

Caring During Covid-19

The experiences of
unpaid carers in a
global pandemic

We asked Wokingham
Borough residents who
provide support to family
and friends for their
stories, and asked "What
can we learn?"

Contents

	Page
Summary	3
Introduction	4
Section 1 - About the survey	5
Section 2 - Who we heard from and who they care for	7
Section 3 - Facts & figures	9
Section 4 - Caree decline	10
Section 5 - Carer workload and time out	12
Section 6 - Carer wellbeing	21
Section 7 - What helped carers	24
Section 8 - Conclusions and recommendations	28
Section 9 - Service Providers Responses	31
Appendix 1- Wokingham Borough Council Initiatives	33
Appendix 2- Questionnaire	35
References	40

Summary

In 2020/21 Healthwatch Wokingham surveyed unpaid carers in the Borough to find out about their experiences of caring during the Covid pandemic. 89 carers completed our questionnaire.

- 2 out of 3 questionnaire respondents didn't know their rights as a carer.
- 30% didn't know what a carer's assessment was.
- 40% weren't registered as a carer with their GP.

Top concerns reported by carers:

- Decline of the person they look after.
- Workload and lack of time out
 - 👉 78% said the number of hours of care they provided had increased.
 - 👉 70% hadn't been able to get regular breaks.
- Carer wellbeing, notably the negative impact on their:
 - 👉 mental health (84%) and physical health (62%)
 - 👉 family wellbeing (73%)

Other findings

- 👉 Carers found it easier to get food and medication during lockdown than carers in other areas- thanks to Wokingham's community response.
- 👉 Direct payment recipients reported Council inflexibility and delays.

Introduction

What is Healthwatch?

Healthwatch Wokingham Borough is the independent champion for people who use health and social care services in the Borough. We are here to find out what matters to people and help make sure their views shape the support they receive.

What do we mean by unpaid carer?

A carer is anyone....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. The care they give is unpaid.'

NHS England

Covid-19 in the UK: a recap

Covid-19 is an infectious disease caused by a type of coronavirus first identified in December 2019 in Wuhan, China. The World Health Organisation (WHO) declared the outbreak as a pandemic on 11 March 2020. On 16 March 2020 the British Prime Minister announced the first UK restrictions due to Covid-19.

Social distancing rules and other precautions remained in various forms all year. To date, three full national lockdowns have taken place, starting on 26 March 2020, 5 November 2020 and 6 January 2021ⁱⁱ. During lockdowns nobody was allowed to leave their homes except for certain permitted purposes such as daily exercise, and care of a vulnerable person. Wokingham Borough also spent ten days in Tier 4 - the strictest non-lockdown restrictions. To date, over 128,000 people in the UK have died with Covid.



1. About the survey

Background and literature review

It is safe to say that the worries, sadness and restrictions of the past year have been difficult for everyone. But Healthwatch Wokingham became aware of some specific effects on a particular cross-section of residents: unpaid carers.

Carers often contact us for information or to give feedback about their loved ones' experience of health and care services. From these contacts we were hearing that:

- existing carers were finding their responsibilities had increased and the pressures were greater.
- other people had taken on caring responsibilities for the first time.

This feedback was corroborated by national surveys. In July 2020, the Office of National Statistics (ONS) reported:

Almost half (48%) of UK adults report providing help or support to someone outside of their household during April 2020. 32% were helping someone who they did not help before the pandemic and 33% reported giving more help to people they helped previously.

Coronavirus and the Impact on Caring - ONS, July 2020

1 in 3 carers in the study reported symptoms of poor mental health compared to 1 in 5 prior to the pandemic.

In its report *Caring Behind Closed Doors: Six Months On*, Carers UK too, reported that of the carers who responded to their online survey (September 2020):

- 81% were providing more care than they did before the pandemic.
- 64% said their mental health had worsened as a result of the pandemic.
- 55% said they were reaching breaking point.

However, these national surveys did not ask carers what support or improvements to services would help them. And, at the time of our review, there had been no local surveys of Wokingham Borough carers in 2020.

What we wanted to find out and why

We want health and care decision-makers to be aware of and accurately address the current and future needs of unpaid carers in the Borough. This required:

- up to date information about the experiences of Wokingham Borough carers.
- feedback about the services and support accessed during the pandemic period.
- carer views about what has helped or would help them.

What we did to find out

Between May-November 2020 we distributed a questionnaire (Appendix 1) and held three focus group sessions. Carers could complete the questionnaire online, or respond by e-mail, phone or via social media.

To explore the questions raised in more detail, we ran three focus groups with members of ASD Family Help and Promise Inclusion (local voluntary sector groups working with families affected by autism and/or learning disabilities including carer support) and Wokingham Young Carers.

13 people participated in the focus groups, and in total we received 92 completed questionnaires.

Limitations of the survey

- The data collected only represents a small proportion of carers: 14,000 people identified themselves as carers in the 2011 Census.
- It only included self-identifying carers: often people providing support to loved ones don't necessarily recognise themselves as 'carers'.
- Focus group participants were also invited to fill out the questionnaire. This means that parent carers are particularly strongly represented.
- To make it easy for busy carers, we had to keep it short. Questions we did not ask included the number of hours they spent caring and whether they cared for more than one person.

2. Who we heard from

A total of 92 people responded to the survey, including carers of adults and carers of children. Not all respondents answered every question.

