in the hours devoted to caring
- Difficulty explaining the pandemic to vulnerable people
- A lack of recognition and respect

- Problems accessing health and social care services
- Unsure of the help and support available for carers

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. Responses document 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.

Young carers' experiences

- Problems engaging with schoolwork
- Digital exclusion
- An increase in young carers' responsibilities at home
- Financial pressures on their family
- Breakdown in support networks
- Changes in family relationships and home life
- Negative impact on young carers' mental health

What did carers find helpful?

- Getting a break
- Keeping connected with friends, family, and peers
- Support and advice readily available when needed
- Regular "check in" calls
- Help getting essentials like food and medication
- Local community schemes
- Being able to use technology

What carers said they needed for the future

- Access to respite and day services

- Being recognised as a carer by GP surgeries
- More mental health support
- Financial recognition for caring roles
- Joined up services
- Easy, quick ways to get advice
- Being aware of what services there are for carers
- More support before a crisis

Section One:

The challenges carers faced during the pandemic

Unable to get a break

"I care for my husband who is totally paralysed and there has been no one to leave him with."

70%

of carers have not had access to regular breaks.

We asked carers if they had been able to take regular breaks during the pandemic. Many of those who responded said that they had not been able to take any breaks at all, as there was no one to look after the person they cared for, and it was not safe to leave them on their own.

I am completely on my own with this, I don't get any help, support or advice and am struggling with my own health.

My husband has dementia, I do not like to leave him alone in the house, so I rarely take a break. He might be fine for a couple of hours, but it is a risk.

"No one else is available to do any of the caring I do."

In some cases, people were not able to take a break because the services they usually used were closed because of the pandemic.

All day services stopped during the lockdown.

Any services, charities, and short breaks that we normally use are closed.

Local carers centre closed. Groups my husband went to all closed. Sitting service closed.

I was used to my husband going to a care home for the day on Mondays and Fridays from 10am till 5pm.

"With schools closed but my husband and I still working we struggled with our son at home all day. We don't get much help anyway, but it was completely impossible in lockdown."

Several carers pointed out that the lack of respite care was not a new occurrence as they did not have access to regular breaks before the pandemic.

Never get breaks, husband is now housebound due to social anxiety and it's getting worse.

The eight years I have been caring for my husband, I have never been given that opportunity.

"I have done the caring myself. I am happy to do this, but it would be lovely to feel I could leave him for a day on a regular basis and I would not need to worry."

"Life before Covid-19 was a struggle, life now is beyond awful. We used to have a break from caring once a month, but this was cut before covid due to the austerity measures. We now rarely get a break."

Other reasons for not getting regular breaks

The cost of respite care

"Getting someone to sit with a severely disabled elderly man is difficult and expensive. My family work, two of them for the NHS and their time off is precious."

Respite care does not allow the carer to leave the house

A few carers pointed out that the type of respite care offered did not allow them to leave their house.

"Total hours of support have declined. Most help has been in short breaks which do not permit the carer to go out. Help the Aged care has been increased but they now will not take my wife to the lavatory because they say they are not covered by insurance. The result is that I have to stay in the house."

To shield the person from infection

Several responses mentioned not wanting paid carers to visit the house due to concern about the person they cared for being exposed to the virus.

"Unable to have anyone coming indoors when advised to shield."

"Worries over letting another untrusted person into home with potential virus."

Problems getting essentials like food and medication

“The 89-year-old concerned was not identified as vulnerable and as a result there was limited help to draw on.”

Carers spoke about finding it difficult to get food shopping and medication, particularly during lockdown. Going out to collect essentials was stressful, as they were concerned that they might bring the virus into their home and put the person they cared for at risk.

Some struggled to get online food deliveries as the person they cared for was not considered vulnerable, or they had not received a letter allowing them to register for priority delivery slots with supermarkets.

“I could not get a food delivery as I myself, was not disabled, my son is tube-fed with milk so gets that delivered but I had to go to the shops and risk catching it and passing it on to him, I was very upset, angry and guilt-ridden about this. My mental health was affected by the fear I had if my son caught the virus as I know he would probably not pull through. This system needs to change! We also never received a letter about shielding so were not even able to register my son for home food delivery, I couldn’t understand why as he suffered regularly with chest infections, pneumonia, epilepsy and many other health conditions.”

“Acute difficulty in accessing online food deliveries as the person I care for doesn't qualify as vulnerable despite having multiple health conditions including diabetes and asthma. Difficulty getting repeat prescriptions as the person I look after has no photo ID so I could not use the NHS app.”

Carers also found it difficult to order repeat prescriptions and said there were long waits for collecting both medication and prescriptions. Several said that errors had caused them to make unnecessary trips out to rectify mistakes.

“Sorting out the medication and prescription for my parents and myself was a nightmare in the early days of lockdown - I had to wait in queues at the chemist for up to 1.5 hours so eventually I took a deckchair! It wasn't just the waiting around, but the number of errors that the chemists made - at one stage 8 out of 9 sets of prescriptions were wrong.”

“I tried to only go out when absolutely necessary to shop for food, medicines and do caring duties. Errors in prescriptions by GP practice and pharmacy meant I needed to pick up medicines more often than I should have needed to. Queueing for medicines when I find it so painful to walk or stand made my situation worse.”

Closure of day services and schools

“The main problem is that all the groups the person I look after goes to, have closed down, so she is stuck at home.”

Day services for adults and children provide activities and opportunities to socialise for people with disabilities or health conditions. Their closure had a profound effect on the health and wellbeing of both the cared for person and their carer. In their responses, carers spoke about witnessing a rapid decline in their loved ones mental and physical health, which they believed was caused by the loss of routines, the lack of meaningful activities and not having the opportunity of interacting with different, but reassuringly familiar people. The loss of established routines was particularly difficult for people with Alzheimer’s who find familiar people and routines calming and reassuring.

