

The hidden impact of Covid-19 on carers

November 2021





Carers stories, voices and supplementary information



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1 Introduction

Carers, providing care and support to a family member or friend, in their own home or elsewhere, are vital to reducing the pressure on statutory health and care services and even more so during the Covid-19 pandemic. However, the support carers themselves receive to enable and maintain such a caring role is often insufficient, even more so considering the extra and ongoing challenges with their caring roles since the outbreak of Covid-19.

The Healthwatch Sandwell report "**The hidden impact of Covid-19 on carers**" reflects the experiences of being a carer in Sandwell during the Covid-19 pandemic and highlights the hidden impacts on carers health and wellbeing 18 months on from the outbreak of the pandemic.

Overall carers have taken on additional caring responsibilities and had less access to support. Normal functions, such as food shopping, have become a worry and burden as carers have tried to protect the vulnerable people they are caring for, including those in the shielded categories. Carer's lifestyles, physical and mental wellbeing have been impacted. Carers need support to restore and recover from the impacts of Covid-19.

The report also outlines impacts of Covid-19 restrictions on the support service offers available to carers. The initial responses to the pandemic meant many care and support services suddenly stopped, such as respite and day care services. Care services requiring face-to-face services were impacted by Covid protection measures.

Most support services adjusted to a remote offer by telephone or on-line and some services stopped for a while. Care and support and welfare reviews and assessments have been affected. Since the Covid-19 "unlocking" over the summer of 2021 some services have started to resume more of a face-to-face offer, but others remain as a remote service offer or closed.

The Healthwatch Sandwell (HWS) project aimed to:

- gather insight on the experiences of caring during Covid-19
- gain a picture on information, care, and support services for carers during Covid-19
- hear from carers, including young carers, about the impacts of reduced services and Covid-19 restrictions on their lives and wellbeing
- seek carers views on support services needed to restore and recover from Covid-19

Based on the report findings and carers voices the report includes recommendations to improve and develop a comprehensive support service offer for carers in Sandwell. Some immediate adjustments are needed to improve upon the support offer carers have experienced since the outbreak of the Covid-19 pandemic in March 2020. Other recommendations may inform and influence the draft Joint Carers Strategy for Sandwell, which is currently in development.

This document contains **Carers stories**, **voices and supplementary information** on services and recommendations. Key findings are presented in the **Executive Summary**.



2 Methodology

HWS undertook the project between June and September 2021. Covid restrictions and safety measures presented challenges with less public face-to-face engagement opportunities. HWS worked in collaboration with a range of Voluntary and Community Sector (VCS) organisations, who provide support services to carers, to promote the project and encourage involvement.

An on-line survey was created and widely promoted including through social media. Printed versions were also provided to ensure responses from carers who may have been digitally excluded or needed help to complete the survey, including language support. 40% of surveys completed were printed copies. Completion via telephone support was also offered.

The 2011 census stated there were 33,530¹ unpaid carers in Sandwell out of a population of 308063. This equates to 10.8% of the population. Sandwell Council has projected that the 2021 census figures will show a significant increase in the number of carers.

102 surveys were completed

50 individual carers stories and insights were gathered - through one-to-one interviews and focus groups undertaken by HWS and VCS organisations. The conversations were held face-to-face, where possible, with individuals and carer forums, by telephone and through on-line virtual meetings. Carers participating reflected a good balance of age and ethnicity representation for Sandwell population however the majority were female.

Summarised case stories are included in the report to illustrate key points, caring scenarios, and Covid-19 impacts. Carers voices and views are also reflected throughout the report.

Overview of caring roles

HWS Survey responses stated that **45%** of cared for people were on the Covid clinically extremely vulnerable shielded category list. **78%** of the people cared for lived in the same house as the carer, **19%** in their own home and **3%** in supported housing. Carers said they felt cared for people had lost independence, connections, confidence, and skills as a result of Covid-19 restrictions and impacts.

"My parents are now not able to do the things they used to do for themselves due to worsening health during the pandemic. I am now having to do 3 times as much for them as I did before the pandemic."

"Confidence doesn't come back overnight; my mum is now housebound my dad is mobile but no longer has the confidence to leave the house alone and pay for items at the shop"

¹ <u>https://www.ukcensusdata.com/sandwell-e08000028/provision-of-unpaid-care-qs301ew</u>



3 Impacts of caring during Covid-19

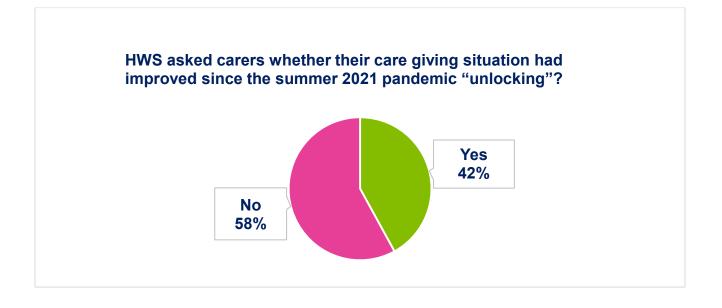
As outlined in the **Executive Summary** almost every aspect of carers lives has been adversely impacted by Covid-19. The quality of relationships with cared for people and carers spouses was a more balanced picture – **data from the survey results are at the end of this report.**

Comments below from carers indicate the frustrations with services and Covid-19 impacts:



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Very little appropriate support now available for him that he could access previously.

Now back at school getting autism support during school hours.