Of the carers who gave an answer:

- 88% were existing carers and 2% had become carers during the pandemic
- most were from either of two age groups:
 - a. the 'sandwich generation' - 35-54 year olds - commonly balancing children and aging parents (34 carers)
 - b. elderly carers aged 65 or over (32 carers)
- In addition 20% (17 carers) fell between the two: 55-64 year olds (17 carers). A further 1% were under 18, and 2% aged 25-34.
- 83% identified as female and 16% as male.
- 89% described their ethnicity as White British, White Irish or White Other (in line with the ethnicity profile of the Boroughⁱⁱⁱ). 1% described their ethnicity as Asian.
- 34% considered themselves to have an impairment or disability
- 93% described their sexual orientation as heterosexual/straight. Others did not specify.
- 25% were from Winnersh. 19% were from RG40 (Wokingham town centre and East, Finchampstead, Barkham South). 16% were from Earley and 13% from Woodley. Others were from RG2 (7%), RG10 (6%), and RG7 (4%).



Who they care for and why - some examples:

Mrs A's husband was fit and well until he was hit by an episode of severe pain. "I became a carer out of necessity". He was diagnosed with cancer. As another carer said: "You just get on with life, managing uncertainty - you don't abandon your commitment to a partner."

Ms B: "We live together. We were going to get married. He changed, three and a half years ago. He's a young person with dementia. It wasn't a decision".

Carer C's partner spent time in hospital after diagnosis with a mental health condition. When she came home he ended up as a full time carer as "working and caring became too much".

Carer D's father is in his 90s and lives in his own home. He cooks and does his own laundry but no longer drives. Carer D lives nearby and gives support by helping maintain the house, delivering a few meals, and providing transport. "If I didn't do it, who would? I do it willingly".

Carer E - "When my Dad died, Mum moved in with us. She's getting older. It's my duty"

Mrs F - "It took me a long time to consider myself as his carer." For elderly couples it can be a mutual caring relationship, although one partner's support needs may end up overtaking the other's, "We both did our part...and gradually I found it was all up to me."

Carer G - "My son can't look after two autistic children by himself". Several grandparent carers responded to our survey. Becoming a carer can come about when family move in with grandparent/s for support due to illness or relationship breakdown.

Carer H - "I gave birth to a profoundly disabled son with complex needs [over two decades ago]."

Not all carers are family. Carer I became a carer "by default" when the elderly couple he lodged became unwell.

3. Facts & figures

About carer support

Of the carers who responded:

- 60% had registered as a carer with their GP
- 57% said they knew about local carers support groups
- 30% had had a carers assessment.
- 30% said they didn't know what a carers assessment was
- 2 out of 3 (68%) said they didn't know their rights as a carer
- 40% weren't registered as a carer with their GP

About caring in the pandemic

- 78% said the number of hours of care they provide had increased
- 70% hadn't been able to get regular breaks
- 84% said their mental health had been negatively affected
- 73% said that their family wellbeing had suffered
- 62% said their physical health had been negatively affected

4. Caree Decline

We asked carers to tell us what it was like being a carer during the pandemic. One of the most common responses was to describe the impact on the person they look after. This is not a deflection - caree decline negatively affects the carer too in terms of (i) feelings of anxiety and sadness and (ii) increasing their practical workload.

" She normally is [i.e. pre-pandemic] fairly independent, can get to clubs etc a mile away walking. All of her social activities have stopped due to Covid...She has lost all confidence in going out alone with her long cane"

"A noticeable impact on the progress of dementia with regard to my cared-for, due to a lack of external contact/stimulation with others "

There is another type of impact if the person being looked after does not have the cognitive or emotional regulation skills to remember or adapt to the new restrictions. This increases supervision requirements and stress for carers.

"[My] special needs son: unable to fully understand the restrictions...and lacking the capacity to cope with negative feelings. Increased stress impacting on both physical & mental health of self & spouse. "

Several report the onset or worsening of symptoms: e.g. *"Increased fear of my son harming himself"* and *"My daughter is now showing signs of high anxiety"*.

Comments suggested that for many carers the Covid period has brought a new or increased responsibility for maintaining their loved one's mental wellbeing.

"[Cared-for person] is fed up, dependent [on carer] for her own mental health support (has had clinical depression before), needs to go for a daily walk, needs entertaining. She...often tells us we would be better off without her."

And it was more difficult:

"I struggle being the only source of conversation in a world where very little is going on".

Where specified, the consequences of pandemic life blamed for causing decline were:

- less or no social interaction
- fewer activities
- travel and exercise restricted

Three aspects of their wellbeing were mentioned by respondents:

- mental health - including anxiety, self harm, outbursts
- loss of skills - e.g. communication, using mobility aids, social skills.
- withdrawal - reluctance to interact with carer or leave room/house

A small minority of carers, however, reported improvements in the wellbeing of the people they cared for because of the pandemic.

One parent carer was able to toilet train their child during the first lockdown due to uninterrupted time at home together. Another reported that when schooling was conducted at home, their child's mental health improved.

A third carer acknowledged the benefits of hobbies her learning-disabled daughter had taken up at home while external activity groups were shut.

"She has always been a fussy eater. Now she's doing all the cooking and she's eating it too! She redesigned our front garden and planted from seed."



5. Workload & time out

Many carers can't take a break unless someone else looks after their friend or family member. This is particularly common among certain types of carer such as carers of children and people with dementia. Their loved ones may not be safe left on their own due to mental health, cognitive or behavioural issues, or require frequent practical help e.g. lifting/turning, continence care, or mobility.

Some form of time out is essential for all carers in order to run errands, attend medical appointments, catch up on sleep, manage their stress levels, and maintain friendships and interests and in some cases fulfil paid work commitments.

