

Adult unpaid carers in Oxfordshire: are they getting the right support when needed?

'I think it was when our doctor happened to say something to her...and she said, "You know you are actually a carer, do you realise?'

March 2021

Contents

Executive Summary	3
1 Background to the report	8
2 Methods.....	9
3 Results	9
3.1 Who participated in the survey?	12
3.2 Who do unpaid carers in Oxfordshire care for?	12
3.3 How does caring impact carers?.....	15
3.4 Support for unpaid carers	19
3.4.1 What support do unpaid carers receive?.....	19
3.4.2 What types of support do carers find most helpful?	20
3.4.3 What barriers do carers face in accessing adequate support?.....	22
3.4.4 What types of support would make a difference for carers?	24
3.5 People’s experiences of the Carer’s Assessment	27
3.6 The COVID-19 pandemic.....	28
4 Conclusions.....	29
5 References	31
6 Appendices	32
Appendix 1. A carer’s Life (modern day Cinderella)	32
Appendix 2. Looking after my wife - a carer’s story	34
Appendix 3. Survey questionnaire on unpaid caring in Oxfordshire	35

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Healthwatch Oxfordshire would like to express our sincere gratitude to everyone who took the time to tell us in our survey about their views and experiences of caring for someone at home, and to those who talked to us in more detail about their personal stories. We also thank Action for Carers Oxfordshire for sharing their knowledge and ideas with us.

Executive Summary

Unpaid carers are people who help a family member, friend, or neighbour in their home because of their age or an illness, disability, mental health problem, or addiction and who are unable to manage without support.

In 2019 there were as many as 8.8 million adult carers in the UK. These unpaid carers saved the UK economy around £132 billion per year. Since the start of the COVID-19 pandemic in 2020, the estimated number of people caring has increased to around 13.6 million.

The Oxfordshire Joint Strategic Needs Assessment (JSNA) reports that there are more than 61,000 unpaid carers in Oxfordshire. However, in 2019-20, only 4,540 were known to the social care service and as of September 2020, 18,682 had been reported by Oxfordshire GPs. This figure can change by as much as 20,000 per year as people come into and out of the caring system. Reports estimate that unpaid carers save the Oxfordshire economy an estimated £1 billion a year.

Healthwatch Oxfordshire conducted an online and paper survey and had telephone conversations with adult unpaid carers between August and November 2020 to listen to their experiences of caring, accessing support services, and the impact that COVID-19 has had on their lives.

We analysed the survey responses of 160 adult unpaid carers across Oxfordshire. Of these, 82% were female and 16% male, reflecting a gender bias in caregiving whereby women make up a greater proportion of carers across most age groups. Most survey respondents were in the middle to older age groups (45-84), with much lower representation from younger carers. Although we reached out to black and minority ethnic and other seldom heard communities, few responded and around 92% of respondents identified as white British.

Findings

The findings of the report reflect the challenges that unpaid carers face in Oxfordshire and nationally. The diverse impact that caring can have on carers is highlighted, as is the burden that many carry beyond caring itself. Also highlighted are the problems carers face in getting the right type of help at the right time. The study supports other work on the experiences of carers and the impact it can have on their physical, mental, and social wellbeing.

The COVID pandemic has had a profound impact on many carers and those they care for, in terms of the direct effects of the virus on physical and mental health, disruption to support services, and access to health and social care. Although service providers have tried to continue offering support where possible, carers and those they are responsible for will continue to experience the effects well into the future. Local government and service providers must do as much as possible to minimise further disruption to essential services and ensure that mechanisms are urgently implemented to support carers and their families in the long run.

The need for carer support is well-recognised, and the various strategies, schemes, and services already go some way to helping people in their caring activities and to protect their physical, mental, and social health and wellbeing. However, unpaid carers still appear to be insufficiently recognised and some feel undervalued and excluded. Our findings suggest that there is still an unmet need for help and support, which some find confusing or fragmented. Furthermore, coverage of the carer's assessment seems low, and many carers are either unaware of it or are not offered one.

Improving support for unpaid carers

There is a need for a more coordinated and accessible approach to making support available to unpaid carers in the county. Specifically:

- Greater coordination of
 - support, prompt help and practical solutions that are tailored to carers' individual circumstances and needs, including more opportunities to have regular short breaks from caring and occasional longer respite care.
- Improve public awareness and ensure adequate coverage of the carer's assessment and the Carer's Passport scheme, including:
 - Continue to support carers to complete self-assessments using what means are suitable for their individual requirements and when they encounter problems.
 - Ensure that the information, support, or services are provided to people who have completed an assessment are sufficient and appropriate to their individual circumstances.
- Create a 'one-stop shop' for information, advice, and other support from professionals and other individuals (experts, experienced carers, champions) so that carers can easily access contacts with specific questions, get tailored advice or arrange practical support, or to be referred to a service that can provide them with the support they need.

The above improvements should be addressed by **Commissioners and service providers including Oxfordshire County Council, Oxfordshire Clinical Commissioning Group, Oxford Health NHS Foundation Trust, AgeUK / Carers for Oxfordshire, Rethink**

What next?

Healthwatch Oxfordshire invited the agencies, organisations and carers involved in delivering support for unpaid carers to a round table meeting on Wednesday 3rd March 2021 to discuss the findings of this report and how support for carers can be improved and developed in the county.

Invited organisations were:

- Carers Oxfordshire
- Age UK

- Rethink
- Oxford County Council
- Oxfordshire Clinical Commissioning Group
- Oxfordshire Hospitals NHS Foundation Trust
- Oxford Health NHS Foundation Trust
- Oxfordshire Mental Health Partnership

Actions and outcomes from the round table discussion

The round table discussion was attended by six unpaid carers who had taken part in the research and representatives from Oxfordshire County Council (OCC) - Commissioning, Oxfordshire Clinical Commission Group (OCCG) - commissioning, Age UK Oxford - CEO, Carers Oxfordshire, Oxfordshire Mental Health Partnership, Rethink, Oxford Health NHS Foundation Trust, and a Trustee of Healthwatch Oxfordshire.

The report was welcomed as it was timely and reflected what carers' organisations and commissioners of services had been hearing. The meeting was particularly welcomed by the carers who attend as an opportunity to hear responses to the report from those who commission services and deliver support to unpaid carers.

New carers service from April 2021

Early in the meeting, Ian Bottomley, Lead Commissioner in the joint commission between OCCG and OCC informed that a new Carers Pathway has been developed and will go live on 1st April 2021. Kay Francis, Head of Carers Oxfordshire explained that the service will be based around a 'one-stop shop' principal and reflects the findings of the Healthwatch Oxfordshire report. It has been co-produced with OCC and carers organisations and is a partnership between Carers Oxfordshire/Age UK Oxfordshire, Rethink, OCC, and health services. The service will be based in social services and health teams and should help fill gaps in carer support as well as personalise the services currently offered to carers.