> “*Husband has Alzheimer’s and for him not to be able to understand what is happening and for myself shielding made it doubly difficult. All routine out of the window and he is very depressed and anxious.”*
>
> “*Life has been very difficult during the pandemic as all the groups my husband was attending were closed. He has Alzheimer's and he has definitely deteriorated during this year and consequently I have found it very stressful trying to manage him by myself. He has times when he is extremely confused and/or agitated and this has taken its toll on my mental health. I have been at my wits end knowing what or whom to turn to.”*

The closure of day services for adults and children also amplified the pressure on carers by increasing the hours they spent caring and, in many cases, leaving them without any respite from their responsibilities. Carers reported that their loved ones experienced increased frustration, anxiety and agitation, which made caring for them more stressful and demanding.

> “*A 22-year-old with learning disabilities unable to access any of his normal services. We did what we could to help him to stay busy, but he has gradually become more and more frustrated and low in mood.”*
>
> “*I had no respite by being able to take mum to her usual older persons activity groups. Her Alzheimer's disease worsened considerably during lockdown with increasingly challenging behaviour. I felt trapped with nowhere to turn to for a break. As a disabled 67-year-old, not in the best of health myself, I felt dragged down even more.”*

Carers spoke about feeling guilty because they could see the person they cared for was deteriorating, but were unable to help. They also said they felt frustrated, as they struggled to manage increasingly challenging behaviours without support or respite.

> “*Frustration that I am unable to support my brother and his mental health is worrying.”*
>
> “*Frustration. Guilt. Sadness.”*

The closure of schools and youth groups impacted on children with disabilities or health conditions, for whom school provided structure, positive activities, and social opportunities.

> “*Really, really hard work physically. Mentally draining. Our son can do a lot of things for himself, but he needs a lot of support, encouragement, motivation and a positive environment. Usually, we can share being upbeat with school staff and wider friends and family.*
>
> “*My son enjoys going out and socialising regularly at groups and doing sports for kids with disabilities. He is out of school whilst we try to find a suitable new one so these groups are his (and my) only breaks. They have been closed or limited due to the pandemic.”*

An increase in the hours devoted to caring

The number of hours people spent caring increased during the pandemic, due to services not running and elderly and vulnerable people who were shielding being more dependent.

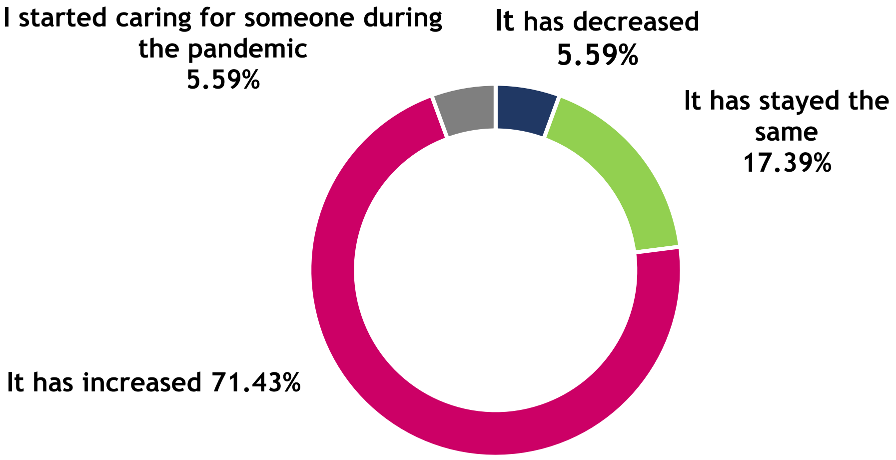


Figure 1 Has the number of hours you dedicate to caring changed during the Covid-19 pandemic?

“Now day services are starting up we have to provide transport which entails a lot of travelling and trying to fit in to work schedules.”

Care duties increased dramatically when mum was shielding. No one else went in her home and I really struggled doing it all.

I ended up doing virtually everything because all her helped stopped due to the pandemic.

In some cases, carers moved their loved one into their home, as they did not have the level of support needed to cope with living independently.

> *[My daughter] has been diagnosed with autism which is why she couldn't cope with so much change. Moving her into my house was the only option. I was working from home and it meant I could keep her calm, shop and cook for her and she didn't need to deal with the strange world outside. It was tiring physically but very draining mentally.”*
>
> *There was no emergency support that I could access so I moved my mum into my dining room for approximately 6 weeks and became her full-time carer. Whilst I did this willingly, I often felt over-whelmed and "on my own".*

About 6% of carers said that the amount of time they spent caring decreased as their loved one was hospitalised or in a residential care setting. Although this meant that they had less responsibility meeting the person’s day to day needs, carers said that being separated from the person caused them both to experience anxiety, especially when they had limited opportunities to visit them.

Hard, as many people don't understand the personal dilemma faced deciding if it’s safe to visit a loved one or not.

Isolation and not being able to support by visiting causing emotional distress for cared for and carer.

“I have not been providing the same physical support, but emotional support has increased significantly. It is not unusual to have several calls a day checking we are OK and asking how long this will go on for and whether he can still come for Christmas etc..”

Difficulty explaining the pandemic to vulnerable people

Carers said that some elderly people and people with disabilities struggled to understand the implications of the pandemic, or the guidelines that would keep them safe. This caused carers to worry that they might put themselves or others at risk by going out unnecessarily and not adhering to social distancing rules. It was also difficult for carers to explain why they could not see friends or extended family and why the services and social activities they used were no longer operating.

> “*It has been difficult at times with no experience of caring for an old person let alone someone with health issues during a pandemic when they don’t understand why they can’t go out or know what the rules are.”*
>
> “*The person I look after has a learning disability and could not understand why everyone who helps out was not coming to see them, they felt very lonely and isolated this then led to severe distress”*

Lack of recognition and respect for carers

“We are not prioritised within the NHS…They don’t understand that I can’t leave her alone, and I don’t have time to wait. Carers should be prioritised.”

Many people told us that they felt their role as a carer was not valued or recognised within the health and care system or by their wider community. They felt that carers were invisible, taken for granted and ignored.

Unpaid carers should be respected more.

Tiring, exhausting, lonely, skint, ignored by government. Dismissed as a human being. Undervalued. Invisible.

Several carers shared experiences of their encounters with health professionals who did not respect their caring role or understand their unique relationship to the person they cared for.