Some carers don't need help to be able to carry out these activities because their caring responsibilities only take a small proportion of their time (e.g. a weekly visit to check Mum is OK). But they too might need cover if they were to fall ill, go on holiday or need hospital treatment.

Being given a break from caring by someone who takes on your responsibilities temporarily is called 'respite'. Respite care might be provided by a friend or relative, although the term often refers to access to a service arranged and paid for by the local Council if you are eligible, or paid for privately.

There are lots of respite care options. They range from getting a volunteer to sit with the person you look after for a few hours, to a short stay in a care home...The person you look after could go to a day care centre. Or, a paid carer could visit them at their home to look after them.

<https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carer-breaks-and-respite-care/>

Our carers' stories highlighted the impact the pandemic had had on both formal and informal respite care, together with other indirect forms of respite (such as school attendance) and additional barriers which had prevented many from getting time off from continuous caring during this period.

a. Informal support

"I would love to bundle the kids in the car and drive to my mum in law's. She would look after them. I could sleep. I don't know if I would be stopped on the motorway...or fined".

Government guidelines specify that respite care is a permitted exception to Covid travel and household mixing restrictions^{iv}.

Yet several carers indicated that the pandemic had curtailed in-person support. One stated: *"Our pre-Covid support was from family members and friends who can no longer visit"*.

This may be due to one or more of the following factors:-

- i. Respite care wasn't specifically listed as a permitted exception to lockdown guidance until November 2020.
- ii. Even then not all carers may be aware that it was allowed, or that it included informal respite. It was not publicised as much as childcare bubbles.
- iii. Some carers may have been aware of the option but chose to avoid it in order to minimise risk of Covid transmission.
- iv. Friends and family may not have offered due to similar factors - the Covid risk or not realising it was permitted.

b. Reduced services for carers and carees

Availability of services was reduced, especially in the first few months of the pandemic when, as one carer put it, "Covid stopped everything".

After that, availability and access varied. For instance, Healthwatch Wokingham's mini-audit of availability in Summer 2020 found some day services still closed (e.g. Earley Day Centre and Woodley Day Service) and others open to restricted number of users (e.g. Westmead Day Service and the Acorn Community Centre).

One carer described the precariousness of their situation: *"The day centre was closed during the initial lockdown, opened for a short while and then closed again"*.

It is important not to underestimate how hard closures hit carers, particularly those looking after adults and children with the highest support needs, often 24/7. For many, organised services or groups for their loved one had been the only opportunity for them to get a break.

"Tuesday afternoon stroke club closed down so I no longer have the two hour slot each week for 'me' time".

Any services which were accessible were extremely highly-prized.

- *"We have had some respite from Loddon Court which has been wonderful and helped to keep us going"*
- *"Optalis Day Service/Out & About have been lifesaving"*
- *"Bridges [re]opened and I got back some of my respite there. If I hadn't have had that I just wouldn't have coped."*

Positive comments about services are always good - and will be fed back to the services concerned, run by staff who have obviously worked very hard to offer their services during a very difficult year.

However, it should be noted that Healthwatch wants people who use services to feel like, and be treated as, empowered consumers - not grateful recipients who feel lucky to access a service for which they are eligible. *"I felt quite privileged in a way."*

It would be damaging if carers and carees emerging from the pandemic permanently retain the same sense of **indebtedness, powerlessness and vulnerability** which restrictions brought. *"[I] appreciate respite but worry it could stop again at any time".*

Meanwhile rationing of places also risks friction, resentment and a sense of competition - questions were raised by those who saw others accessing services which they or their carees couldn't, e.g. *"There were people who were going, perhaps some who didn't need it as much as others. How did they make that decision?"*

c. School closures

" When Covid struck and schools closed ...I found it incredibly hard. I went from being a carer that had respite in the day ...Suddenly everything disappeared."

Schools in England closed on 20 March 2020. They only fully reopened in September 2020, then closed again on 4 January 2021 for two months. Unless they were offered special places (e.g. children of key workers), children were at home all week. This affected a significant proportion of carers, namely:

- those caring for under-18s with special needs or disabilities
- any carer with school age children (or grandchildren requiring childcare)
- young carers

Parent and grandparent carers told us that, pre-pandemic, the school day had been their respite. *"My caring role is now 24 hours a day"*. Young carers too lost that ring fenced time free of caring responsibilities. *"School was my safe space and that was taken away"*. Other carers had previously relied on child-free school hours to visit other relatives or friends they looked after.

Children were encouraged to continue studying, so parents were expected to home school and/or support remote learning. This could also apply to young carers - one reported she helped with her siblings' studies as well as her own.

"It was not just caring 24/7, there was schooling [and] keeping their mental health stable... Mother-in-law also needed care..."

The impact of school closures upon families across the nation has been widely acknowledged. But for carers it was an extra load on top of other responsibilities they have which other families do not.

As UK lockdown restrictions evolved, more children were allowed to attend otherwise 'closed' schools - including children with an education, health and care plan (EHCP). Parents whose children were allowed to attend school spoke gratefully of the difference it meant.

"In the current lockdown my child has been allowed into school. He wasn't allowed in the first lockdown and the situation became unbearable and unsafe at times."

Several other carers, when we asked what they would like to see changed, suggested allowing their children to attend school during lockdown.

d. Working from home

In March 2020 Britons who could were directed to work from home. Many offices and workplaces closed. Home working advice, gradually eased from mid-May, was reintroduced in September. The proportion of people working from home more than doubled in 2020 during the Covid-19 pandemic^v.

For working carers living in the same household with their caree, being home-based in office hours reduced the time and space they had away from their caring responsibilities.

"Before March [2020] I worked in an office or out and about...[Now] at home I am available....too available."

