



Caring During Covid -19
Carers Experiences in
Sandwell
January 2021

healthwatch
Sandwell



Engaging
Communities
Solutions



Introduction

Healthwatch Sandwell (HWS) are the independent voice of the public in health and social care services. We collect feedback about people's experiences of using health and social care services in Sandwell and use that feedback to work with service commissioners and providers to look for ways to improve services.

One of the ways that HWS do this is to carry out projects that focus on particular services or groups of people using services in Sandwell. On this occasion HWS facilitated a focus group, on 30th September 2020 on Microsoft Teams, with adults who are carers¹ to share how COVID-19 had affected them in their role as carers.

Background

The COVID-19 pandemic has affected every walk of life. HWS had spoken to many of adults (aged 18+) who have had their support services disrupted or paused during the pandemic. This had caused an immense amount of stress for all concerned, especially for parents of people with learning disabilities (L.D.) and carers for people with dementia or mental ill health.

The session was attended by 5 carers plus 2 members of staff from HWS and Local Authority Commissioning Officer (Sandwell MBC). There were 2 carers who were unable to access the focus group but sent their experiences via e mail and these have been included in this report. Researcher's² recommend that the ideal size of a focus

group is usually between five and eight participants, this enables participants to participate comfortably.

All information in this report is provided anonymously and is generalised to protect the identity of the participants. Carers, facing specific situations have been signposted by HWS to appropriate places to raise their concerns. However, the participants who have had their support services disrupted wanted their issues raised with the Commissioners of day care and respite services for adults especially L.D.

Purpose of report

This report will provide an overview of the feedback from the focus group. The discussion was formulated around 5 key questions and the feedback has been provided in this report using these questions as headings.

1. What support did you receive before COVID-19?

Participants described a range of services that they received before COVID-19, that were either organised by the carers or social care professionals:

These included:

- day care at centre
- respite care at residential care homes
- live in care
- Sandwell Crossroads
- domiciliary care which provide personal care i.e. showering
- direct payments³

¹ A carer is someone who helps another person, usually a relative or friend, in their day-to-day life. This is not the same as someone who provides care professionally, or through a voluntary organisation. The Care Act 2014 relates mostly to adult carers – people over 18 who are caring for another adult.

² www.sagepub.com/sites/default/files/upm-binaries/24056_Chapter4.pdf

³ Direct payments are payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local authority.





In addition to this support participants described receiving informal care from friends and other family members too.

2. How has COVID-19 affected you as a Carer?

Carers described a variety of ways that COVID-19 had affected them, these issues have been listed using headings:

Protection

Participants described how their family unit stayed together under one roof, this was as a result of protecting their loved one from the virus.

“Just the three of us”

They described fear of accessing healthcare for themselves due to feeling they would be risking catching COVID-19 and taking it home to their cared for. Also, there was a sense of:

‘I can’t catch it because who would care for my loved one?’

Fear was a big factor at the beginning of the pandemic (March 2020), people described feeling fearful to go out or to let anyone into their home, this included paid carers from agencies.

Carers spoke about fear and protectiveness directing their actions. They described how the individuals that they care for have no understanding of COVID-19 or social distancing. So therefore, one carer shielded continuously, this meant that the carer couldn’t relax or go out as a sitter was needed so that they were safe.

‘Really tough I didn’t leave the house from March to September...it’s like having a small child’

Lack of social contact and exhaustion

Carers described feeling isolated, one male described missing mates and having banter down the pub.

Carers described how exhausted they were, there was a sense at the beginning that everyone was in the same boat and rallied round but as time has progressed with various forms of lockdown and restrictions they have become weary.

‘After 6 monthsI can’t do it anymore...it was okay in the short term, I coped but I’m struggling now....however much you love someone 24/7 is hard....it is leaving us mentally and physically exhausted’

Relationships

Carers described how their own relationships with partners as well as their loved ones were affected and this caused stress too.

‘No time as a couple, as someone has to be with x at all times’

Mental health issues

Carers described how their mental health was affected and acknowledged that being a carer was stressful anyway but being a carer in a pandemic was very hard to cope with.





'Carers have always suffered with mental health due to the stress of caring, but it's got worse...some carers will have developed poor mental health due to COVID-19'

Carers stated that they could feel that their mental health was deteriorating. Some described that they were OK in lockdown but when the restrictions eased, they started to get anxious, afraid of mixing with others. The process of returning to supermarkets was upsetting as the process had altered with social distancing etc. People described a loss of confidence after not going out for 3 -4 months then having to go back to a routine.

People described their mental health before the pandemic as being good, they were making plans and looking forward to holidays, retirement but described that it's all gone, there is no hope!

'Not knowing the future is causing anxiety'

Carers voiced concerns for their cared for, they were concerned for the lack of social contact as well as their physical and emotional health:

'We are also very concerned because x is missing out on social contact with friends at the centre. More particularly, x uses a walker at the centre.... cannot walk unaided, but will walk in the walker, but this has not been possible through

the lockdown. I have noticedbeing less confident standing and walking with our assistance at home and worry that ...may lose mobility. Similarly, x has not been able to go to hydrotherapy ... which x enjoys and is a big help with her walking'

Finances

Carers described the financial impact on them, especially as people were furloughed and some being made redundant. There was concern raised for the economic status of Sandwell as a result of COVID-19 which would increase deprivation and poverty leading to more stress. One of the carers (employed by a Day Care Provider) was being made redundant due to the suspension of day care.

3. How has support that you received before COVID-19 been affected?

Carers described how **all** support at the beginning of March 2020 was withdrawn. This included day care at centres, respite care at residential care homes and personal care which was provided by domiciliary care agencies. Informal support, friends etc could no longer visit or take the individual they care for out into the community.