Nothing has changed as day care still unavailable, which is the only external service normally available I can go back to work and able to speak to people, go to the gym.

> I and three other sisters sharing care rather than one person.



4 Overview of information, care, and support services for carers during Covid-19

Day care and respite opportunities

Since the summer 2021 Covid "unlocking", some services have started to open again and provide a level of day care offer but the provision is greatly reduced compared to the pre Covid position. Sandwell Council and the VCS are currently considering proposed changes from the day care model to expanding day opportunities within the community. The carers insights on lack of suitable facilities within Sandwell for special needs should be included in work on proposals for change. Some cared for people and carers are returning to use facilities, but others are wary of doing so as the Covid pandemic remains a concern.

"Support worker will hopefully help her get back to the day centre but it's building confidence"

HWS are aware that transport is an issue for some carers and cared for people especially if mobility transport is needed, the full-service offer does not appear to have been reinstated.

"Previous day care not currently available due to transport issues, the service should have resumed as previously"

Providing respite care during Covid-19 is a challenge. Very little respite care appears to have been provided and some provision was compromised by Covid circumstances.

"I had grant for myself for a break but had to take my daughter with us"

"All respite was cancelled but I did get one week emergency support in my home, along with my wider family which was unfair on them - the only time I accessed anything"

Some carers spoke of respite in terms of short breaks achieved.

"My son's respite carer can take him out to things"

"She has gone back to school full time so back into a routine, also her carers could start to take her out again giving me and her brother respite"



Information and support available to carers at beginning of the Covid-19 pandemic

At the outbreak of the Covid-19 pandemic most face-to-face support services, including for carers, stopped. In response to the pandemic Sandwell Council, NHS, the VCS and HWS worked collaboratively together to ensure services to the public continued, that the public were informed and signposted and that referrals to meet needs were undertaken.

Sandwell Council and VCS Organisations were able to make direct contact with carers already on their data records to undertake welfare checks, offer direct befriending services, respond to information, and support needs. GP Surgeries and other health care professionals across Sandwell contacted many carers, if registered as such, or via communications with vulnerable or shield category patients.

However, carers not previously connected to any form of support and the high percentage of the Sandwell population digitally excluded through skills, language or "digital poverty" are less likely to have accessed or received information or signposting services.

Only **40%** of carers said they had accessed or received information about support available for carers. Sources included **24%** via Sandwell Council², **62%** VCS organisations supporting carers, **9%** HWS and health professionals. Two references were made to National sites - Carers UK and Gov.UK³

"The system needs to be more joined up and carers given more advice and guidance from professionals"

Ongoing support available to carers during Covid-19

The HWS survey asked carers about access to support and support groups during Covid-19. Response figures indicate that many carers have not accessed any support during Covid-19.

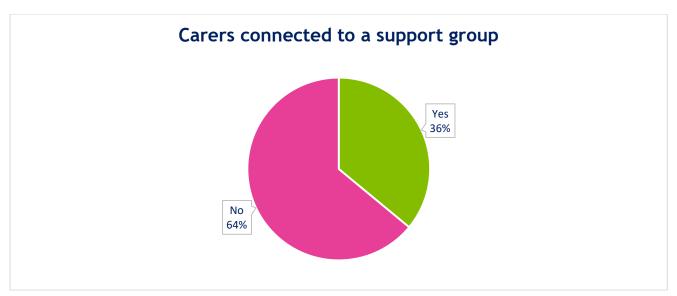
VCS organisation support groups located in Oldbury, Smethwick and West Bromwich were mentioned as well as peer support groups in Wednesbury and Great Barr. There was no specific mention of support groups in Rowley Regis or Tipton area. There are at least 15 VCS organisation and carer support groups operating within Sandwell, though not all receive funding support from Sandwell Council.

"WhatsApp group of carers helped and virtual training"

² <u>https://www.sandwell.gov.uk/info/200218/carers</u>

³ <u>https://www.gov.uk/carers-uk</u> & <u>https://www.carersuk.org/home</u>





VCS organisations adjusted services in response to Covid restrictions but overall maintained contact with and ongoing support to their registered carers by phone and virtual connections, including befriending calls, practical support, information, advice, guidance, referrals, and signposting. Since the summer "unlocking" more face-to-face and group support to carers have started up again. Some of the VCS organisation services are highlighted within the carer experiences and stories shared within this report.

In response to Covid-19 restrictions impacting service access for carers and the increased need for support a new service, Sandwell Crossroads Carers Assistance Line launched in January 2021. The new service offer is holistic and looks at carers unmet support needs including:

- Listening and guidance
- Wellbeing conversations
- Referring and signposting including to specialist support organisations, counselling, and Sandwell Council carers assessment
- Carers Trust small grant application

"You have saved my life, I was going mad, nobody was listening."

The Carers Assistance Line was widely promoted when it launched and access or use of the service is referenced by carers within this report. However, the HWS survey results showed low access to the new service - only 4% of survey respondents said they had made or received calls from the service. As the service is relatively new and developing - a review of uptake and promotion may be worth consideration.



Assessment of carers support needs

Assessment of carers support needs does not appear to be a consistent process – it seems dependent on carers own level of support needs or connection to the specific caring scenario:

The Care Act 2014⁴ and Children and Families Act 2014⁵ give local authorities in England a legal responsibility to assess the needs of carers, support their eligible needs and actively promote their wellbeing and independence. The threshold for carers eligibility for support from the local authority, i.e., Sandwell Council is based on the impact their caring role has on their wellbeing; whether the carer has support needs to be met to effectively undertake their caring role.