The new service will have a wider reach for supporting carers by liaising with GPs and Primary Care Networks, staff based in hospitals, and care staff who are trained to understand the needs of carers. The new service will also talk to employers to raise awareness of carers' needs. Penny Thewlis, Chief Executive of Age UK Oxfordshire added that the service will increase conversational support to carers, listening to them about their individual needs and reducing the confusion and duplication of information that some carers experience by receiving multiple leaflets.

Ian Bottomley, Joint Commissioner for the new service agreed to:

1. Be the first point of contact for future queries about the service.
2. Respond to the plans for evaluation of the service including the involvement of carers in the process.

A request was made for meetings like this to be repeated on a quarterly basis as an opportunity to hear about the care system and the new pathway.

1. Healthwatch Oxfordshire will liaise with the Commissioner to arrange this as part of the ongoing feedback, monitoring, and evaluation of the new service.

Other issues raised, discussed, and actions agreed

1. A question was raised about the OCC budget spend for adults with social care needs. Although 53% of the Council budget is allocated for this, the participant asked for clarification on how this is spent and who receives support, as some carers clearly are not receiving the support they need.
 - a. Ian Bottomley will respond to this and HWO will circulate the response to attendees.
2. There is concern that service providers do not interact directly with carers, only with the patient, client, or person receiving care. This makes it difficult or impossible for carers to represent the person's needs.
 - a. Ian Bottomley replied that it would be important to capture feedback from carers on this once the new service is up and running.
3. Self-help groups were highlighted in the Oxfordshire area as a way of supporting carers.
 - a. Jane Kershaw informed that Oxford Health organise groups that offer various types of support. They also launched carer workshops in January 2021, offering skills sessions whereby experts come and advise carers on specific topics.
4. Home care support for patients discharged from hospital. One unpaid carer recounted a personal experience whereby he was advised by hospital staff that, on leaving hospital, NHS carers would be provided. After waiting for a month without support, it became clear that these carers are being provided on a priority basis. This resulted in him needing to pay for private care.
 - a. Healthwatch Oxfordshire asked Ian Bottomley to take this back to colleagues and respond.
5. Renewal of the Oxfordshire 'Commitment to Carers 2017-2020'. As the strategy has now expired, Rosalind Pearce, Healthwatch Oxfordshire asked whether there is an updated version.
 - a. Ian Bottomley understood that the formal strategy has not been renewed but that the new carers service represents the partnership's thinking for the way forward. Ian Bottomley and Sharon Hopkins, OCCG will discuss this further and respond.
 - b. Ian Bottomley emphasised the relevance of involving carers in scrutinising and helping develop indicators to evaluate the new carers service. Ian Bottomley agreed to be the point of contact for Healthwatch Oxfordshire to follow up on the impact of the service.
 - c. Jane Kershaw, Oxford Health NHS Foundation Trust reported that Oxford Health have a Carers Strategy that was valid up until 2020. A "refresh" was started in 2020, which involved carers, carer governors, and organisations in developing a draft. Due to Covid-19,

the launch has been delayed but it should be finalised over the next few months.

6. An issue arising since the Healthwatch Oxfordshire survey is the impact of 'long COVID' on carers of all ages and those they care for. Rosalind Pearce, Healthwatch Oxfordshire identified the need for this to be included and addressed within the relevant clinical groups.
 - a. Ian Bottomley agreed to raise the question with the clinical groups as he was not aware whether carers needs were currently being discussed or included in plans.

Main Report

1 Background to the report

Unpaid carers are people who help a family member, friend, or neighbour in their home because of their age or an illness, disability, mental health problem, or addiction and who are unable to manage without support.¹

In 2019 there were as many as 8.8 million adult carers in the UK. These unpaid carers saved the UK economy around £132 billion per year. Since the start of the COVID-19 pandemic in 2020, the estimated number of people caring has increased to around 13.6 million.²

The Oxfordshire Joint Strategic Needs Assessment (JSNA) reports that there are more than 61,000 unpaid carers in Oxfordshire. However, in 2019-20, 4,540 were known to the social care service and as of September 2020, 18,682 had been reported by Oxfordshire GPs.³ This figure can change as much as 20,000 per year as people come in and out of the caring system. Unpaid carers save the Oxfordshire economy an estimated £1 billion a year.⁴

A recent Carers Trust national survey has documented the increasing burden faced by unpaid carers. It found that people are spending more time on caring for someone than in recent years and most unpaid carers feel that they do not receive sufficient support from the social care system.⁵

Healthwatch Oxfordshire took social care as our theme for 2020. We published reports highlighting how many families are struggling to provide care for loved ones and experience difficulties in getting appropriate help and support.⁶ These and similar stories motivated two concurrent projects on carers in Oxfordshire: this report focuses on unpaid carers while the other reports on employed or professional carers.

The experiences of people caring for someone in their home, including the positive and negative impact of caring, are well known. This includes Oxfordshire.⁷ Help and support are available from state and voluntary organisations as well as the private sector. National legislation and policies with strategies aimed at identifying and supporting carers include Care Act 2014⁸ and the NHS Long Term Plan.⁹ In addition, several organisations are involved in supporting unpaid carers in Oxfordshire. Various Oxford NHS Trusts, Oxfordshire Clinical Commissioning Group (CCG), and Oxfordshire County Council, together with local carers' organisations have signed up to 'Oxfordshire's Commitment to Carers', an agreement to better identify and support unpaid carers.¹⁰

For many reasons, carers often do not have knowledge of the range of support available to them, how or where to find them, or do not access them until they reach crisis point. The aim of our research was to listen to unpaid carers about their caring experiences and, importantly, about their knowledge, use, and opinions of support.

2 Methods

We developed an online and paper survey with open and closed questions (see Appendix 3). The survey was tested locally before uploading to the internet. We promoted the survey through Healthwatch emails, social media, national and local carers' charities, community magazines, Parish newsletters and noticeboards, local faith and community-based organisations, and GP practices. Many of these organisations represented black and minority ethnic and other seldom heard communities, who we are particularly keen to hear from. We also translated the questionnaire into Arabic to distribute via a local organisation supporting African migrant families in the UK.

We also conducted telephone or video interviews with nine survey respondents who were willing to share their experiences in more detail. Two people also kindly sent us written accounts of their personal caring experiences.

Survey results were downloaded for cleaning and analysis in Microsoft Excel. The data is presented in graphs and described in the results section. We analysed the interview transcripts and responses to open survey questions by searching for themes related to the aim of the project. Themes were compared and contrasted using NVivo 12 qualitative analysis software to identify broader patterns. The combination of survey results and thematic categories formed the structure of the report.

3 Results

As an introduction to the experiences of unpaid carers, the following (Box 1) is a personal account written by a participant in our project.

Box 1. A carers life

Before I tell you my story, let me say, I know I'm one of the lucky ones. The person I care for does not have dementia or Alzheimer's, does not have major mobility problems, does not have to deal with being mentally unwell, has no significant underlying health problems, and does not need help with personal care. She is just plain and simply old. She is 93. We do not get any support from any organisation.