"I work all my tasks around each other and I have breakfast, lunch and dinner breaks with Mum."

e. No escape outlets

"Many things we'd use are closed or very different, so we literally have nowhere safe to go to get out".

The closures of hospitality outlets, social and leisure facilities and restrictions on travel and outdoor recreation created a particular problem for carers.

For carers who live in the same household as the person they look after, it can be impossible to get a proper break from their responsibilities unless they leave their house. Even if someone else has stepped in to look after their loved one, if this respite is provided at home (rather than at a day centre, for example) it is difficult to 'switch off' while on site and within earshot.

So many carers depend on going to a cafe, gym, or other social/recreational facility to get time out. They may go out for a meal or to the cinema with their partner for much-needed relationship time.

During lockdowns, such venues were closed. Leaving home in itself was restricted. Even sitting alone in outdoor public spaces wasn't always allowed. One young carer told us "Usually I would go to the park to take my mind off things, but I can't do that now."

Similarly, overnight breaks - particularly important for carers providing night-time care - were impossible in lockdown due to restrictions on travel, and the closure of hotels, bed and breakfast accommodation, campsites and caravan parks.

"I got some [funds for] nights away but it's not been possible....I'm hoping to use them soon. I'm frazzled".

f. Direct payment difficulties

People who have been assessed as needing care and support can opt for the Council to pay the money straight into their bank account so that they (or their parents, if under 16) can arrange this support themselves. Common examples of how they spend the money include:

- care and support at home
- employing a personal assistant
- short breaks and leisure activities

However, as one direct payment recipient explained, *"In lockdown everything you would have spent it on pre lockdown stopped. That's when the problems started."*

For instance, many activities and venues which direct payment recipients use their funding to attend closed during lockdown. Some families stopped using a paid carer (personal assistant) at home due to the Covid risk.

Government guidance *Using Direct Payments During the Coronavirus Outbreak*^{vi} acknowledges that 'there may be situations where you need to organise your care and support in different ways as a result of the COVID-19 outbreak'.

The guidelines stress that Councils and direct payment holders should work together "to agree how the....direct payment can be used differently".



However, a number of Wokingham Borough parent carers who manage direct payments told us about difficulties they'd experienced in practice:

- reluctance or delay on the part of Wokingham Borough Council (WBC) in agreeing acceptable alternative uses:

'We did manage to get the OK to buy an iPad to go onto Zoom but that took a long time to agree'

"I managed to be able to use some of my son's direct payments to buy an adult sized swing for the garden. It took...three months."

- WBC giving incorrect advice, vetoing suggestions:

"Wokingham said I couldn't use my direct payments to pay for carers or even babysitting. I went through the document with a toothcomb and it didn't say that.. By October they agreed I was right and ...I could have carers in the house."

- WBC informing them they had 'too many' payments unspent which caused stress.

The Government guidance document specifically states that it expects Councils to be as flexible as possible. Council sign-off isn't even always required. In addition, for those who have experienced problems, it emphasises that unspent money should remain available and that it must not threaten future payments or assessments.

The guidance recommends direct payment holders look online to see if their local authority or Clinical Commissioning Group has provided written guidance on how direct payments can be used during the pandemic, as some have e.g. Bracknell Forest. At the time of writing there is no such written advice on the WBC website.

g. Extra self-imposed limitations due to Covid risk avoidance

" We would rather have what we have now than end up on a ventilator.Ultimately, we have to keep her safe."

Carer comments showed that carers' concern for protecting their carees and themselves mean that many adopted extra, self-imposed limitations beyond Government or NHS guidance.

Allowing someone into your home to provide a vulnerable person with essential care was always legally permitted, but for many households it was nevertheless a judgement call. One respondent stopped using paid carers in the first lockdown and did everything herself because "I was fearful of anyone coming into the house".

Another carer told us "I chose to shield my adult son at home....this was gruelling but it was my choice....He has profound learning difficulties and epilepsy [but] he isn't officially extremely vulnerable."

Many carers feared becoming ill themselves - "I am....clinically extremely vulnerable so risking anyone caring for [my family member] and passing on to me is not worth the risk". This too reflected concern for the person they look after - "Who would look after him if I was ill?"

It is important that such measures are respected, and not dismissed as over-anxiety or ill-informed misjudgement. Covid-19 is a highly transmissible disease; indoor mixing and close contact are indeed responsible for a significant proportion of cases; and carers are looking after a very vulnerable population. Looking after your caree and keeping them from harm is the purpose of a carer's role.

Finally, everyone's understanding and choices have evolved over the course of the pandemic. Some carers indicated they adjusted initial decisions (e.g. to stop using paid help) to ensure longer-term sustainability. Equally, some 'unnecessary' precautions were later vindicated: e.g. an extra 1.7 million people (e.g. adults with severe learning difficulties) were added to the shielding list in February 2021.

h. Lack of awareness or information

Comments from respondents suggested that not all carers in the Borough are equipped with the knowledge or information about the options open to them e.g.

"It would not be possible to find anyone [to give carer a break]"

"I am not able to get away - it is a 24/7 responsibility."

"No idea where to get help."

"Have no idea how to 'employ' a carer for respite."

Reaching carers with information early in their caring journey and ensuring they have adequate support helps everyone. Regular breaks from caring not only protects a carer's mental and physical health but enables them to continue providing care for longer, and to do so safely.



6. Carer wellbeing

a. Stress

20% of carers used the words 'pressure', 'stress', or 'stressful' or 'pressure' in describing their Covid caring experience.

"Stressful. Caring for two adults both living alone and refusing paid carers and having an autistic child has taken its toll".