Sandwell Council website includes a page for carers with sections explaining the carers assessment process and eligibility criteria for carers with support needs to undertake their caring role. It also includes advice and guidance and signposting to carer support organisations – though the information content and the pages are not simple to navigate.

Young carers can access support services developed specifically for young people. VCS organisations offering support for specific needs such as mental ill health, learning disability, or dementia also offer support to the associated carers and undertake their own assessment processes to establish carers support needs, match to their organisations offer and provide information, referral or signposting to other services including Sandwell Council.

Carers not matching the support services outlined above seem less likely to be connected or receiving any focused support for their caring role though some carers may access National information sources. Some carers may be connected to other Sandwell VCS organisations offering generic support such as Agewell, for older people, or local social groups. There may be an opportunity to use these routes to establish contact with more carers in Sandwell.

GP Surgeries

50% of carers stated that they were registered as a carer with their GP Surgery. Registration can be beneficial for flexibility with GP appointments, guidance, and support. However only **9%** of carers indicated having had a health check with their GP since March 2020. Unpaid carers were prioritised in the earlier stages of the Covid-19 vaccination programme - **71%** of carers responded that they had received their vaccinations, which is in line with the Sandwell population uptake.

"I haven't been sleeping well for so long it's affecting me physically. If I could get some help it would be appreciated"

"Flexibility with appointments, as often they can clash with things you have to do for cared for, and if you haven't anyone to support and fill in gap you just cancel your own things and think I will do it later"

⁴ <u>https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted</u>

⁵ https://www.legislation.gov.uk/ukpga/2014/6/contents/enacted



Carers Emergency Cards

Sandwell Council offer an initiative issuing Carers Emergency Cards with key contact details linked to Sandwell 24-hour Community Alarms Service. Only 4% of carers indicated having a card.

Welfare benefits

Carers Support Allowance (CSA) is a state benefit for those providing over 35 hours per week of care to an eligible person in receipt of certain benefits - 32% of carers said they receive CSA. However as 65% of carers stated providing over 50 hours per week of care, there may be some eligible carers not claiming this benefit. Carers National Insurance Credits are a contribution to state pension if at least 20 hours per week of care are provided to an eligible person in receipt of certain benefits - only 7% of carers stated that they are registered. 79% of carers answered that they give 22 hours or more to their caring role – there may be low registration or lack of awareness of Carers National Insurance Credits by carers within Sandwell and a possible need to promote the benefit to avoid future financial impacts.

Two carers commented specifically:

"Financially carers allowance is a joke, for the care we provide, and this goes down as employment on tax credits! We are worth £3500 a year."

"If receive Carers Allowance and benefits we have not qualified for extra money such as £500 tax credit grant or £20 extra universal credit. We have had extra care to do and less money than anyone else."



5 Carers stories

Carers stories providing useful insights are reflected in the next sections of this report.

5a General carers stories - A range of caring scenarios captured from conversations are presented to highlight key points. Outputs from some specific focus groups are reflected, including caring for mental ill health, learning disabilities, autism, and dementia. Insights from some ethnic minority, older carers, and young carers

Carer struggling with long Covid

A carer shared challenges of caring for her disabled son while struggling from long Covid. "Support from SAFS and Options for Life gave me a break to recover, I am still affected, even small tasks, I need a lot of breaks" "my mental health and confidence are low, but I am pushing myself"

Impacts on family life supporting a child with autism

A carer shared with HWS some of the challenges of supporting their young child with autism. The son is non-verbal, did not understand Covid-19 impacts on his life, was frustrated with challenging behaviour and self-harming. Home schooling was very difficult "I feel guilty about my daughter, all the attention is on my son's needs". Sandwell Parents for Disabled Children helped with activity packs. The carer had been furloughed, "I missed going to work - it was a break, my respite".

Carers shared their own health issues

"Constantly in pain" "Gone from working & riding a bike everywhere to nothing" "worried about my conditions going back to how they used to be" "If my health issues got bad, I would need support for my wife urgently."

Losing contact in supported housing

A carer spoke to HWS about the impact of Covid-19 on her relationship with her son who has profound and multiple disabilities and lives in supported housing. The parents used to see their son weekly but since Covid-19 had only seen him twice and could not see him at all when he contracted Covid "which was a very worrying time". The carer spoke of fears of her son losing skills or him being able to recognise them as parents.

Connecting services for complex needs

The Carers Assistance Line supported a woman with language barriers to reconnect with Sandwell Council children's social services to get support for her son's increased needs due to his learning disability and mental health issues. The Covid-19 pandemic had made it extremely difficult for the mother to be able to succeed with getting new support in place and this had impacted on the quality of life for all the family.

Carer of young adult with Sickle Cell

"I see my son going through so much pain all his life and there is nothing I can do" This carer told HWS that with her son was in the shielded category and without family in the UK things had "not been easy at all!", she was thankful for her church group that met "virtually on zoom". Emotional, financial and isolation impacts had been high, and she had "been overwhelmed at times".