> “*No one really believes you when you say you care for someone. Doctor’s surgery does not make any special arrangements to try and support - you’re just another number in the system.”*
>
> “*When my husband needed A&E access as told by NHS 111 we were treated like dirt. I was refused access with my husband, shouted at in front of nursing staff and told by a receptionist to shut up! All I was doing was helping my husband answer questions and reassure him. He was so distressed he tried to discharge himself and had to be taken back by a nurse (I witnessed this).”*

Carers felt that their needs and special circumstances were often not considered by their GP surgery or when they visited hospitals. They felt that the lack of recognition or awareness of the issues affecting carers by health care providers meant that services are often not delivered in a way that meets their needs.

In some instances, carers told us about having to delay their own medical treatments, as they had no one to look after the person they care for while they attended appointments.

> “*I have a trapped nerve in my neck which is very painful, but I can’t get treatment for it as there is nobody to care for my daughter, so I have to try to deal with the pain”*
>
> “*If I need treatment who will look after my daughter? I can’t leave her and they won’t prioritise us in hospital. The NHS could do a lot more for us. I don’t have the luxury of being poorly as I have to keep going”*

The survey shows that initiatives aimed at supporting carers, such as being able to register as a carer with your GP were not widely known about, with only 54% of carers saying they had done so.

Some carers pointed out that though they spent more hours caring during the pandemic and living costs had increased, that they had not been given access to any financial support.

“I get a carers allowance which is an insult for the amount of care and hours I have to deal with. Not much room for treating myself to something nice or new... To be able to plan to have a holiday is impossible.”

Difficulty accessing health and social care services

Feeling taken for granted and overlooked, links to a consistent theme that carers have been “abandoned” and “left to get on with it” during the pandemic. This goes beyond the closure of day services, with some carers saying that they had found it difficult to access children’s and adults social care, mental health services and their GP surgery.

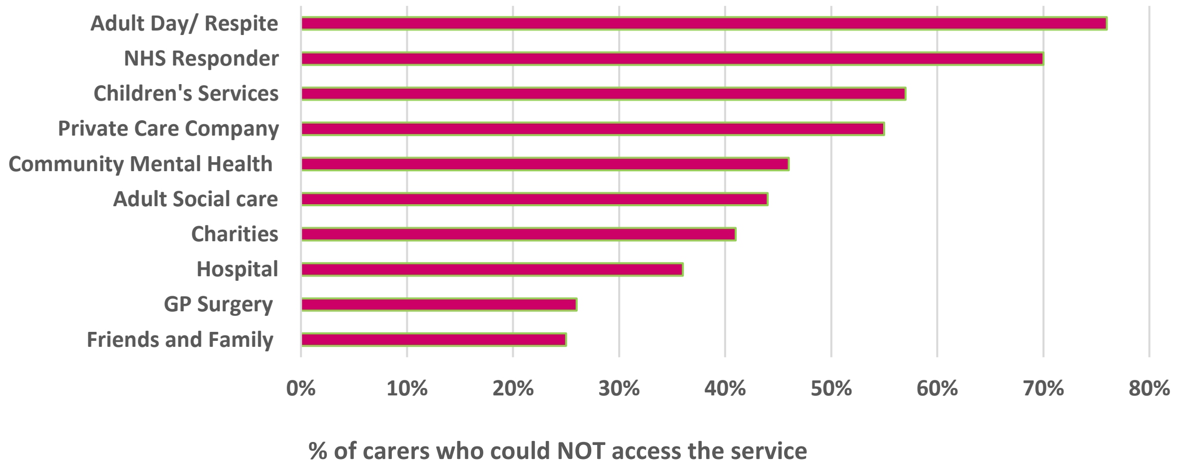
“Not much different to usual, there is and was limited help available to me or my wife. Difficult to near impossible to get in touch with the doctors’ surgery without spending hours waiting for an answer. Not one call or communication from our surgery over the pandemic”

Long waits to access a GP.

Restrictions on home visits has meant risky use of taxis to access GP surgery care for my disabled wife, and buses to enable hospital visits.

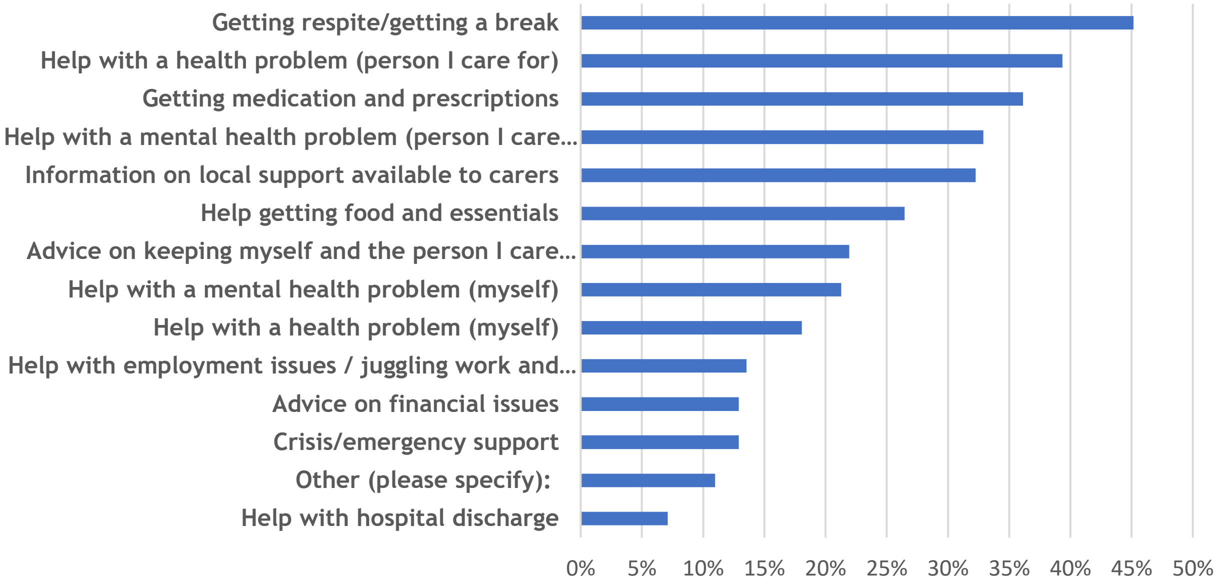
During the pandemic, particularly during periods of lockdown, carers normal support networks disappeared. In some cases, the formal support they received from local services (either through the local authority, care companies or charities) was unavailable to them, leaving them feeling abandoned and alone.