Partners and/or families have been affected too:

"It has caused our family to be near breaking point".

b. Exhaustion

"Being an unpaid carer is bad at the best of times but during the pandemic it has been particularly lonely and exhausting with no respite whatsoever".

"Feel like we're swimming through treacle even more than ever"

"I am over 70 years with heart problems and don't feel physically able at time to do everything that is needed"

c. Fear and worry

Many carers described being in a state of fear.

"I was fearful of anyone coming into the house"

"I have developed more anxiety about Covid and people in my family getting it."

d. Exposed vulnerability

Many carers voiced a specific fear: about what would happen to their loved one if they caught Covid-19.

"It was only on my contact that someone from social services came round. [I] wanted to make sure that my husband would be looked after if I fell ill."

One grandparent who shares care with her daughter, both of them clinically extremely vulnerable, wrote "No one able to make emergency plan in event either of us unable to continue caring."

The pandemic opened up general worries about longer-term sustainability and contingency plans:

"It is a worry as you get older. What happens when you're not around anymore? We might be around and need care ourselves."

e. Feeling alone, invisible or forgotten

"I already felt unsupported and alone. Now I feel that even more".

Over 20% of respondents used the term isolated, lonely or alone.

"Carers are the forgotten ones! I had a call at the beginning of the first lockdown and nothing since from children's services."

"No one cared about what unpaid carers do or about us during the pandemic"

Even those whose loved one is receiving support can feel overlooked:

"The focus has been on the needs of my child and not me as a carer. I feel I don't matter."

f. Despair & desperation

"Just feel that whatever time I have left is ebbing away with not much to look forward to."

"It's a very isolating time leading to desperate families."

"I have been at the end of my tether- when you say "Fine, send me to prison [for breaking Covid rules] - that's 3 meals a day and a good night's sleep.'

g. Devotion and fulfilment

A few carers spoke only positively of their caring experience. They were able to voice some of positive aspects of the experience, and the rewards of being a carer.

"It's family. My privilege to care".

"It's borne of love.

The contrast with more negative feedback may reflect differing circumstances, including part-time as opposed to 24/7 care.

"I am fortunate to live very close to my father and to have the time and resources to help him."



7. What helped carers

Given the high level of pressure on carers, anything which helped sustain them or provide relief during Covid is very important to highlight and share.

Services and support

Services which remained open or re-opened, were highly-valued by carers. Community and voluntary groups have been particularly good at reacting and adapting to the Covid crisis quickly and flexibly. Positive comments¹ were received about the following:

Voluntary groups and mutual support:

Berkshire Blind Society
Churches
CLASP
Food Bank
Me2Club
Parenting Special Children
Promise Inclusion
Rose Street Buddies

SEND Carers [United] Facebook page
SMART
Stroke Association
Sue Ryder Care
The Music Club (Oxon-based)
Wokingham Link
Young People With Dementia (YPWD)
Citizens Advice Wokingham

Wokingham Borough Community Response & One Front Door

One of the most positive findings of the survey was an initiative which respondents didn't directly name. Wokingham Borough Community Response, an umbrella effort coordinated by Wokingham Borough Council, was established at the start of the pandemic. A number of voluntary sector organisations were brought together to deliver a cohesive response to the most vulnerable people in the community. Residents accessed the service via Citizen's Advice Wokingham who triaged referrals through their 'One Front Door' and arranged support such as:

Access to the Link Visiting Scheme's "Talking Buddies" programme for people feeling isolated and lonely; the Wokingham Foodbank for those struggling financially to access food; Wokingham Volunteer Centre who were able to collect

¹ includes some which received both positive and negative feedback:

and deliver pharmacy prescriptions; First Days Children's Charity who supported the Food hub to deliver food parcels.

Survey data suggest that a number of carers used and valued these services, although they did not know or remember the names WBCR or One Front Door. When asked what was helpful during the pandemic, many carers used general descriptions (e.g. "local Council arranging food parcels and phone calls") or referred to the support provided ("Having food delivered and prescriptions delivered") or the end provider ("Foodbank"). The option 'Citizens Advice pandemic response' received the third highest rating for helpfulness after 'Friends & Family' and 'Local voluntary and community groups'.

We are aware that WBC put in place several initiatives to support Carers:

- Carers Welfare Checks - WBC and Tu Vida worked jointly with a team of re deployees to ensure carers knew how to access food, prescriptions, emergency support.
- Carers welfare checks were followed up with a letter
- Providing carers with PPE
- Supporting paid carers to get early vaccinations so that customers were confident in letting them back in their homes

There is more detail about this in Appendix 1.

Most telling of all was that the issue of obtaining prescriptions or essentials was not raised when respondents described the difficulties they had experienced during the pandemic. This contrasts sharply with a similar Healthwatch survey conducted in Hampshire and the Isle of Wight^{vii}.

Other local authority² and connected services

Adult Social Care (and possibly Children's Services where unspecified e.g. 'social worker')

TuVIDA (carers organisation/service)

Dementia Care Advisor (Michelle Gilbert)

Respite services

Loddon Court - run by Dimensions

(Care home providing respite stays and day care for people with learning disabilities and autism, run by Dimensions)

Bridges

² in most/all cases likely to be WBC

(Resource centre for children with disabilities and their families run by WBC)

Out & About - run by Optalis

(Enables people with learning disabilities join in with local events and activities)

School & holiday clubs

Thumbs Up holiday club (for children with SEND); and school attendance when permitted.