I moved back to live with my Mum four and half years ago having been made redundant. I lived in xxx and my sister lived on the south coast, so whilst neither of us were hundreds of miles away we were not able to help easily or regularly. To be honest, my move back to the family home helped both me and Mum who had lived alone for about three years after my father passed away. I grew up with my maternal Grandma living with us so I knew that at some point I would support my parents. I do not think that at 90, you should have to worry about putting the bins out!

I got a part time job in the County and for a couple of years we jogged along comfortably. Mum was still independent and had a full social life, meeting friends for lunch, going to the WI, going to other social groups, much as she had done all her life. My role was just to be there, acting as a chauffeur, supporting with financial issues, shopping, cooking, cleaning and dealing with any other household issues.

In the summer of 2018, Mum had a mini stroke. She recovered well but medication was increased and whilst this was being sorted out, she had a couple of collapses due a rapid decrease in her blood pressure. This led to a loss in confidence and Mum became more dependent and less keen to go out alone. Mum asked if I could be around more so in February 2019, I gave up work and with it my financial independence. Increasingly Mum has become more dependent for dealing with everyday tasks. I ask myself if it is because I am here that, somehow, I have disempowered her? I have constant self-talk: if I do this does it stop Mum from doing it? Am I making her life easier or taking over? How much responsibility should I take or leave for her? Am I enabling Mum to make decisions about her life or just overtaking? How much should I encourage her to take exercise or at 93 does it matter if she just watches TV and eats cake? Who defines the fine line between supporting, encouraging and bullying and taking over? How much should I help when she mislays her glasses or hearing aids (again)?

Mum seems happy enough and is in her own home so I guess I should not be so hard on myself. When she chooses to, we go out for drives in the countryside with a takeaway coffee. This is the only time she goes out of the house, Obviously, due to Covid we are unable to go to garden centres or cafes which Mum used to enjoy. Covid has brought with it a whole heap of challenges. I used to get some respite as Mum could go to my sisters or if I wanted to see my children or friends, I could get someone to come and sit with her, no more!

Covid has brought with it more anxiety for me; what if I'm the one to bring the virus into the home and make my Mum unwell?

Mum has equipment to help her mobility, provided by the council. The best bit of equipment is a commode as mum can use this during the night without walking to the loo - this means my sleep is not disturbed by listening for her to get safely back, into bed. A Godsend but Mum wasn't keen to have one and I must admit, I did override her decision on this occasion, and she is now happy that I did. She has a personal alarm, but I am not confident she would use it if needed, as in the past when she has fallen it has not been pressed! This makes me loathe to be away from home for more than a couple of hours at a time.

My completing a carers assessment was a complete waste of my time as it told me nothing that I could not have found out myself with a bit of internet research.

As I said at the beginning of this, I know I'm lucky, However, it doesn't detract from the anxiety, guilt, worry, concern that I feel as a carer. I have a constant internal 'alert' switch leading to a low level of anxiety at all times - listening for unusual noises, no noises, have I been out too long? What will I find when I get home? Is Mum lonely? Have I done enough? What if I get ill? Worrying if today will be the day. The list is never-ending.

The guilt is full on too: was I too harsh with my tone of voice? Have I talked with Mum enough today? Am I taking over? Do I give her enough choice about food she eats etc.? Again, it's easy to feel guilt about everything and each day I go to bed thinking that tomorrow I will behave differently and be nicer (not that I am mean or unkind and unloving or resentful or angry or impatient but I feel that I'm not always as nice and kind as I could be).

Mum gets attendance allowance, but I am not eligible for carer's allowance. My Mum's pension is sufficient for us to live on fairly comfortably, so at least there are no money worries at the moment. However, I worry about my financial future and how I will live in

my old age as at the moment I am unable to add to my pension pot. I am 62. I started a home business which has stopped entirely due to Covid - who knows if it will ever come back.

I worry about my future and being alone myself. I divorced 10 years ago and currently I am not in a position to start a relationship with anyone. I worry that my life is slipping away from me. There is not a whole lot of fun in my life. There's also quite limited conversation - hearing issues make it quite hard to converse with mum. I have noticed that her world is getting smaller and what she is interested in is also getting smaller. A natural progression with the ageing process, I guess. Fortunately, I have a positive disposition and try to have a pragmatic approach to the situation. Who knows how long it will last, so I have to make sure that I do not turn into a 93-year-old woman before my time.

I have to find time to fulfil my needs as without being fulfilled it would be harder to give my all to Mum. I walk the dog, do online yoga and when possible meet friends for a coffee. I also keep in touch with family and friends via social media and watch far too much TV. I am also doing some online learning. Maintaining a sense of humour and a connection to the outside world is crucial. However, all this, with one eye on the clock or one ear open for unusual noises. There is no spontaneity in my life. I too, am pretty much housebound.

Being a carer is about finding little pots of joy wherever you can.: sharing a favourite TV programme, laughing over a shared memory, politely listening for the umpteenth time to the same story from the past, having a sneaky Friday night glass of bubbles, watching Mums' face talking to her grandchildren and seeing her baby great grandchild on Facetime, the fact I get a free flu jab!

When I am frustrated, I try to remember that looking after my Mum is a privilege and I try to do things from a place of love. But please ... other people, whilst it's lovely that you are concerned about the welfare of my Mum, please ask me how I am first - we aren't one and the same and please do not tell me what a good job I'm doing ... it's not a job, it is what people do for those they love and who love them. I feel it is a moral obligation to look after Mum and make her life as comfortable and stress free as possible for as long as possible.

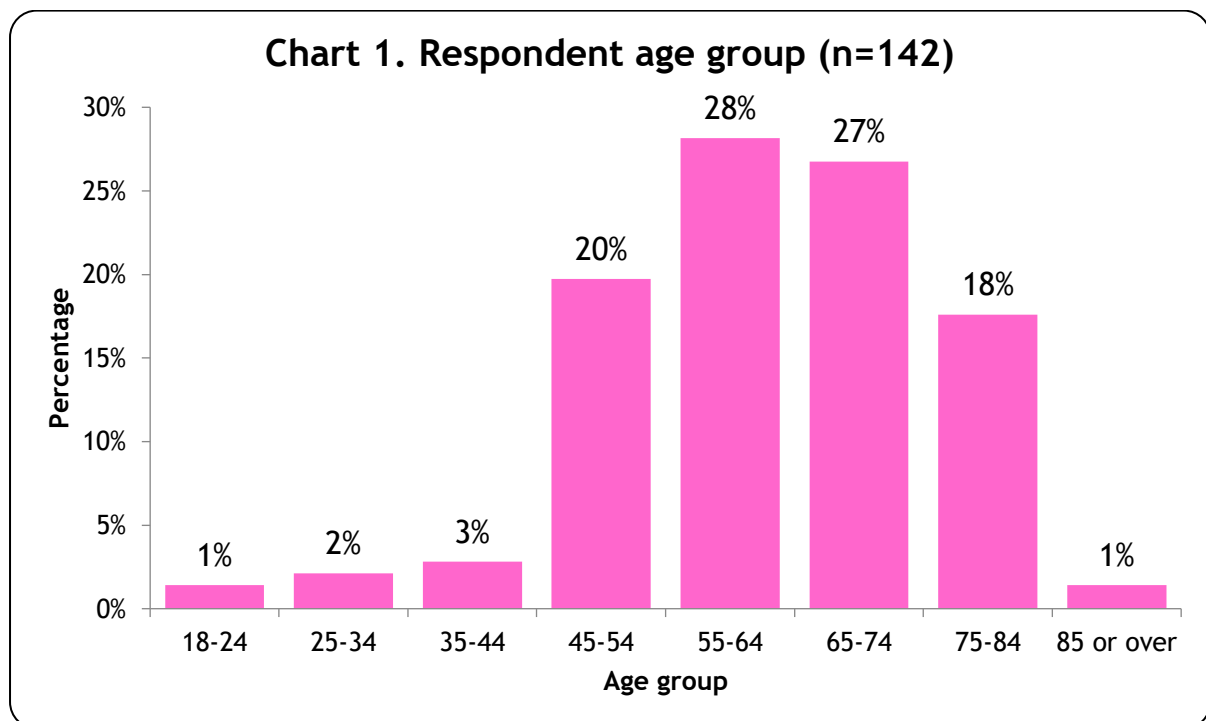
Having reflected on what I have written, Am I really a carer? Surely, what I do is just what we should be doing as a society, supporting and caring for our elders. Many other cultures do this just because it's what you do. My Mum has many friends who are still living in their own homes, alone, seemingly coping well. Would they prefer to be her, living with a family member? I think so.