Impacts of caring as a working single parent

"Ms H" is a single parent living with her 2 children and a live in elder relative. Ms H's son has disabilities and a range of support needs, the elderly relative is ill with long term conditions. Ms H shared with HWS some of the impacts and changes to lifestyles caused by Covid-19. Her son has "missed out on some therapies" and affected his physical development, day, and holiday activities to support her son's needs had stopped during Covid-19. The elderly relative's health has degenerated, Ms H feels this was not helped by lack of face-to-face GP appointments to monitor his conditions fully. Due to vulnerable people living in the household Ms H's daughter has been unable to physically attend school. **Ms H** was full time working prior to the Covid-19 pandemic but with extra support needs and lack of alternative support available Ms H reduced her working hours. This reduced income which is a concern, "specially to cover fuel bills for heating and heavy washing loads" for her son and relative's needs. Ms H said the caring role has taken a toll on her physical health with lifting and that assessments of care and support and carers needs require an update. Though things have been hard, and Ms H has been more socially isolated she told HWS there were positives, it was easier to flex part-time work around caring needs and family relationships were good "I want to be at home now, spending more time - I want this to be my new normal now."

5b Carers of people with mental ill health, learning disability or autism

Sandwell African Caribbean Mental Health Foundation (SACMHF) and Sandwell Carers Mental Health Team (SCMHT) and Sandwell Asian Family Support (SAFS) all supported the HWS project. Each of these VCS organisations provide support to minority ethnic groups whose voices are reflected. Individual and focus group conversations were held with carers who support people with mental ill health, learning disability or autism.

Focus – African Caribbean carers of people with mental ill health

Sandwell African Caribbean Mental Health Foundation provide a range of culturally responsive services for people of African and Caribbean descent affected by mental ill health, and the wider community. They work to influence equitable mental health services for people of African and Caribbean descent.

HWS spoke with **6** carers who joined the focus group. The group were not aware of carers support or carers assessment services available through Sandwell Council or of the Wellbeing hub. They were also not aware that GP Surgeries held a carer's register.



"I don't know why no one has told us about this."

"We need support ourselves to support who we are caring for."

All the group said the Covid-19 pandemic impacted their mental health and wellbeing.

"Covid Stats were draining. My anxiety transferred to my children."

Positively all the group mentioned improving their digital technology skills and keeping connection with family and friends through virtual meetings.

"I am able to Zoom now. If I could not, I would have just been isolated."

"I have been using WhatsApp for a friend's group."

Focus – Carers of mental ill health, learning disability and autism

Sandwell Carers Mental Health Team (Black Country Healthcare NHS Foundation Trust) provide support, training, signposting and guidance to over 200 carers of people with mental ill health, learning disabilities, autism and those caring for a child accessing CAMHS. Around a third of carers supported are from minority ethnic communities. There are several carers support groups including a men's group and an Asian women's group, the groups have continued to provide support to carers throughout the Covid pandemic.

HWS attended one of the carers support groups called "COPE" where 7 carers shared their experiences of caring during Covid-19 and gave feedback:

The carers gave insight into the additional emotional and mental stress they had been under since the Covid-19 pandemic including:

Two suicides were referenced.

A carer whose husband passed away from Covid was still providing care for mental health support needs and felt she had not received sufficient bereavement support.

Isolation during Covid-19 lockdowns and access rules within supported housing, including for support staff, were very challenging for the carer and cared for people to cope with.



A carer shared that her son, a father with children, had been sectioned following a mental breakdown, he had been isolated in hospital for weeks with no post hospital follow up service.

"Mrs A" was driving when ambulances passed with flashing lights and sirens, she became convinced they were going to help her son with his mental ill health. This set off her anxiety and she has not been able to drive since as there are more ambulances on the roads. This has affected her independence.

"Mrs B's" husband acquired a brain injury many years ago, the household income reduced from 2 salaries to reliance on welfare benefits. She had developed anxiety and was unable to leave the house or seek support. She had eventually accessed the carers mental health team services and developed confidence. However, the Covid-19 pandemic has re triggered the anxiety, "now I can't travel on a bus or train - I feel like Covid-19 has set my life back to 20 years ago again".

One carer stated that they felt being registered as a carer with their GP Surgery had not made a difference - despite serious health conditions and newly developed problems they had struggled to be physically seen face-to-face by their GP.

Carers Mental Health Team have been very helpful. When we had Covid and I lost my Husband, they delivered groceries and medical supplies for my daughter.

The group expressed frustration about mental health services needed by those they care for:

CAMHS "The Occupational Therapist left, you get closed down, or the phone. No post hospital home visit to assess needs.

CRISIS MH Team "is a waste of space"

An assumption that the carer will continue, no planned or joined up service plan. Since Covid none of the services have gone back to helping people.



5d Focus - Caring within Asian Families

Sandwell Asian Family Support (SAFS) provide domiciliary care and support in the home, community outreach and centre-based day services to families caring for children and adults with disabilities. SAFS spoke with HWS about some of the specific experiences and impacts of Covid-19 within Asian families. There have been higher levels of vaccination hesitancy within some minority ethnic communities. SAFS, as a trusted community care and support provider, offered a vaccination clinic within their centre, they told HWS about the relief expressed by carer parents when they were able to get their autistic son vaccinated.

SAFS told HWS that families are very anxious and want things to go back to normal routines, to access full support and social interaction opportunities. However, this is challenging with Covid-19 safety measures and financial constraints within Sandwell Council Social Services impacting on contract delivery. A carer shared that in Asian culture, and especially applicable to women, it is instilled that

"You will cope."

An Asian woman's story of caring experiences during Covid-19:

"Ms G's" mother is in her late 80's and lives with her daughter. Normally Ms G shares the caring with her sister, but Covid-19 restrictions prevented normal visiting arrangements. Ms G has found it challenging to balance working from home during Covid-19 and keeping this distinctly separate to caring for her mother. She has been unable to switch off from the domestic environment and feels she has ended up doing more for her mother and that her mother has become less independent. Ms G expressed that she has been unable to relax and tune out to things, that she is always on alert, including supporting her daughter's mental health. Ms G said the combination of responsibilities and intensity of home life has had a knock-on effect, some neglect to her own health issues and impact on her mental wellbeing.