Benefits

Carers allowance (1 respondent) and blue badge (1 respondent)

NHS

GPs (some positive feedback although practices unspecified), Royal Berkshire Hospital staff, access to medical appointments, specialist nurses (e.g. MS nurse).

Communication channels

Although its limitations were noted, **video conferencing** (e.g. Zoom or Teams) was generally welcomed when face to face contact was not possible. The exception was young carers (under 18s) who expressed dissatisfaction.

"Zoom is OK but I have 8 hours in front of a screen for school and I don't always want to spend more time [on it]."

Online support for carers and their careers were greatly appreciated. Many positive and creative examples of **online forums and events** were quoted, e.g.

"The Music Club (Oxfordshire based charity group) provided weekly online discos and other music sessions which my son enjoyed and helped to keep him occupied."

TuVIDA and WBC are keen to note that people without digital access must not be disadvantaged, although our respondents didn't raise this issue. Our survey may have been less likely to reach people in this category, and/or such respondents were unaware of the support accessible to others.

In fact, many carers cited phone calls as a valuable source of support, notably calls from/with family & friends, but also voluntary sector, a specialist nurse, the local authority and connected services. Comments included:

"YPWD have been really good. A chap would take him walking every Friday before the lockdown. Now he rings for a chat"

Own resources, networks and environment

When asked what had helped them during this period, common responses were family, friends, fresh air and exercise.

Going for a walk enabled some carers to have time out in one of two ways: either by going out alone or by someone else taking their loved one for a walk.

Other sources of comfort and distraction included pets, indoor hobbies and volunteering. A few cited their paid work and/or their work colleagues.

Some respondents identified specific attributes in themselves which they drew on: conscience, knowledge, resilience, and 'picking your battles'.

Some carers explained how apparently negative circumstances had turned out in their favour. One carer gave the example of breaking her leg! It had forced her to introduce paid support which had reduced the pressure.

Other resources which made life easier

Stores and pharmacies which offered 'click and collect' or, most of all, doorstep services, were highly valued: prescription delivery and online shopping - particularly for groceries. Access to supermarket priority slots was appreciated.

A few carers referred to the benefits of transport (having a car and/or blue badge). Responses to other questions indicate that non-drivers are a particularly vulnerable subset of carers, especially during Covid.

"He can't drive (epilepsy)...Worried my driving licence may not be renewed...which will really limit what I can do/get to."



8. Recommendations

Covid-19 has been the biggest challenge the health and care system has faced in living memory. It is essential that lessons are learned from this experience... so that the health and care system can support the greatest possible improvements in health and wellbeing for everyone, well beyond this crisis.

The Kings Fund^{viii}

In summary, the main concerns emerging from our carers' feedback: the decline of those they look after, carer workload and lack of time away from caring responsibilities, and the impact on carers' wellbeing. Not all carers understood their rights. Not all carers knowing that they can register as a carer. Direct payment users raised a specific complaint about lack of flexibility. Services and support which received positive feedback have been highlighted and will be shared beyond this report. We have discussed the initial findings of our survey data with representatives of Wokingham Borough Council and TuVIDA.



Whilst this report as being written WBC and the Wellbeing Board have started to introduce initiatives, projects and their local priorities from the recent West Berkshire Joint Health and Wellbeing Strategy which will start to address some of the areas mentioned in the report, for example mental health, isolation.

Healthwatch Wokingham Borough recommends that:

- A. A **collaborative campaign** should be carried out by NHS Berkshire West (specifically its Wokingham locality team and Primary Care Networks), Wokingham Borough Council, Healthwatch, TuVIDA, and the local voluntary sector, where appropriate, to:
 - ☞ identify '**hidden**' carers and others who lack information and support
 - ☞ review and improve Borough-wide **GP surgery support** for carers, including sharing and extending examples of good practice (e.g. dedicated surgery phone line and/or staff champion for carers)
 - ☞ **increase information and support** offered to registered/known carers to address the challenges affecting them (caree decline, their own emotional and physical health, getting time out). To include more information about respite care and carers assessments.
 - ☞ continue and potentially expand what worked well (see section 7) during the Covid period
- B. Wokingham Borough Council to publish **written guidance for direct payment recipients** who cannot spend their payments normally. To be accessible via a link on their website and sent to those who aren't digitally enabled. Training and monitoring to ensure staff apply it consistently.
- C. Prioritise provision and take up of respite options especially for exhausted full-time carers looking after carees with the highest support needs.
 - ☞ WBC has discussed the potential of Assistive Technology (AT) but it must clearly identify and acknowledge the type of carer/caree/break that AT is appropriate for and isn't appropriate for
 - ☞ recognise the importance of **non-AT respite options** especially for the carers who most need help

The Carers UK campaign 'Give Us A Break'^{ix} calls for **increased funding and access to breaks.**

D. Clinical Commissioning Group to consider **updates to the carers information** on GP surgery websites, including:

- ☞ Providing more information about the benefits of registering as a carer with a GP practice.
- ☞ Include, on all GP practice web sites, links to other Carers services in the Borough, including but not necessarily limited to, Wokingham Borough Council website relating to their carers offer and contact number for adult social care hub. Links to TuVida carers service, links to Crossroads Care.
- ☞ Ideally create a Carers specific tab or tile on the home page of GP practice web sites so Carers information is quick and easy to navigate to.

E. There is a disparity between the number of carers registered with GP surgeries (approximately 4404) and the number of carers registered with Wokingham Borough Council (approximately 738). In order that carers have the knowledge of the carers offer from GP surgeries and Wokingham Borough Council, create a process, if not already in place, where GP practices sign post newly registered Carers to Wokingham Borough Council and their Carers offer and vice versa.