(female, aged 55-64, caring for 3-4 years)

These reflections on a carer's daily experiences clearly and powerfully reflect the complex and multi-layered issues that many face when supporting someone in their home. Being a carer often means giving up your time for someone else and putting their needs before your own. New carers may have to deal with feelings of worry, anxiety, and guilt, as well as doubting their capacity to properly care for the person. The carer's story highlights the need for early and effective support to help take care of the person they look after as well as for themselves.

3.1 Who participated in the survey?

We analysed the survey responses of 160 unpaid carers across Oxfordshire. Of these, 82% were female and 16% male, reflecting a gender bias in caregiving whereby women make up a greater proportion of carers across most age groups. Most survey respondents were in the middle to older age groups (45-84), with much lower representation from younger carers (Chart 1). Although we reached out to organisations led by black and minority ethnic and other seldom heard communities and other seldom heard communities, few responded and around 92% of respondents identified as white British.



3.2 Who do unpaid carers in Oxfordshire care for?

Most respondents (86%) said they were caring for only one person, while 14% were caring for two or more people. Although carers were looking after adults of all ages, most (78%) were caring for people aged 65 or older, while two-thirds (66%) were aged 75 or over (Chart 2).

Chart 2. How old is the person you care for? (n=158)

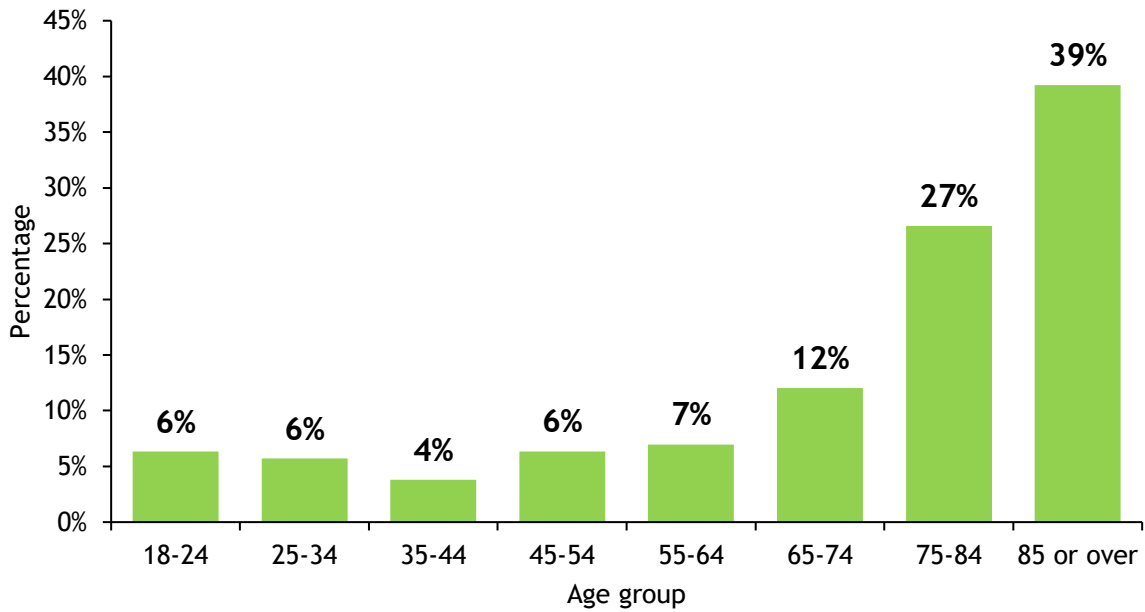


Chart 3 shows the reasons that cared-for people required the help of an unpaid carer. The main reasons included being elderly (56%), long-term illnesses such as arthritis or chronic pain (43%), and disability (34%). ‘Other’ conditions included injuries and recovering from illness. In total, 361 conditions were mentioned, indicating that carers were looking after people with multiple health conditions or problems.

Chart 3. What condition does the person you care for have? (n=160)

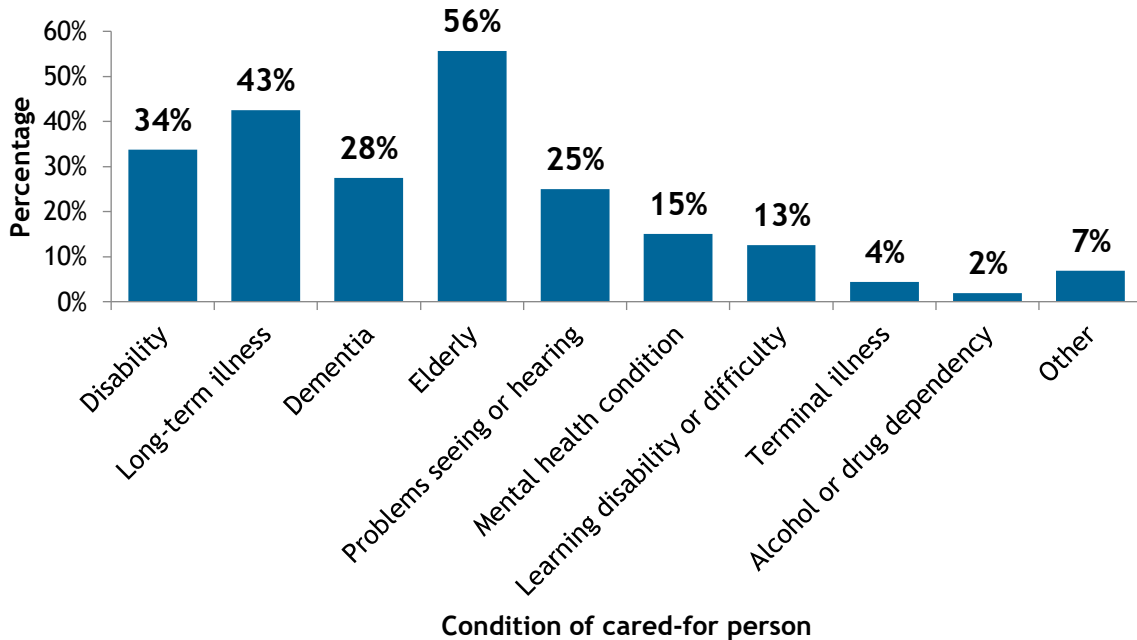


Chart 4 shows how long carers had been supporting the cared-for person. Most had been a carer for between three and nine years (41%). However, 18% had been caring for 20 years or more.