5e Elderly Carers and caring for people with dementia

Better understanding of dementia for Sandwell (BUDS) supported the HWS project by holding individual focused conversations with carers of people with dementia and by providing anonymous case study insights.

BUDS provide specialised support and advice to carers of people with dementia and work collaboratively with Agewell who support older people, and Crossroads support for carers. Combined services were adjusted to ensure connection and support to carers including telephone befriending, remote support, and signposting.

Agewell provided falls prevention information and virtual exercise classes. BUDS offer day services for people with dementia and their carers with transport and a meal included. Face-to-face services halted during the Covid -19 pandemic but have restarted.



BUDS and Agewell shared their views on the impacts of Covid-19 on older carers:

- Dementia in patients exacerbated by the lack of sociable and active opportunities, placing greater burdens on carers.
- Respite care had disappeared.
- Frustration with not being able to see GP's face-to-face and hospital referrals.
- Some carers isolated, lonely, not connected to families, due to Covid restrictions.
- Older people, including carers had become physically deconditioned due to Covid restrictions with higher risks of frailty and falls.
- Many carers were not yet re-engaging as services begin to open up.
- Older peoples voices within services now less heard, and partnership focus on health, care and support needs had also been affected.

HWS held a conversation with a man in his 70's who had become isolated from his social connections due to Covid-19 restrictions and was becoming anxious and depressed by his domestic and family situation. His wife was helping her sister daily with supporting the Brother-in-law with his declining mental wellbeing. All 4 elderly people were entwined in the cross support of each other but had not and were reluctant to seek support. HWS recommended making some GP appointments and signposted to Agewell services.

"Mrs C" is a carer over 65 years old. Her husband's behaviour, due to dementia, had become increasingly challenging during the Covid-19 as he had not understood the pandemic, or the restrictions imposed. The carer felt burdened and stressed "everything had to revolve around my husband, my life was put on hold". Paid carers had not worked out well during Covid-19, a decision was made, "Mr C" moved into a care home in April 2021. This had left Mrs C, as a wife and carer, even more isolated, unable to visit her husband in the care home and unsupported. HWS signposted Mrs C to Crossroads Carers Assistance Line, BUDS and Agewell.



3 carers for dementia, all over 80 years old with a disability/long-term condition, expressed:

Support services are very poor at present - much more services are needed.

> GP's have fobbed us off they still won't provide face-to-face appointments

BUDS befriending service was a lifeline during lockdown.

"**Mrs D's**" husband has a heart condition and dementia, he physically deteriorated during Covid-19 affecting is mobility and communication. **Mrs D** struggles to support her husband's personal care as she has also become increasingly unwell during Covid-19 and been hospitalised. **Mrs D** is very upset that "**Mr D**" is left on his own at these times as family are all at work and friends no longer visit. BUDS activity sessions were closed in lockdown, but **Mrs D** was grateful for the BUDS befriending and care support calls and relieved to now be getting some respite support.

"Mrs E's" husband with dementia moved into a care home during 2019. Covid restrictions meant Mrs E's visits were limited and only through a window. Mrs E felt isolated, lonely, guilty, and depressed. Her husband contracted Covid in the care home, he was hospitalised, issues then arose with a planned return to the care home. "Mr E" died in hospital; the funeral was impacted by Covid restrictions. Mrs E still receives phone support from BUDS – "I don't know what I would have done without you".

"Mr F" has provided care to his wife with dementia for the past 7 years. Mr F feels his wife's social skills and mobility declined when groups and day centres closed during Covid-19. Mr F felt "let down" by the lack of support from closed services as his wife's condition deteriorated and he struggled with lone caring. Mr F has become frail and sustained an injury which meant he could not undertake some of the care for his wife. Social services provided visiting care, "Mrs F" was recently hospitalised and moved into a residential care home. Mr F feels that "social services should be doing more for elderly people living with dementia" and that "counselling for carers would be a good idea, giving people somewhere to vent their frustrations"



5f Young Carers

Sandwell Young Carers (SYC) and Sandwell Advocacy Young Carers (SAYC) supported the HWS project to ensure young carers voices were heard. Support workers engaged directly with young carers to hold individual and group work conversations. SAYC also captured young carers voices in some video engagement workshops.

SYC worked in partnership with Sandwell Council to set up a Vaccine Clinic at Tipton Sports Academy designated for young carers. Over 2000 people were informed about vaccination, over 50 young carers were vaccinated and around 100 flagged on GP practice records as young carers.



Young carers roles intensified during Covid-19 with many lives being constrained to the home environment, including for education, and more responsibilities being taken on to protect against Covid-19 risks.

Covid-19 has had specific impacts and placed a heavy burden on young carers including:

- Extra responsibilities for protecting the persons cared for from Covid risks.
- Increased housework cleaning and sterilisation of food deliveries.
- Education switched to remote learning for many not working well for some.
- Physically isolated from their peer group
- Unable to physically socialise with friends to protect vulnerable cared for.
- Concerns about losing friendships.
- Anxiety about Covid-19 heightened by the fears of the people they provide care to.
- Worrying about keeping the cared for safe.
- Intense home living situations feeling unable to escape/have outlets.