We asked carers to tell us whether they had been able to access the services they needed during the pandemic. The results show that, respite services were the hardest to access with 76% of people saying that they had not been able to get respite.



During our online workshops some carers and professionals from support organisations highlighted that families could not get through to children's services to request support. Staff also reported that they had seen a big increase in parents contacting them in a "very distressed state" as they could not get help. Carers of children and young people with mental health problems said that high thresholds excluded them from getting any support.

We also asked carers what help they were most in need of during the pandemic. Respite services were the most sought after support, followed by help for the person they cared for with a health issue.



The survey also asked carers to tell us how helpful or unhelpful the services they had used had been. Friends and family (69%) and GPs surgeries (49%) were seen as the most helpful during the pandemic.

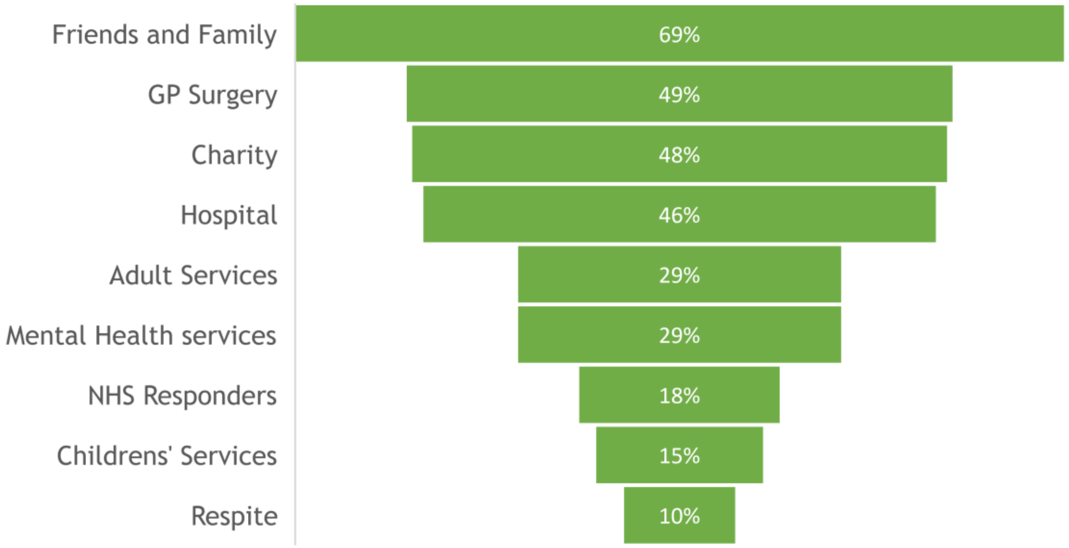


Figure 2 % of people saying the service was 'Very Helpful/Helpful

Unsure of what help and support is available

"I have just been given three hours a week on 'Take a Break' but only because I had reached rock bottom, and someone suggested I contact Hampshire County Council for a carers assessment."

Anyone who helps another adult (usually a relative or friend) in their day-to-day life and needs support, has the right to a carer's assessment, regardless of the amount or type of care they provide or their financial circumstances. Carers' assessments give people the opportunity to reflect on their needs and identify what community services and charities can support them.

Our survey asked carers if they had been able to get a carers assessment during the pandemic. The results show that 11% of people had been able to get an assessment, 38% had not been able to get an assessment and just over half (51%) did not know what carers assessments were.

Most of the responses we received were from people who had been carers for over a year (90%) which suggests this lack of awareness of carers' assessments is a longstanding issue and not due to an influx of people who started caring during the pandemic.

The fact that so many people are unaware of carer's assessments is concerning, as they are a gateway to accessing help, advice, and support.

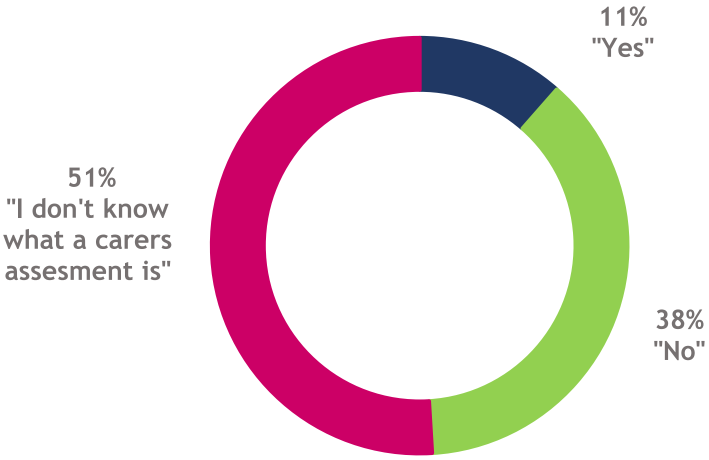


Figure 3 Have you been able to get a Carer's Assessment during the pandemic?

Find out about carers' rights and local support

[Healthwatch Hampshire website carers information pages]

[Care Act 2014 Factsheet 8: The law for carers]

[Visit Carers Trust website 'Carers and the Law' section]

Section Two: The impact on carers

The challenges faced by carers during the pandemic have had far-reaching consequences on every aspect of their lives, including their mental and physical health, their relationships and family life, their finances, and their ability to work.

Family life and relationships

50% of carers said caring during the pandemic had a negative impact on their families' wellbeing

Responses demonstrated the impact that being a carer has had on longstanding relationships and family life.