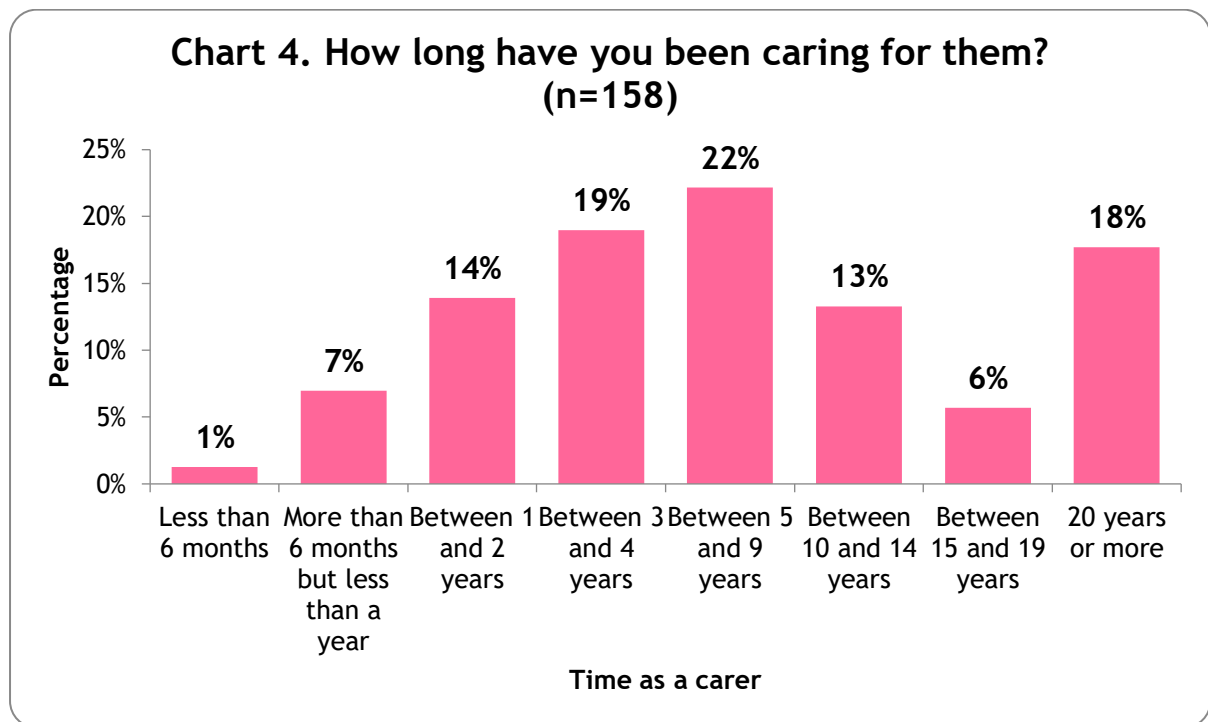
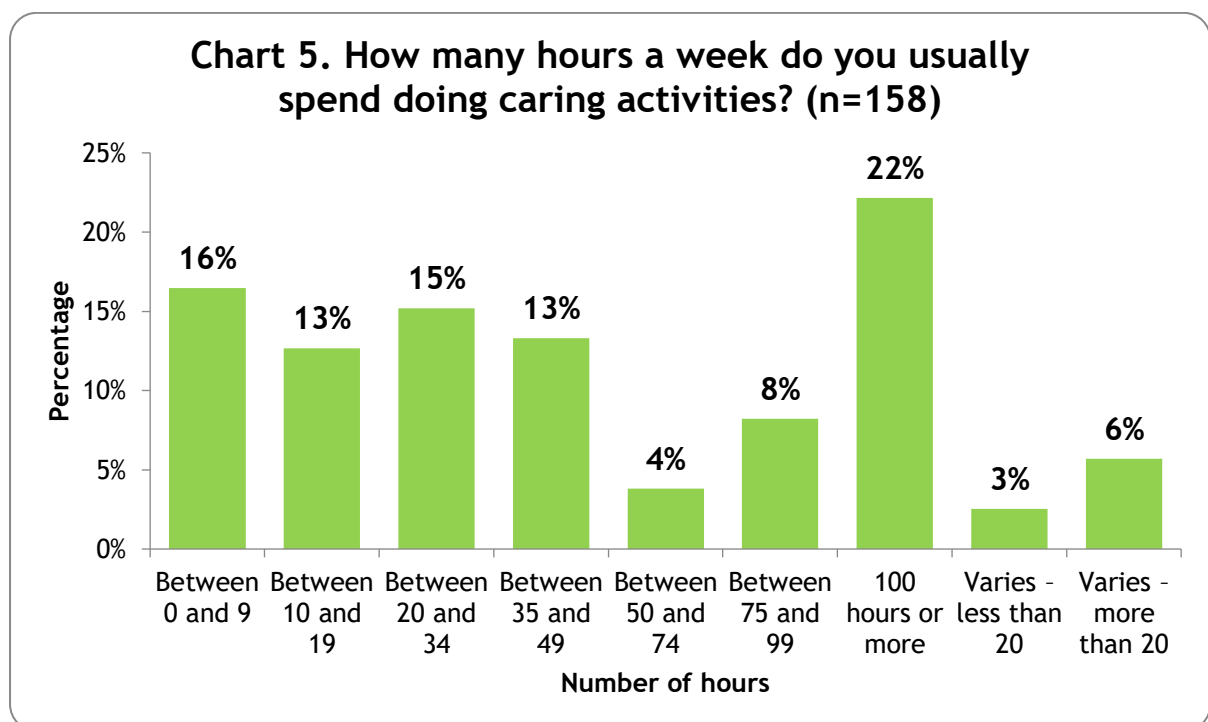
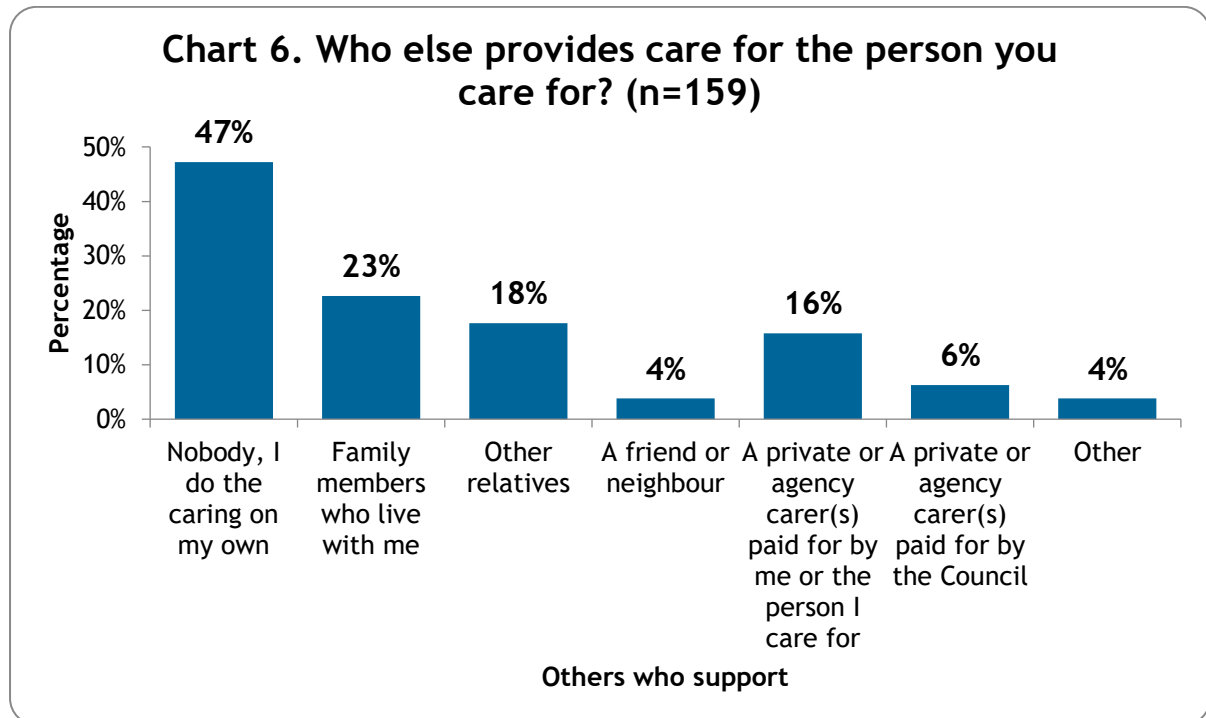