Key words expressed by young carers about caring during Covid-19 included:



Young carers shared some experiences and feelings about caring during Covid-19:

"My family is really important to me. That is why I always stay in bubbles, and I take care of them"

"I have had a lot of anxiety build up because I worry about my Mom getting Covid, as she has no immune system and during online learning my brother, with additional needs, has had meltdowns stopping me from doing work" "I did have a lot of mixed emotions during Covid 19, it made me worried as all my family and my grandma had to avoid getting it, so it was difficult to socialise with others and I was worried about falling behind on schoolwork."

"I have been very stressed lately with chores and college which is why I've had to start using my stress toys"



Sandwell Young Carers shared their views on the impact of Covid-19 on young carers:

Prior to Covid research already identified the various potential impacts children and young people faced from undertaking a caring role. The Covid pandemic exacerbated these, including higher levels of caring roles and responsibilities, increased levels of stress and anxiety, amplified levels of social isolation and greater challenges in their education. There may be new young carers emerging due to family members having long Covid and the impact on their mental and physical health.

The young carer's role went from having a break at school to now being full time carers, they were not allowed to see their friends and other family member which they needed to help relieve any stress or have a break from their caring roles. The stress has shown in forms of self-harm, mental health, eating disorders and generally not feeling like themselves, the fear of taking the virus home has had a big impact.

"As we return to the 'new normal' it is vital that professionals understand young carers and ensure this cohort of children and young people, and their families, are identified and supported. Every individual and their family will have unique needs for support therefore it remains imperative that support is individualised."

> Mum is too paranoid!

Wearing masks ALL the time! It feels like a prison being sat in your room, any room, doing lessons or homework

It can be difficult to get your education done because your caring role takes your priority of other things you may need to do - that is more important.

> I had to go to places alone. I had to do forms on my own. I became more independent because of it.

I can't go out; my friends can't come round – Mom won't let us.

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6 What support do carers need to restore and recover from the impacts of Covid-19?

HWS asked carers what information, support, or services they would benefit from to reset and restore carers lives after the impacts of Covid-19. The main responses are provided in the Executive summary linked with the report recommendations.

Further comments and suggestions from carers included:

A free "sitting service" for carers to be able to attend appointments

A forum for carers to meet and talk to decision makers. More help, respite to take off the strain.

A carers information folder – on becoming a carer and support available.

Based on the old Cares model. It worked, wasn't broken and didn't need fixing. Services actually running properly that are needed to be accessed by my child.

An app for carers – accessible 24/7, FAQ, wellbeing section and forum for carers. Lists of services open and new services, support services that can be accessed if we go into another potential lockdown.

Training.

A variety of services on offer to people with mental ill health – Recovery college does not suit

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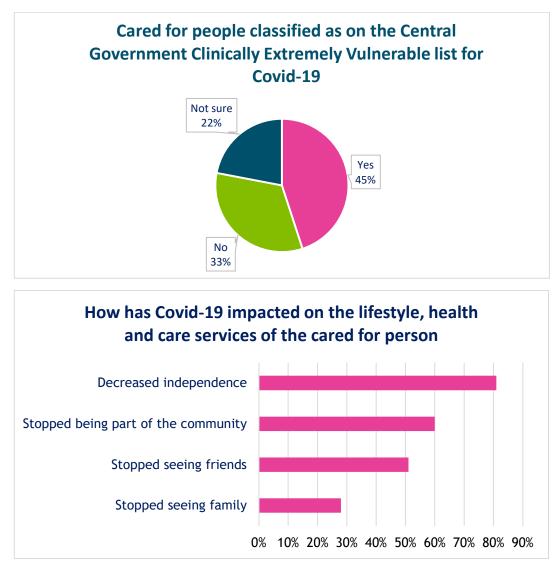


7 Supplementary information from survey results

Much of the findings of the HWS survey are presented within the main body of the report. The data within this section is supplementary information.

Overview of caring roles

HWS gathered a picture of the caring scenarios and asked for carers views of the impact of Covid-19 on those they cared for:

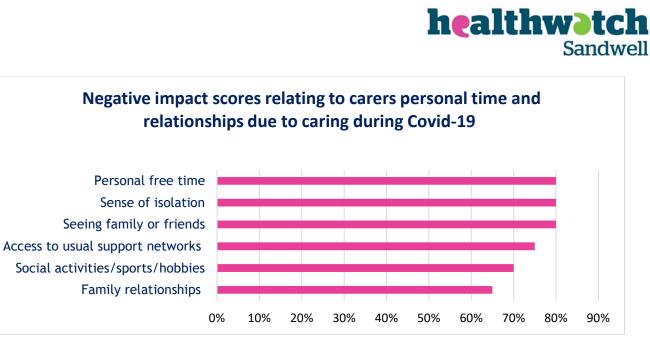


Impact on carers relationships

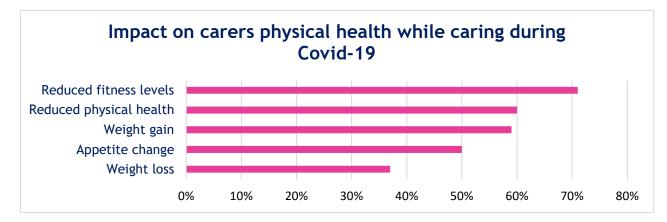
58% of carers said there had been an increase in the level of care and support provided.

47% indicated a decrease in quality of time spent with the person cared for, **30%** an increase. Similarly, **45%** of carers indicated a negative impact on their relationship with the person they cared **29%** a positive impact.