> “*I felt totally abandoned. My husband has dementia. I was told he had to have socialisation, but everything closed down. The only person he had to talk to for five months was me. Our loving 46-year marriage has broken down and now all we do is argue.”*

> “*It has taken a toll on mine and my partners relationship to the point we have considered if it would be better to separate. It has been mentally, emotionally and physically draining with so many different needs under the same roof day after day, with no help, support or advice.”*

> “*Worst case scenario possible. Husband with PTSD triggers noise and people struggles in half-term with children home. I was six months pregnant, working full time with two children to home school. Very stressful with no let-up took me to breaking point. Planned a home birth that couldn't happen ended up in hospital for four days to be induced with no-one able to help look after other children or care for husband.”*

Mental health and wellbeing

75% of carers said that being a carer during the pandemic had affected their mental health

Responses showed people were feeling isolated, sad, alone, worried, bored, trapped, and afraid for the future. Carers said that because they were responsible for someone’s welfare, they had no choice but to continue despite their own health problems.

“*Feeling alone and lonely due to isolation. Feeling of grief at watching the decline in husband due to dementia.”*

“*It has seriously impacted my mental health, in turn the mental health of the person I care for. It’s a vicious cycle of negative energy.”*

“*Feel left alone. Need a break for a week but can’t have one. Mentally and physically lower, but just have to get on with it.”*

“*Very lonely. My husband has Parkinson’s with Lewy Body Dementia so I have missed having conversations particularly during lockdown.”*

“*Not getting a break had a negative effect on my mental health, e.g. tedium/boredom of day after day of doing basic activities with my child (endless colouring) and not being able to have space in my day to have a shower or get the housework done without being interrupted.”*

“*It has been an extremely lonely time and has had a massive impact on my mental health, being shut in the house with the person you care for 24/7 is very stressful as they also are finding it difficult not interacting with anyone else. I have never had mental health issues before but now I find that I get very emotional but feel unable to talk to others about it as I feel that I should be able to cope and not appear weak, the person that I care for has also deteriorated mentally which adds to the stress.”*

Employment

25% of carers said that caring had a negative impact on their employment

Experiences of balancing work and caring during the pandemic was varied. A few carers said that working from home had been useful for them as it gave them more flexibility to attend to their caring responsibilities.

However, those who were homeworking with the person they cared for, said it was difficult to fit work around the demands of caring, and managing their family life, meaning they had no time to themselves.

“*It has taken a lot more of my time up on top of my normal Monday to Friday job. Having to care for someone with dementia, do their shopping, sort medication, managing their finances, clubs, ensuring they are not feeling isolated, arranging activities, being on call for any issues meaning not getting much time for myself. Feels like having two full time jobs not including my home or personal life.”*

“*Juggling an Asperger’s 19-year-old with work and increased counselling requirements with heightened anxiety and depression developing because no support into spiralling depression and suicidal thoughts.”*

“*Not necessarily harder because being at home enabled me to spend more hours doing tasks. It’s just exhausting not having someone to help me with everyday tasks.”*

“*I am exhausted physically and mentally with trying to maintain my home, my caring responsibilities and hold down full-time job. Working from home is a great idea but it does not allow for any break for time for yourself and the pressure to always be available during working hours as well as home life is exhausting.”*

“*Being able to work from home has been really great, I can work, care for mum etc.. without having to worry that I need to rush home.”*

Financial impact

37% of people said that caring had a negative impact on their finances

Carers faced financial pressure due to having to pay for more care, cutting back on work hours, and increased travel costs as they visited relatives/friends more often to deliver food and medication, or to keep them company if they were alone for long periods.

“*The stress has been unbearable with no chance of any breaks. All food shopping got really expensive and there was no financial help given.”*

“*It’s a duty of love but also can be very draining for our family the financial impact has been the worst strain.”*

“*I can only do jobs that were isolated with very little face-to-face contact with customers, and while my wife tries to make her hospital appointments convenient, I am often out of pocket because I have to take her and not be at work.”*

“*I absolutely hate doing food shopping because it's so depressing seeing all the food you’d love to buy but can’t afford to and then the fact that during lockdown my shopping bill went from £100 per week to £180 per week.”*

Section Three: The experiences of young carers

Healthwatch Hampshire wanted to ensure that we heard the experiences of young carers and so we sought feedback from young carers groups across Hampshire. We asked the young people:

- **What has been difficult for you since the outbreak of Covid-19?**
- **Is there anyone or anything that has helped you?**
- **Is there anything that would make your home or school life less difficult in the coming months?**

Difficulties engaging with school

During lockdown young carers were struggling to maintain their schoolwork in the absence of consistent adult support. Many of their parents were looking after a disabled sibling, or had issues with their health, which meant they did not have capacity to provide support. Some young carers were worried about being left behind at school and frustrated as they did not understand the work. They also reported there was “nowhere quiet to go” and there was “too much pressure with other worries” to focus on schoolwork.

Those young people who had parents or siblings with health conditions were often afraid to go to school, despite being allowed to, as they were worried about bringing the infection home.

“Worrying that my disabled brother might be badly affected. He keeps getting symptoms but tests negative.”

“Really hard now because my mum can't walk and I have to push her in a wheelchair. We can't eat the things I like because mum's boyfriend is diabetic and can only cook one meal. I am worried because they are both so vulnerable and if we have even the tiniest cough we have to isolate.”

Young carers and their parents were also worried about returning to school after a long time off. Those who were transitioning to high school were particularly concerned about how this would be managed.

***“Our Year 6 young carers have a lot of worries about transitioning and not seeing their old school again. It’s a massive change to go to secondary school especially after such a long time off. We have had several young carers say they are worried about going back to school because it’s been so long, and they don’t know whether they have kept up or how behind they are going to be”*.** New Forest Young Carers Group

Digital exclusion

A further reason that young carers struggled with schoolwork was that many did not have good enough access to the technology needed for online learning, such as laptops, tablets and fast internet connections. Those who did have access to the internet might also be sharing the computer with multiple siblings.

> *"Our young carers have been struggling to keep up with schoolwork due to a lack of access to the appropriate technology and connectivity."*
>
> **Hart and Rushmoor Young Carers Group**

An increase in young carers' responsibilities at home

During the pandemic, many young carers reported that the time they spent caring had increased. This was caused by them taking on responsibility for getting food, the decline in a family members health and spending more time looking after siblings who were not at school.