Chart 5 shows how much time people estimated they spent caring for someone each week. Times varied according to the needs of the person they cared for and the type of support they gave. However, more than one-third (34%) of carers said they spent more 50 hours a week on caring responsibilities and almost a quarter (22%) spent at least 100 hours a week.



We asked unpaid carers about any other people who were involved in caring for the person they looked after (Chart 6). Almost half (47%) said they cared for the person alone (Chart 6). Of those who did receive help from others, family members who lived with them or other relatives were the most common source, with 16% coming from privately paid carers and 6% from Council-funded carers.



We asked carers about who was aware that they were caring for someone. Being identified as someone with caring responsibilities is key to providing them with information and practical support. People told us they had mostly told their family or friends (87%) and their GP or other health professionals, such as a palliative care team or district nurses (63%). Others said that Oxfordshire County Council (35%) or social workers (19%) were aware, as well as local voluntary groups or charities (20%). Only 4% said that nobody knew they were caring for someone.

3.3 How does caring impact carers?

We collected information on the impact of caring in open-ended survey questions and interviews with carers. We heard about the many ways it impacted carers:

Well, it is very, very tiring hard work. Mentally draining. Well, it's a full time, you know, 24/7 job that I don't think people really fully appreciate just what's involved (female, aged 45-54, caring for 15-19 years)

People in our survey told us about the everyday challenges they faced as carers. These were related to the personal burden of caring as well as managing the person's care both with the cared-for person and with the health and social care system. As graphs 4 and 5 above show, carers invest a great deal of time and effort

to help the person they look after. Despite this, many said they felt undervalued and that their contribution was often overlooked:

I think it is a very unrecognised ... in that sense, unrewarding thing, and very much taken for granted (female, aged 65-74, caring for 3-4 years)

*... for decades that I've been involved in this I've felt completely ignored. Invisible, in fact, shunned, blocked. I was always struck by that movie about erm - Stephen Hawking. The wife had written it - it was all about the wife's ... and yet it never, even after all of that about her separation and things like that, it still ended up [being] a movie about Stephen, not about her experiences, and I remember sort of feeling complete sort of envy that Stephen Hawking had a twenty-four-hour, twenty-four-hour, seven day a week technician for his wheelchair and I thought, "jammy bastard, fancy having that!" Whereas, you know? I think, "God how would I love to have an engineer around twenty-four-seven to fix the chair or the computer or the bed, or the hoist."
(female, aged 55-64, caring for 20 years or more)*

Related to this lack of recognition, carers said they were often excluded from decisions and interventions related to the person they looked after. Although patient confidentiality prevents health care providers sharing personal information, carers said they found it frustrating when they were unable to contribute to the cared-for person's care or be given information that would help them.

Several carers said they felt it was normal and rewarding to look after their loved one. However, many told us it was extremely challenging. Our survey found that 80% of people had experienced negative effects from caring. The word cloud below (Figure 1) shows the most common words that people used when describing the impact of caring on them.

Table 1. Categories of impact of caring on carers

Physical	Psychological	Social	Financial
Tiredness/exhaustion	Stress	No free time	No financial support (e.g. if unable to work)
Feeling run-down	Emotional strain	Restricted exercise and socialising	Difficulty claiming or getting help
Problems sleeping	Mental fatigue	Never go out	Unable to earn salary
Hernia	Difficulty coping	Loss of freedom	
Back pain	Feeling overwhelmed	No holidays	
Weight gain (e.g. emotional eating)	Frustration	Need time off work	
Deteriorating health	Worry and anxiety	Putting the cared-for person's needs first/your needs last	
Migraines	Sadness/depression	Strain on family relationships and marriage	
Rotator cuff injury	Anger	Difficulty forming long-term/intimate relationships	
Hand injuries	Low self-confidence	Need to change jobs/work from home	
Health problems due to chronic stress (e.g. high blood pressure, stomach ulcer)	Feeling restricted	Sense of responsibility towards a parent who brought you up (pay back)	
Self-neglect	Social isolation	Feeling unsupported	
	Burden of responsibility		
	Procrastination		
	Helplessness		
	Self-doubt (doing the right things at the right time?)		
	Guilt (e.g. doing something for yourself)		

An important aspect of the impact that caring had on carers' physical and mental wellbeing was its cumulative negative effect. One mother explained how intervening in her son's episodes of ill health affected for days afterwards:

It's very debilitating actually. I was exhausted to the point where I couldn't actually sleep, so then you have this knock-on, the next day you're not firing on all cylinders because you haven't had the rest or been able to recover. So, an episode in the afternoon will have an impact on my ability to function for probably 2 or 3 days (female, 55-64, caring for 20 years or more)