Carers appreciated the restrictions:

'We appreciate that things have to be Covid-secure, but this is very hard for us to cope with'

There was an acknowledgment from the carers that care agencies, and the Local





Authority were following Government guidelines to protect their staff and the families. However, as the time has progressed this situation has caused a lot of stress on carers who described reaching ‘*breaking point*’.

From March to September support was given remotely and can be described as emotional support for the carer. Those who had received support from Day Centres (L.D.) described having received 2 – 3 emails to see how they were but have received nothing else, as all day centres were closed. Some described receiving phone calls from care agencies, intermittently, but these calls did not provide support other than a general ‘*how are you?*’

Although participants were happy to stop external visitors to their homes as the time has gone on the lack of outside support has caused a lot of stress.

Frustration was expressed about funding approval for Continuing Healthcare ⁴ for service users with complex needs who require two members of staff at any time, although outreach work had been offered, this has not been arranged due to delay in funding approval.

4. What support and coping mechanisms have you utilised ?

Support Mechanisms

Carers described support they had received from The Carers Service (Black Country Partnership NHS Foundation Trust) during COVID-19, which was appreciated and how residential care homes were keeping in touch by phone to update on their loved ones.

Carers described how some support had been restarted (September 2020) this included:

- Sandwell Crossroads have started to visit 2 hours a week.
- Some daily personal care back in place.
- Better Understanding Dementia in Sandwell (BUDS) are offering home consultations to alleviate loneliness and isolation.
- Day services have started taking service users out in the community.

Concern was expressed about the latter support as the cold weather is approaching, especially as their loved ones were being taken outside (as they cannot go to day centre due to COVID-19 restrictions) were being put at risk of the virus e.g. going on buses etc.

Carers described how they were receiving support in different ways since COVID-19, using digital technology and teleconferencing: WhatsApp groups and Zoom etc, however, concern was expressed for those with no access to technology especially due to digital poverty.

‘Zoom is helping me to not feel so remote, but I’m concerned about people who have no access to IT especially as the libraries are closed’

This support was described as ideal for checking in and had relieved social isolation:

‘you don’t feel as alone’

⁴ Continuing healthcare (CHC) helps with health care needs that come from a disability, accident or illness. It's also known as CHC funding. ... it is for people who have ongoing health care needs and

may include social care costs which would normally be paid for by an individual or the council.





The carers had found online support from various support organisations invaluable. These included:

Omega – telephone befriending, Carers UK, Age of experience, Ageing Better (Birmingham Voluntary Service Council) and Men’s support group (Black Country Partnership NHS Foundation Trust).

The Local Authority Commissioning Officer (Sandwell MBC) recommended a list of support organisations which HWS agreed to e mail to carers.

Coping mechanisms

Carers described how having open green spaces to walk the dog were helpful as well as watching birds, nature and listening to bird song. Getting out for exercise has helped with feelings of isolation. Concern was expressed for those who were not able to go out, perhaps due to shielding.

‘It’s good to see families with children going to parks and getting outdoors too. You’ve got to look on the bright side of life’

Other coping mechanisms were listed:

- Having a short break with a relative...*‘it did me the power of good’*
- Reconnecting by telephone with people who normally the only contact is a Christmas card.
- Watching a lot of TV especially ‘Homes under the hammer’ which encouraged people to do DIY.
- Returned to lane swimming at Wednesbury leisure centre...*‘it’s free now I’m 60!’*
- Carers described less healthy coping mechanisms – being more sedentary, drinking alcohol and smoking more.

5. What do you need to assist you in your life right now?

- Carers for adults of people with learning disabilities would like day centres to be re- opened.

They expressed concern about the future of respite and day care and were concerned that it may collapse.

‘What’s going to happen after OctoberI can’t see any future....we are dealing with uncertainty’

- Accurate information about the future of services.

There was a suggestion that staff from day centres may work in people’s homes to offer support once restrictions have eased. The group would like clarification about this.

- A return to normality.

Carers stated that they wanted to return to some sort of normality as they are scared and anxious to protect their loved ones from COVID-19. Carers described a sense of returning to “square one” because of increased restrictions in Sandwell.

- Carers stated that they needed “*our time*”

This is the reason why there is concern about the future of day services and respite care.

- Online support to continue.
- Care packages to be re-assessed.

These re-assessments to consider the current changes, especially with regard to day activities in the winter that are COVID-19 secure. This re-assessment to include the needs of carers under The Care Act 2014.





- Access to technology for people who do not have IT equipment. (iPad or tablet)
- Financial and welfare rights advice to made available to carers due to unemployment.

Conclusion

This report has identified the difficulties that carers are facing due to COVID-19, it has highlighted what they need to assist them in their role. In the light of these findings HWS would make the following recommendations:

Recommendations

- Adult Social Care to produce a communication plan about the future of day care to include accurate information about services for adult service users including respite.
- Relevant organisations to provide access to welfare rights advice and technology for people who do not have IT equipment. (iPad or tablet) for carers.
- Statutory, independent and voluntary sector to continue to provide online support for carers.
- Funding approval for Continuing Healthcare for service users with complex needs to be actioned by Sandwell and West Birmingham Clinical Commissioning Group.
- Care packages to be re-assessed by Adult Social Care take account of the current changes and this to include the needs of carers under The Care Act 2014.

Additional Information:

Since the facilitation of this focus group HWS have been informed of the Crossroads Carers Assistance Line which offers a caring, listening ear and support to any carer living in Sandwell over the age of 18, which is free to access Call 0121 803 6830 or email:

CAL@sandwellcrossroads.org



For more information:

Contact:

Anita Andrews Engagement and Information Lead



07885 214421



anita.andrews@healthwatchesandwell.co.uk