> *"No respite away from caring and an increase of caring. Family members health has deteriorated, resulting in further caring."*
>
> **Fareham and Gosport Young Carers**

Financial pressures

Young carers were acutely aware of the increased financial pressure their family faced. Many families were struggling to get the food they needed without access to free school meals. For families who were on a low income one parent being furloughed had a big impact on already tight budgets, causing them to have to turn to foodbanks.

> *"A lot of families have had money problems - and this has obviously impacted on young carers. There have been issues with school food vouchers…We have issued more food bank vouchers and been asked for help with support for bills more than normal - particularly in families where parents normally work and they aren't sure where to go for help and what they are entitled to."*
>
> **New Forest Young Carers**

Breakdown of support networks

Access to their normal support networks, such as their extended family, friends, teachers, other young carers and staff at their young carers' groups have been limited.

During the lockdown period activities for young carers significantly reduced due to social distancing guidance. Although some support did move online, not all young people engaged well with these types of activities or they did not have the necessary technology to participate fully. The breakdown of this support made young carers more isolated and alone.

"Harder to get out and see my friends and have a break from home."

"Very hard not being able to see our wider family."

"Young carers faced new levels of isolation, whether it be restrictions from just being in lockdown and not having the club support, school support or because they are shielding or self-isolating."

Eastleigh Young Carers

"Missing the routine of school, interaction with other young people, food cooked by someone other than the young carer, missing decompression aspects of young carers, organised sports."

Andover Young Carers

Changes in family relationships and home life

The family life and routines of young carers were affected by the pandemic, whether these were positive or negative largely depended on individual circumstances. Some young people reported having more arguments with siblings, particularly those whose siblings have autism and challenging behaviour. Without the break provided by school they felt stressed and trapped at home.

"If we are locked down, my brother hurting me and I can't get away"

"Arguments with brother who has a learning disability and doesn't understand the lockdown."

For others, parents being on furlough or working from home meant the young carer had less responsibility. Also, some young people said it was less stressful as there were fewer arguments in the mornings about going to school.

“For two parent families it has tended to mean the other adult has been around more and been doing more to help so the young carer has been able to play more, and actually family time has been very positive.”

New Forest Young Carers

Impact on young carers’ mental health

All of the young carers’ groups highlighted that the pandemic was having an effect on young carers mental health, which in turn was affecting their schooling, family life and friendships

“Isolation, family conflict, online bullying, anxiety… boredom, withdrawal and lack of contact with ourselves.”

Off the Record

Section Four: What helped?

We asked carers to share what, if anything, had been helpful to them during the pandemic. Many said that they felt that nothing had helped their situation, however, some did highlight small things which had a positive impact on their wellbeing.

Getting a break

"During my radiotherapy friends have looked after my wife for a few hours."

The most sort after type of support were respite services, but only 30% of those surveyed said they had been able to get regular breaks. Carers who had been able to get breaks told us that this had been possible as they did not live with the person they cared for, or it was safe to leave them alone for short periods of time.

Carers who looked after someone that needed round the clock care, tended to rely on family and friends to share caring responsibilities or to step in to help when needed. A few people also said they had been able to employ carers who had been coming to their homes to provide short periods of respite each week.

My two daughters help when they can.

My wife shared the caring for our son.

During lockdown when households were not able to mix, some families/friends were put in the very difficult situation of either having to watch their loved ones struggle or to break the rules and provide support.

> *Despite Covid-19 rules my daughter helped."*
>
> *It is my own resilience and a padre's wife that broke Covid-19 rules to step in and help us out in the end."*

As lockdown was lifted over the summer, some respite services became more accessible. However, carers said the hours of respite they received were lower than normal, even after lockdown had been lifted.

Not for 6 months but things are better now.

No break during lockdown, but now yes.

“I have a personal budget from Children's Services, so I did have some hours of respite which I was grateful for, however I am entitled to nine hours a week but got two hours a week over August as this was all that was available”

Carers mentioned Hampshire County Council’s ‘Take a Break Scheme’ as a means of having a few hours break each week. This scheme offers a replacement carer for a maximum of three hours every week and is only accessible to those who have completed a Carers’ Assessment with Adult Health and Care.

“I have a ‘Take a Break’ of three hours. I have the same lady each week to care for my husband with dementia and during this time she sits and talks to him while I go out. I don’t always go out due to my health but she is there to talk to and during the shutdown was a total life saver.”

“Yes, through HCC [Hampshire County Council]. Some two and a half years after my wife was diagnosed with Alzheimer’s.”

The responses we received also show that for many carers these short ‘breaks’ are often taken up with doing essential tasks, such as food shopping, attending appointments about their own health issues and collecting prescriptions.

“Trying to fit everything in, in the three hours break I got a week was a nightmare as I had to queue just like everyone else.”

Keeping connected with friends, family and peers

Carers spoke about the practical help family and friends provided, such as delivering food and medication. Responses also highlight the personal sacrifices and dedication people demonstrated when supporting vulnerable friends and relatives.

“My son - He lived in the garage to help keep my mum isolated. She's 83 in a wheelchair and with dementia gradually increasing...he shopped for us to get things that were not available at the local shop and looked after the dog with regular visits through the window...”

Being connected with the outside world was very important to carers. Having the opportunity to see and speak to friends, family and peers helped them by relieving isolation, giving them a chance to talk about their worries or just have some time to unwind.

“Support of friends and family to meet needs for food, medication and to unwind.”

“My very good friends who invite me to sit in their gardens and have coffee and cake.”

Although they missed face-to-face contact many said that online social activities provided by voluntary sector organisations had been a “lifeline”. Several carers also said that being able to attend their church services online had been important to them.

“Zoom meetings from ‘Singing for the Brain’ and ‘Mind For You’ Dementia Holiday Group running sessions to help isolation. Church zoom.”

“When support started up again as Zoom groups, not as good as face to face but nevertheless a lifeline in highly anxious times.”

Prompt access to advice when needed

Having access to support and advice from the right professionals was also important to carers.

Mental health crisis team to speak to over the phone.