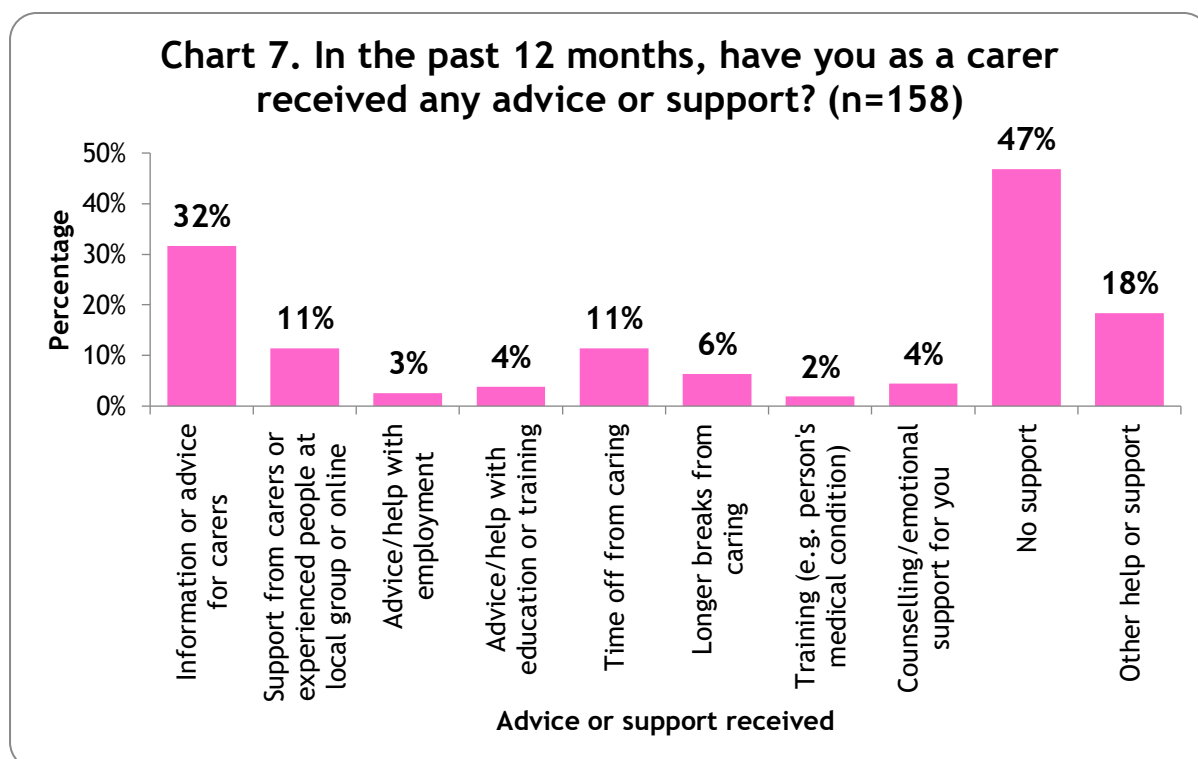
Some carers also talked about the prolonged effects of the physical effort and emotional strain of caring for a loved one with a life-limiting condition, which left them "burnt out".

3.4 Support for unpaid carers

3.4.1 What support do unpaid carers receive?

Chart 7 below summarises the main types of support that carers reported receiving for themselves as a main carer in the past year. The commonest type of support was information and advice (32%). This included being given booklets about the health condition of the person they cared for, advice from GPs or other health professionals, and being signposted to other local organisations or support groups. Other types of support that carers reported receiving included visits from occupational health visitors, nurses, and local organisations (e.g., AgeUK, Carers Oxfordshire), equipment to help the person they cared for, training courses, financial assistance, and informal support from family and friends.

Few people reported receiving practical help in the home or with looking after the person they cared for. Only 11% said they were able to take some time off for themselves during the day and only 6% said they had taken a longer break or respite care in the previous 12 months.



Worryingly, the chart shows that 47% of carers said that they had not received any support in the last year. These included carers of all types and with different levels of caring responsibility. Of the 79 people who gave reasons why they had not received support, only seven said they did not want any. A further 31 said they had not asked for support mainly because they did not spend a lot of time caring or because the person they cared for had lower support needs. A few people said that the person they cared for did not want to admit they needed help and others were

resistant to accept it. This made some carers reluctant to look for support. For example:

I haven't received any support but then I haven't asked for any - Dad is a very private person (female, aged 55-64, caring for 10-14 years)

Importantly, 30 people told us they were unaware that support was available and another 30 said they did not know how or where to look for it. Some new and inexperienced carers said they felt uncertain about what they were doing and where they could turn to for information and advice. A further 28 people said that they had not been offered any help or support. One carer who was experiencing psychological problems himself said:

I have been caring ... for almost 2 years now. I have spoken with people in the caring industry but personally have received no support whatsoever physically or mentally or financially, there is so much talk about support but none given (male, aged 55-64, caring for 1-2 years)

When new carers are not identified and offered support early on they may become disillusioned or hesitant to seek help. It is well known that unsupported carers often reach crisis before reaching out. On the other hand, busy or overburdened carers often lack the time or opportunity to find out what help is available. One experienced carer who, reflecting on why she had not contacted a local care organisation before now, said:

Maybe because the care work takes so much 'administration', I don't want to talk about it anymore, even if it's talking about my role (female, aged 55-64, caring for 20 years or more).

3.4.2 What types of support do carers find most helpful?

We asked people to tell us what types of help and support they had found helpful. Survey and interview participants described a wide range of useful help and support both for themselves and the person they cared. These included (1) information and advice, (2) practical support, and (3) personal and emotional support.

3.4.2.1 Information and advice

Several people said that information, advice, and guidance from local voluntary organisations such as Dementia Oxfordshire, Age UK, and Carers Oxfordshire had helped them, for example, to get a blue disability badge, apply for financial assistance and benefits, receive support for the person they cared for, and know about other services and support groups available to them. However, other carers found the variety of written information (e.g. booklets) confusing or unhelpful for their particular situation:

We have had a lot of advice (often in form of papers and documents) but it actually becomes quite confusing ... All too often you are just told where you can get support, but nobody makes the link for you and you have to use your own initiative, this is hard when you are feeling

overwhelmed and helpless about the situation. Very little if any has been of significant help ... Booklets and handouts given but these are really not like having someone to talk to (female, aged 65-74, caring for 3-4 years).

Carers like these felt that information and advice was not enough and would have preferred to be able to contact knowledgeable or experienced people for specific advice. Others said they had benefited from online training related to caring or about the health condition of the person they cared for.

3.4.2.2 Practical support

Many people told us that getting practical support was essential to their ability to provide effective care and for protect their own wellbeing. Types of useful practical support included getting help to apply for benefits or financial support such as a Carers Fund grant. Others said that equipment and aids, and other services and support for the person they looked after helped both themselves and the person they looked after.