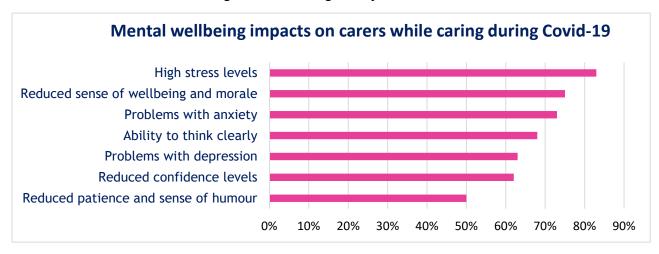
Carers with a spouse or partner were asked about the impact of caring during Covid-19 on the relationship -51% indicated a negative impact, 32% no effect and 16% a positive impact.



Most carers responded that they have become less physically fit and mentally well during Covid-19. **80%** of carers indicated a lack of time or ability to attend to their own physical health, fitness, or mental wellbeing. However, **11%** of carers indicated a positive impact on physical fitness levels.

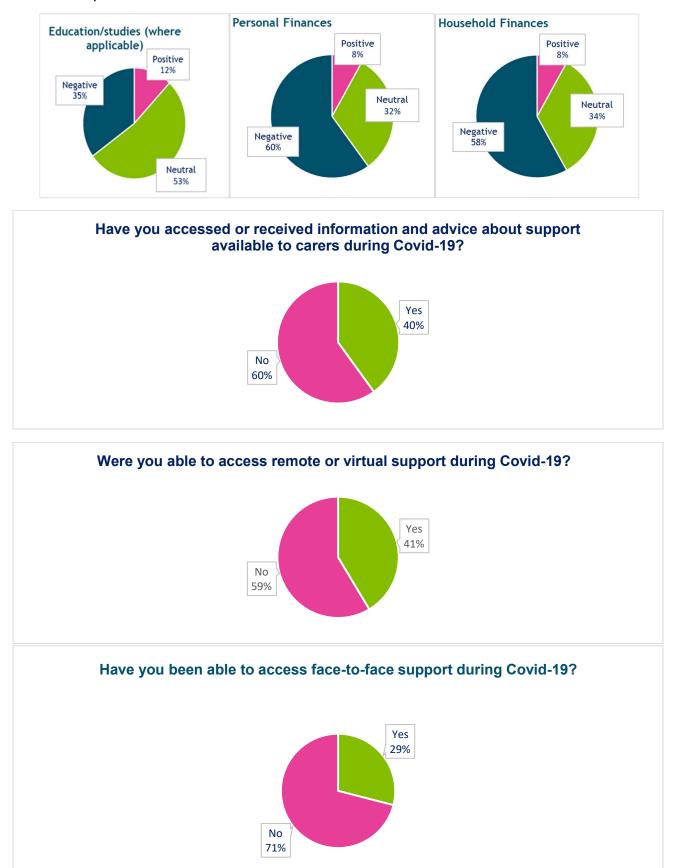


Around **10%** of carers responded stated a positive impact on overall mental wellbeing but overall carers mental wellbeing has been negatively affected:





HWS asked carers about impacts on their financial circumstances during Covid-19. The reasons were not explored in detail. The charts give an indication of impact for carers where the question was relevant.



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WHO WE SPOKE TO



102 people completed our survey

15 people - 65 - 79 years 39 people - 50 - 64 years 43 people - 25 - 49 years 1 person - 18 - 24 years 4 did not specify

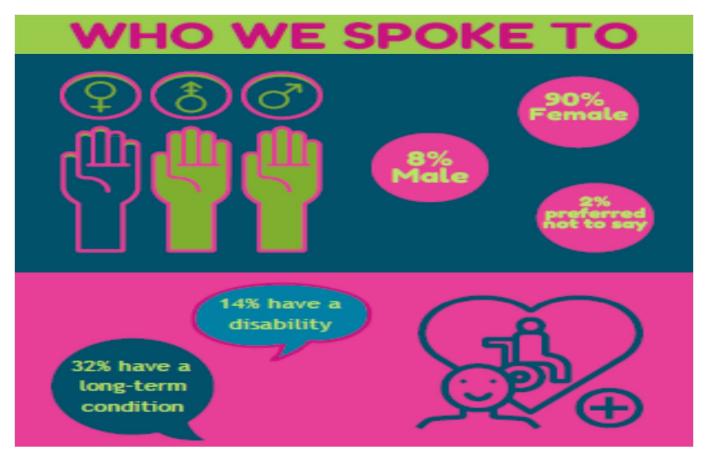




Including people from ethnicities of:

- 20 Asian/Asian British: Indian
 - 5 Asian/Asian British: Pakistani
- 5 Black/Black British: Caribbean
- 53 White: British/English/ Northern Irish/Scottish/Welsh
- 4 White: Any other White background





CARED FOR PEOPLE



Carers told us about people they cared for:

26% under 18 years old 45% 18 - 64 years old 29% over 65 years old of which 48% over 80 years old