A specific senior social worker who just listened.

Carers valued hospital staff, GPs and social workers being responsive to their individual needs. The best examples show staff signposting to different agencies/organisations enabling carers to get the support, advice, and practical help they needed from a range of specialist services.

Sarah from Age Concern has been amazing and called regularly and pointed me in the right direction for various services from equipment to prescription collection and delivery. Andrea at Adult/Dementia Care who has also been amazing and helped with form filling telephone calls/zoom calls to navigate the complexity of the care system.”

I visited my GP for an unrelated condition and she asked me if I would like to be referred to the Intermediate Care Team. They have been really amazing, within a week I had a visit from a nurse…I was also referred to Social Services.”

The Housing Association put us in contact with HCC Social Services and Richard visited. This was probably the most useful contact we have been directed to.”

Carers who had positive experiences at their GPs surgery sited that they felt their GP was supportive, interested, and willing to adapt services to meet their needs.

“My GP surgery arranged for me and my husband, who has dementia, to have our flu jabs done at home together, saving us going out twice.”

“Phone conversations with supportive GPs.”

“My GP surgery arranged for me to get my flu and pneumonia jabs early.”

Regular “check in” calls

Carers said they had appreciated staff from the services they usually used (such as day centres and dementia cafes) regularly calling in to check on them. They said this gave them continuity, made them feel like they had “not been forgotten” and meant they could get advice from people they trusted, and who knew their individual circumstances.

“Eventually I was put in touch with Andover Mind for Carers and Dementia. Also, the day centre made weekly visits and zoom meetings and were available to call 9-3 if required.”

“The phone calls from various organisations have been a lifeline each week.”

“My husband also has a mental health nurse from Solent Mind who has kept in touch and made a couple of home visits to try to reassure him and to support me.”

Help getting essentials like food and medication

Although some carers expressed frustration that they had struggled to get recognised for priority delivery slots at supermarkets, those who were able to take advantage of this scheme said they found this service very useful. Carers also praised the local shops and pharmacies who worked hard to ensure that vulnerable people in their community had food and medication.

“My local pharmacy has been very helpful and has worked hard to serve the community.”

Local community schemes

Local schemes set up within communities and run by volunteers who delivered food and medicines to carers, elderly and disabled people were also mentioned as sources of help, especially for people who were shielding during the period of lockdown. Groups were also set up by community members to combat loneliness such as Andover Self Isolation Help Group which offered a befriending service.

"The most useful thing has been the network of volunteers set up by my local MP. This has been invaluable in getting prescriptions collected."

Being able to use technology

Many of the things which people found helpful, such as Zoom social activities, online prescriptions services, video GP appointments or family WhatsApp groups, all relied on having the equipment, skills and desire to use technology. Being able to use technology improved people's ability to connect with others without risk of infection, reducing people's isolation, keeping them informed.

What helped young carers?

Young carers told us that doing positive activities with their family and being able to stay in contact with their friends was important to them. The young people also valued the support given to them by their young carers' group.

"It was better when we could make bubbles with another family and go out with them."

"Baking with my family."

"Talking with friends on computer games."

"Two of my friends are really nice and I get to video chat to them."

"Young carers activities and support."

"Making new friends through 'lockdown school'. "

"My teddy to comfort me."

Section Four: For the future

A. Young carers

Many of the young people rightly said that finding a cure for Covid-19 would be what they wanted for the future. One young person went further and said they wanted to “grow up to be a scientist and find cures”. Others said they would like a pet dog to play with. Overall, young carers said they wanted help with staying connected to the people that were most important to them.

“To be able to see all our family when we want to.”

“Getting a phone so I could stay in touch with my friends.”

“Being able to talk to friends who aren't in my bubble.”

“A tablet that works so I can video chat/do activities online.”

“More money.”

B. Access to respite and day services

Access to day services for the people they cared for and respite services for themselves, were the most mentioned things carers said they needed for the future. They acknowledged the difficult circumstances caused by the pandemic, but some felt that more innovation could be used to keep essential services running.

> “*Social groups for dementia sufferers should be started again with social distancing, quite feasible by better spacing of chairs, wearing masks and activities without direct contact quite possible. NHS services should stop using Covid-19 as an excuse to stop services and look for ways to open again.”*
>
> “*It seems ridiculous that very well organised day services with Covid-secure setups are only allowed to accept people who are at risk of harm in their homes. Even a reduced number of hours would help our son as well as us to maintain our mental health.”*

Some carers spoke about ways they have worked within the guidelines to provide safe activities for the people they cared for.

“I’ve asked the carers to take her to the park, or anywhere outside that is safe, to reduce the risk. This has had a huge impact on her wellbeing. I’ve phoned ahead to the pub and asked them to set aside a safe, quiet area for her and her carer. This has worked well.”

C. Being recognised as a carer by GP surgeries

When asking carers what would help them in the future the most commented on service was GP surgeries. Many said access needed to be improved, as there were long waits to get through on the telephone and that the move to online services had meant that older people were being excluded. A recurrent theme is that they felt it would help if their surgery recognised them as a carer and was able to provide services in a way which met their specific needs.

“A ‘carers check-up’ with my GP regularly if needed.”

“I would like the doctors to be more accessible as even a phone call could take a week.”

“A monthly meeting/drop in/coffee morning held at a place such as the local surgery for sole carers to enable them to chat with each other and exchange information and possibly feel less isolated and abandoned to cope on their own. The local surgery should know who the carers are.”

“GP surgeries to be more open to be able to support and advise patients.”

“GPs to be more aware of who the carers are and who they care for.”

“Having my primary care providers aware of my care role of 2 adults.”

D. More mental health support

Carers felt that they needed more support with their mental health.

“Mental health lead in each practice...responsible for and understanding the complexities of autism and depression.”

“Parent carers to be offered respite & mental health support.”

“It's hard, because resources are so scarce. Need more people really, more staff. There are not enough mental health care workers to provide the care needed by mental health sufferers in the community.”

E. Financial recognition for caring roles

Many carers said they did not get adequate financial support for their caring work.