9. Service Provider Responses

Thank you for sending me a draft version of Healthwatch Wokingham Borough's report entitled Carers during Covid-19. The Report contains useful insight into the carer experience that system partners need to hear and consider.

I have circulated the draft report to various Directors within Berkshire West Clinical Commissioning Group for feedback, which I have summarised below

It might be worth pointing out that the number of people registered as a carer with general practice increased by 10% between February and October 2021 (4,047 to 4,404). This may be attributable to carers being urged to make sure they are registered so they do not miss out on their invitation to get a Covid-19 vaccination.

With respect to the recommendations in the Report:

- F. A **collaborative campaign** should be carried out by NHS Berkshire West (specifically its Wokingham locality team and Primary Care Networks), Wokingham Borough Council, Healthwatch, TuVIDA, and the local voluntary sector, where appropriate, to:
 - ☞ identify '**hidden**' carers and others who lack information and support
 - ☞ review and improve Borough-wide **GP surgery support** for carers, including sharing and extending examples of good practice (e.g. dedicated surgery phone line and/or staff champion for carers)
 - ☞ **increase information and support** offered to registered/known carers to address the challenges affecting them (career decline, their own emotional and physical health, getting time out). To include more information about respite care and carers assessments.
 - ☞ continue and potentially expand what worked well (see section 7) during the Covid period

We support the idea of a collaborative campaign on carers. We suggest that Healthwatch Wokingham Borough present the report to the Wokingham Integration (Leadership) Board to consider how this can be taken forward.

D. Clinical Commissioning Group to consider **updates to the carers information** on GP surgery websites, including:

- ☞ Providing more information about the benefits of registering as a carer with a GP practice.
- ☞ Include, on all GP practice web sites, links to other Carers services in the Borough, including but necessarily limited to, Wokingham Borough Council website relating to their carers offer and contact number for adult social care hub. Links to TuVida carers service, links to Crossroads Care.
- ☞ Ideally create a Carers specific tab or tile on the home page of GP practice web sites so Carers information is quick and easy to navigate to.

Recently there has been a reorganisation of digital support to the CCG. I have reached out to the new programme manager to discuss these recommendations and how they can be taken forward. I shall get back to you once I have met with the programme manager. However, I am cautious about the second recommendation, that links should not be limited to the Wokingham Borough website. The CCG or practices do not have the resource to maintain and update a range of links and contacts across all our web sites. It would be more straightforward to have the council site as the main repository of information for carers. As a system, this would mean updates only need to be made once.

Thank you once again for sharing the draft Report with us. The CCG looks forward to working with Healthwatch Wokingham Borough on taking the Report forward.

Best wishes,

Andrew Price
Wokingham Locality Manager
NHS Berkshire West Clinical Commissioning Group

Appendix 1

WBC Initiatives And Data

During the Covid-19 pandemic Wokingham Borough Council (WBC) developed a number of initiatives both internally and externally.

Carers Welfare Checks:

WBC and Tu Vida worked jointly with a team of re deployees from across the council making telephone calls to make sure our carers were OK and had access to the resources that they needed. We asked them if they had access to food and medication, whether they had any contingency plan in place in case they themselves were taken ill. Most importantly though we asked them how they were and if they had any concerns. Carers fed back that they welcomed having someone to talk to. We offered follow up calls, which many took us up on. Those most in need we kept in contact for many weeks and Tu Vida are still maintaining some carers welfare calls.

Carers Communication:

WBC sent follow up letters (emails to those who requested) after the phone calls so that carers would have this information to hand providing carers with contact numbers that they may need during the Covid-19 pandemic, of e.g. 'One Front Door', Wokingham Crossroads for contingency planning and the number of our emergency duty team.

Providing carers with PPE:

WBC provided carers with PPE free of charge and arranged delivery or collection.

Supporting paid carers to get early vaccinations:

WBC contacted paid carers and arranged for them to get early vaccinations so that customers were confident in letting them back into their homes.

Worked with our commissioned carers services to support them in delivering services more creatively:

WBC supported our providers in delivering carers services during the pandemic by being flexible in what we had contracted and helping some services think about how to do things differently e.g. dropping activity packs to young carers houses, using Zoom/Teams to run workshops, making welfare checks by phone.

Numbers of Carers Welfare Checks:

295 carers were called by WBC and Tu Vida during the first lockdown. **131** of these carers received follow up calls on several occasions.

172 young carers received welfare checks by WBC Childrens Services and Tu Vida. **57** of these received several follow up calls offering support.

550 carers were phoned by WBC's Adult Social Care. These calls were repeated in wave 2.

'Thanks for your email. At the moment we are coping as well as can be expected with the help of the neighbours and family. Keep up the good work'

'Thanks for offer of help if I need it, Cheers.'

'I really appreciated the carers outreach telephone number and will definitely be calling them'

'Thank you for your email and staying in touch - it is appreciated'.

'My daughter is very grateful for the support WBC have provided'

Appendix 2

Questionnaire

Section One: Please tell us about the person you care for

1. I am a carer for:

Please select all that apply.

- An adult(s) with an impairment/disability
- An adult(s) with a long-term health condition
- A child/children (under 18) with an impairment/disability
- A child/children (under 18) with a long-term health condition
- An older frail person(s)

Section Two: What it has been like caring for someone during the current Covid-19 pandemic ?