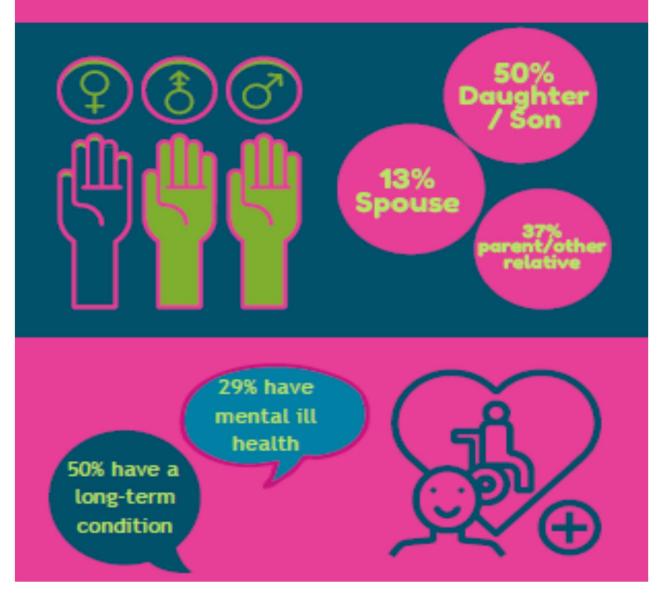




CARED FOR PEOPLE



Care and Support needs to be met: 9% weekly 9% once a day 18% throughout the day 8% during night time 55% through 24-hour period 14% 22 - 49 hours per week 65% over 50 hours per week





8 Conclusion

The HWS project looking at **"The hidden impact of Covid-19 on carers"** aimed to capture and reflect carers experiences, stories, and views. The impacts of being a carer during Covid-19 are profound and ongoing. Support services for carers have stopped or been greatly reduced and provided remotely at a time of greatest need. Maintaining connections between carers and support services have been challenging. Some contact links with previously supported carers have dropped away and other carers have had minimal or no connection to any support services. Carers in Sandwell have experienced an inconsistency in receipt of information and support.

There is much to address to reset services for carers to help restore and recover carers lives as a "new normal" is established. Some support services for carers have fully resumed but continue to operate in an environment subject to change from ongoing Covid-19 impacts. This position needs scoping with contingency planning incorporated to enable services to continue to function despite the impacts of Covid waves.

The services for cared for and carers landscape is shifting regarding design and commissioning and the move to local and regional integrated care systems. Partnership, collaboration, and co-design in consultation with cared for and carers is vital to ensure that service modelling going forwards fully meets needs and addresses the impacts of Covid-19.

9 Recommendations

Delivery of improved and more comprehensive services to carers in Sandwell requires a partnership approach between health, statutory care, and the voluntary and community sector with carers voices at the centre of decision making.

Development and conclusion of the Joint Carers Strategy gives an opportunity to refine the support to carers offer. However, work on this should not delay more immediate responses to correcting gaps in information and support services for carers:

Based on the full report which reflects the voices of carers in Sandwell HWS recommends:

Information for carers

1. Review and create an updated picture reflecting current services and support offers available for carers in Sandwell. Promote the information widely across Sandwell (including printed formats) aim to reach, inform and connect with as many carers as possible.

Young carers

2. Consider the findings within this report and explore in more depth the information and support needs of young carers. Work in partnership with young carers support services, including education and mental health, to address the specific needs and impacts of Covid-19.

Support for carers

3. Prioritise scoping the current support service offer for carers in Sandwell, reflecting on the findings of this report regarding the impacts of Covid-19 and relevant carer support needs. Identify and seek to address immediate gaps in the service offer commencing early 2022.



- 4. Work in partnership to ensure assessment of known individual carers support needs are up to date and planned to be provided for across the carers support services offer model. Seek to incorporate well-being checks on physical health, mental wellbeing and financial position and refer or signpost to relevant services accordingly.
- 5. Work with the Primary Care Network to maximise the carer registration at GP Surgeries, and uptake of health checks and relevant vaccinations.
- 6. Review the Sandwell offer of accessible toilets, changing places, indoor facilities, and outdoor spaces to suit disabilities and vulnerabilities and enable maximised options for cared for people and carers.
- 7. Link the project findings and other relevant insights into a review of transport and options across Sandwell for people with relevant support needs. Seek to provide some immediate improvements to the local offer to support carers.
- 8. Explore opportunities for voluntary support to carers including the potential to link to the SCVO "Let's go Sandwell" programme.
- 9. Consider provision of a bespoke mental well-being service to address the impacts of caring during Covid-19 on carers, cared for and family members.

Development of a Joint Carers Strategy

- 10. HWS recommends that the experiences, stories, and carers views reflected within this report help inform the service remodelling and that carers, as well as service users, are included within the consultation processes.
- 11. Plan a Carers Conference to discuss findings of this report, identify immediate health, care, and support service adjustments, promote services and consult on the draft Joint Carers Strategy.
- 12. Ensure the draft Joint Carers Strategy 2021-25 action plan incorporates learnings from this report and seeks to ensure an integrated health, care, and support service for carers.
- 13. Scope and model information available to carers ensuring all carers can receive a consistent package of information regarding support options available irrespective of access point. Provide the information in the range of accessible formats to address identified specific needs, language barriers, and carers who are digitally excluded.
- 14. Consider options to create a database of all carers in Sandwell for relevant communication purposes.
- 15. Review the validity of carers emergency cards including considering plans for "shared care records."
- 16. Explore options to develop or support a carers forum accessible in a range of formats.



Further information

To feedback your comments on this report or for more information please contact:

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10 Acknowledgements

Healthwatch Sandwell appreciate the support of the following Voluntary and Community Sector organisations who worked collaboratively to ensure that a wide range of carers were engaged in the project and that their experiences and voices were captured.

Healthwatch Sandwell extends appreciation and a "Thank You" to:



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