- “*More support, funds for unpaid carers and the people they look after. It seems they want more people to be independent and living in the own homes with family/friends looking after the person to help the NHS with funds and resource, yet we aren't getting the support or any benefits for doing this.”*
- “*The requirements for paid caring needs to be altered.”*
- “*Recognition for carers. Appropriate amount of pay for long term hours.”*

F. Joined up services

The survey suggested that multi-agency working (involving NHS, social care and voluntary sector services) got the best outcomes for carers, by referring to the best place service to meet their support needs.

“Services and care pathways that integrate with each other improved communication between acute and community services.”

G. Easy, quick ways to get advice

Having easy access to personalised advice when needed was important to carers. Some said they found negotiating adult and children’s social care systems complicated, or felt they were not able to contact practitioners for advice when needed.

- “*Clearer information for carers and a helpline to call if worried about something.”*
- “*I am going to need more help in looking after him and probably more time off. I would like training in how to help him more.”*
- “*Having a central point of contact for elderly care.”*
- “*To be able to get advice on how best to cope with my situation. It would have to be someone who is really listening.”*

Carers also stressed the importance of getting regular contact with the same professionals who were familiar with their history and situation.

“People living at home with dementia need targeted support and regular professional advice/contact in the same way that people with cancer or Parkinson’s or any other serious illness would expect to receive.”

H. Being aware of what services there are for carers

Many carers are unaware of what help is available to them in their local community.

Being told what you are entitled to and what is available.

I had to wait some two and a half years before being contacted by organisations that I knew nothing about.

I. More support before a crisis

There was also consensus that support services needed to be targeted to help carers before they reach crisis point.

“Social workers to not just focus on crisis families but acknowledge those that appear to be coping who may reach burnout much sooner than previously anticipated.”

“More support services for carers.”

“Continual help.”

Section Five: Our recommendations

We listened to the experiences which unpaid carers shared with us from across the County and there were some clear themes which emerged from all of the stories we heard. Carers were telling us what their challenges had been, but also what had helped them and what needed to change.

We have grouped these themes into three areas:

- **Protect** - elements which helped carers during the pandemic, which they want to protect and keep going into the future
- **Grow** - elements which need to increase or improve in the future to offer more support and help to carers if they are to remain useful
- **Create** - things which don't exist currently but would be really helpful to carers in the future

From these themes, we have developed recommendations which Healthwatch Hampshire will share with partners and stakeholders to help develop and implement throughout next year. Updates will be provided via our quarterly newsletter, and via our social media channels.

PROTECT and GROW

- **Having a break from caring**
- **Easier access to respite and day services**
- **Keeping connected with friends, family, and peers**
- **Support and advice readily available when needed. Easier/quicker ways to get advice. Being aware of what services are available**
- **Regular check in calls**
    - **from local VCSE providing support**
    - **from residential home providers keeping families in touch with relatives they have not been able to visit**
- **Help getting essentials like food and medication**

CREATE

- **Local community schemes that provide support**
- **Financial recognition, reflecting hours spent caring have increased dramatically due to the Covid-19 outbreak**
- **Joined-up services that work together effectively**
- **More support before a crisis develops**
- **More understanding from NHS staff to eliminate the lack of recognition and respect of the carer's role**

Recommendations

These are the recommendations we are going to take forward with partners and key stakeholders to help ensure the voices of carers are heard and to create improvements in services they rely upon.

1. **Ensure carers have quick, easy access to the information they need**
   a) Centralised carer information resource/directory developed. This should be accessible, current and available in multiple formats (digital and non-digital).
   b) Development and implementation of a standardised Carers Pack for use across the county.
   c) Healthwatch Hampshire to undertake a 'GP mystery shopper' exercise to identify provision of Carers Leads and availability of Carers Packs.
   d) Review outcomes and share learning from the GP Pilot Project in NE Hampshire and Farnham which aimed to raise awareness of carers needs in GP practices in the area.

e) Identification of GP surgeries delivering good practice in carer identification and registration, provision of carer support and information. Develop best practice tools for implementation across GP practices/Primary Care Networks.

f) Primary Care Networks identify community assets that support carers and integrate to social prescribing/navigation pathways.

2. Ensure carers can easily access the information they need regarding accessing Carers Assessments

a) Review Local Authority websites to ensure that Carers Assessment information is easy to find, informative, and that a phone number and contact email address is available.

b) Carers assessment campaign to be developed and launched to increase uptake of Carers Assessments across the county. Additionally, ensure that those who are not digitally enabled/hard to reach are specifically targeted as part of the campaign.

3. Establish which local community schemes have worked well, with a view to sharing good practice and encouraging the creation of new, sustainable schemes across Hampshire

a) In partnership with carers identify existing community provided schemes that have worked well. Compile and publish good practice and share with all partners.

b) Ensure all community provided schemes are included in any carers directories and packs as appropriate.

c) Publish the map of best practice schemes on the HW website so all carers have easy access.

d) Health and Social Care commissioners /providers to explore how to further support and capacity build community provided schemes.

e) Healthwatch Hampshire to consider utilising its Community Cash Fund grants programme to support innovation in community provided scheme development.

4. Raise awareness within the NHS of the role, responsibilities and priorities of carers

a) Healthwatch Hampshire to Identify a willing NHS Acute provider to work with unpaid carers to develop a dedicated Carers Charter.
b) Additional NHS providers to consider adoption of the Carers Charter once developed.
c) Healthwatch Hampshire to consider establishing dedicated Healthwatch Carer Ambassadors to ensure that the voice of unpaid carers is heard on a continual basis and that their feedback is used to improve services. It is proposed that such Healthwatch representatives could undertake quality improvement activities e.g. ensuring the effective application of a developed Carers Charter, auditing services against the NHS 15 steps challenge and ensuring carer resources are fit for purpose.

5. **Raise awareness of carers feedback that there has been no financial recognition that hours spent caring have dramatically increased during the pandemic**
    a) Provide copies of our report to organisations which are raising awareness of this issue at a national level, including Contact, and Carers UK.
    b) Continuous monitoring, carer participation and engagement to ensure that the experiences of carers are captured and used to influence service design, delivery, and improvement.

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