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

- It has decreased
- It has stayed the same
- It has increased
- I started caring for someone during the pandemic

3. Have you had a carers assessment by the council or local carers support group ?

- Yes, before the pandemic
- Yes, during the pandemic
- No, I don't know what a carers assessment is
- No, I don't want a carers assessment

Other (please specify):

4. Are you aware of your rights as a carer?

- Yes
- No

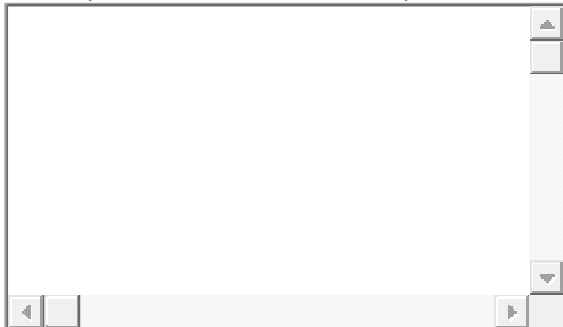
5. Do you know about the local carers support groups ?

- Yes
- No

6. Have you been able to access regular breaks from your caring responsibilities ?

- Yes
- No

If Yes, please tell us how? If No, please tell us the main problem?



7. What impact (if any) has caring for someone during the pandemic had on your: finances, employment, physical health, mental health or family wellbeing? (options- negative, positive, no impact)

8. Where have you been getting help and support? How helpful were these services (Options- Couldn't access, not helpful, helpful, very helpful)

GP surgery, hospital, local community/ voluntary groups, children's services (local council), adult social care (local council), adult day/ respite services, community mental health teams, NHS responder scheme, citizens advice pandemic service, private care company, friends, and family.

9. What kind of help and support were you looking for ?

- Help with a health problem (myself)
- Help with a health problem (person I care for)
- Help with a mental health problem (myself)
- Help with a mental health problem (person I care for)
- Help with hospital discharge
- Help with care after hospital discharge
- Getting respite/getting a break
- Getting prescriptions
- Getting food delivered
- Information on local support for carers
- Information on keeping myself and cared for safe during the pandemic
- Help with employment issues e.g. juggling work and caring
- Other (please specify)

Section Three: Tell us your story

10. What is your experience of being an unpaid carer during the current Covid-19 pandemic? (Maximum 250 words)

11. What has helped or been useful to you during this time? (Maximum of 250 words)

12. What would you like to see changed or would have helped you during pandemic and/or in the future? (Maximum 250words)

Section Four: Tell us about you

13. How long have you been a carer ?

- 6 months and under
- 6-11 months
- 1-4 years
- 5-9 years
- 10+ years

14. Why did you become a carer ? (maximum 100 words)

15. Have you registered as a carer with your GP ?

- Yes
- No

16. What is your age ?

- Under 18
- 18-24
- 25-34
- 35-54
- 55-64
- 65+

17. Please tell us which gender you identify as

- Prefer not to say
- Male
- Female
- Other (please specify):

8. Which ethnicity do you identify as:

- | | |
|---|---|
| <input type="radio"/> White British | <input type="radio"/> Mixed: White and Black African |
| <input type="radio"/> White Irish | <input type="radio"/> Mixed: White and Asian |
| <input type="radio"/> White Other | <input type="radio"/> Any other mixed background |
| <input type="radio"/> Arab or Arab British | <input type="radio"/> Black or Black British: Caribbean |
| <input type="radio"/> Asian or Asian British: Indian | <input type="radio"/> Black or Black British: African |
| <input type="radio"/> Asian or Asian British: Pakistani | <input type="radio"/> Any other black background |
| <input type="radio"/> Asian or Asian British: Bangladeshi | <input type="radio"/> Chinese or Chinese British |
| <input type="radio"/> Any other Asian background | <input type="radio"/> Gypsy or Traveller |
| <input type="radio"/> Mixed: White and Black Caribbean | <input type="radio"/> Any other Ethnic Group |
| | <input checked="" type="radio"/> Prefer not to say |

19. Which part of Wokingham do you live in?

Please add the first part of you post code. This is so we know who is responsible for providing services in your area.

20. Do you consider yourself to have an impairment or disability?

- Yes
- No
- Prefer not to say

21. What is your sexual orientation?

- Heterosexual/straight
- Gay

- Lesbian
- Prefer not to say Other (please specify)

References

-
- i <https://www.england.nhs.uk/commissioning/comm-carers/carer-facts/>
- ii <https://www.instituteforgovernment.org.uk/sites/default/files/timeline-lockdown-web.pdf>
- iii <https://www.wokingham.gov.uk/community-and-safety/life-in-the-community/census/?assetdet91f252ff-550d-4cfa-a838-92ef2cb5f83c=232529&p=2>
- iv <https://www.gov.uk/government/publications/coronavirus-covid-19-providing-unpaid-care/guidance-for-those-who-provide-unpaid-care-to-friends-or-family>
- v <https://www.theguardian.com/world/2021/may/17/home-working-doubled-during-uk-covid-pandemic-last-year-mostly-in-london>
- vi <https://www.gov.uk/government/publications/coronavirus-covid-19-guidance-for-people-receiving-direct-payments/coronavirus-covid-19-ga-for-people-receiving-a-personal-budget-or-personal-health-budget>
- vii <https://www.healthwatchhampshire.co.uk/report/2020-12-16/almost-200-people-tell-us-their-experiences-caring-during-covid-19>
- viii <https://www.kingsfund.org.uk/publications/covid-19-road-renewal-health-and-care>
- ix <https://www.carersuk.org/news-and-campaigns/campaigns/give-us-a-break>

**Healthwatch
Wokingham**

0118 418 1418
enquiries@healthwatchwokingham.co.uk
www.healthwatchwokingham.co.uk



c/o Town Hall,
Market Place
Wokingham RG40 1AS