Many carers said they had benefited greatly from health practitioners and support organisations that were proactive and coordinated short- and long-term support with them. For example, one carer who recounted occasions when attending paramedics included her in assessing her son's condition said they were "brilliant and know exactly what to do. They are incredibly supportive, and they deal with the situation." Another carer said:

[The] GP has visited and organised wound checks, blood tests, etc., meaning I didn't have to arrange these services myself (male, aged 55-64, time caring unknown).

Carers said they had benefited from being able to take short breaks from caring during the day or longer respite breaks. The physical and emotional impact that many carers experience, often over a long period, meant that having an opportunity for a break from time to time was enjoyable but also essential:

Several years after that my husband's doctor said ... there is some money here for respite ... My husband said, oh well my wife needs a break and then I was given some support - I think I went away for two or three days. That was wonderful! It really was! (female, aged 55-64, caring for 20 years or more)

However, some felt that short breaks were not enough for them to rest and recover:

Respite for 1 maximum 2 nights per month has started last month - that helped a bit but not enough to charge battery (female, aged 55-64, caring for 20 years or more).

3.4.2.3 Personal and emotional support

We heard that having understanding, supportive GPs, employers, and family members was a positive resource that helped them cope with everyday caring.

Also, being able to talk about their situation and their concerns either with people they knew or someone with professional or caring experience was helpful. For some, this meant having a trusted individual or a support group. Besides providing a space where carers and the person they cared for could share their experiences with others in a similar situation, they offered beneficial activities such as exercise classes and social events:

We belong to the local branch of the MS society ... That was a terrific sense of support. The people who run it have done an absolutely brilliant job ... It is good for people with similar problems to be able to get together like that, to just chat generally, if they didn't have any problems, but also to exchange any tips or information that they have (female, aged 75-84, caring for 10-14 years)

Not all carers favoured support groups. Some found it distressing to talk about their situation or did not want people to feel sorry for them. Others said they did not want to share their frustrations and experiences with strangers or in public, preferring to speak to a professional or experienced individual. For example:

"One feels very disloyal about one's husband or wife, telling a group of unknown people about the things you find difficult with them. It doesn't feel very nice. I could talk to one person, a bit like a GP, you can talk to a GP because it's a one-to-one and it's not a room full of people." I don't know how good a format a group setting is where you have about 8 people all with things to get off their chest (female, aged 65-74, caring for 3-4 years).

3.4.3 What barriers do carers face in accessing adequate support?

We asked carers to tell us what made it difficult for them to access the right type of support at the right time. Responses centred around personal factors and barriers related to everyday caring, and obstacles in the support system.

3.4.3.1 Personal factors

Not everyone saw themselves as a 'carer'. Identifying oneself as a carer depended on several factors, including how much time and effort was spent on caring activities and the type of help and support the person required. Three of the carers we interviewed did not identify primarily as carers, preferring instead to describe themselves as a husband/wife or son/daughter whose responsibility it was to look after their loved one. Only in specific situations or as the person they helped became more dependent on them, did they recognise their caring role:

I think I just sort of fell into the role type thing and it wasn't until Mum really started to deteriorate quite rapidly ... when I realised that I have to start sort of dressing her, washing her and all that type of thing that I suddenly thought, "Hang on a minute, I'm doing a lot for her" rather than just sort of, you know doing the general bit and pieces ... I think it was when our doctor happened to say something to her, we had a very, very good doctor, who unfortunately is no longer there, and

she said, "You know you are actually a carer, do you realise? (female, 55-64, caring for 20 years or more)

I do think of myself as a carer when he needs me, I wouldn't present myself at his health centre and say 'I'm the carer' ... I'm his mother first but his carer when he needs me to be. I certainly wouldn't go into the surgery and say 'record me as his carer'. I wouldn't think of it (female, 55-64, caring for 20 years or more)

Evidently, not identifying oneself as a carer can be a barrier to seeking or receiving support. The second quote above highlights the importance of health and social care providers being sensitive to family members who might also be carers.

Some carers who had taken steps to seek support found it difficult to find or access the right type. Newer carers were less aware about available support for them or how to find it. Some carers told us that their caring responsibilities made it difficult to find time for themselves. A few said they could not leave the person they cared for alone or the person they cared-for objected to them being away, or that they felt uncomfortable or worried about them while absent:

Even if I'm lucky enough to go away for a weekend or something, I'm left wondering ... what's he up to? He's acting out on his beliefs and his mental illness, then what damage is he doing, and I can't control that (female, 55-64, caring for 20 years or more)

The only way that I could get a break really is if he goes into respite care, which he doesn't like doing - he hates it ... he just didn't like me not being there, and he didn't like not being at home (female, aged 75-84, caring for 10-14 years)

These conditions made it difficult for carers to have time to themselves or breaks from caring.

3.4.3.2 System-related barriers

Carers often told us about aspects of the health and social care support system that either made it difficult for them to get the support they needed or that the support provided was poor or inadequate. These were mainly related to the usefulness of information and advice, the adequacy of support services for carers, and the coordination and follow-up provided by care and support providers.

Some carers felt confused by the quantity of information and diversity of support providers. They said it was not always clear which organisation was the most appropriate one to turn to and that it was difficult to navigate the care support system:

I've spoken to lots of people - I have no idea who I have and who I haven't spoken to, that's the problem. I've spoken to so many people I don't really know because they all come under different things, but half the time they're the same people. So, I don't know who I've spoken to to be honest, but I know most of it's about, it's all my mum,

*not for me so ... I think it is bit difficult to navigate, because I don't know who deals with what, and you go through one and it's not them
(female, 55-64, caring for 20 years or more)*

As the above quote shows, carers sometimes felt that support services were often directed solely at the person they looked after and that carers themselves were overlooked. Some carers of people with more specialised or complex needs felt that there was a general lack of support and that they often had to push to get help for themselves:

*You still have to find out, and you seem to be, especially at the beginning, you seem to be on the phone constantly saying what about this, what about that. Nobody comes forward, including doctors okay ...
We need to find out and make sure that you're entitled to it, and you're not told, you're just sort of left until you almost ... (female, aged 55-64, caring for 20 years or more)*

A mother of a young adult with autism said:

Most other support from professionals is mainly directed at our son's need with very little attention given to us as his primary carers ... Also, in spite of asking, no one seems to want to tell you what may happen further down the line which allows you to worry unnecessarily. The carer needs to be very proactive getting advice as to what equipment might be available (female, 45-54 years, caring for 15-19 years)

These carers felt that support organisations and providers needed to be more proactive in offering services and coordinating with them to provide timely and adequate support. Very few people had heard of the Carer Passport scheme¹ or knew how it might help them access services and support.

A few people told us about problems they had experienced with private carers or agencies in terms of lack of coordinating cover, carer sickness and absenteeism, overcharging, and poor-quality services. Others said they found the costs of private care too expensive to use. Some carers said that these problems meant they were unable or unwilling to use private care agencies when they needed extra support or breaks from caring.

Some carers told us about difficulties they had experienced understanding the Council's social care charges, resolving discrepancies, and communicating with Adult Social Care and the finance team (for example, see Appendix 1).

3.4.4 What types of support would make a difference for carers?

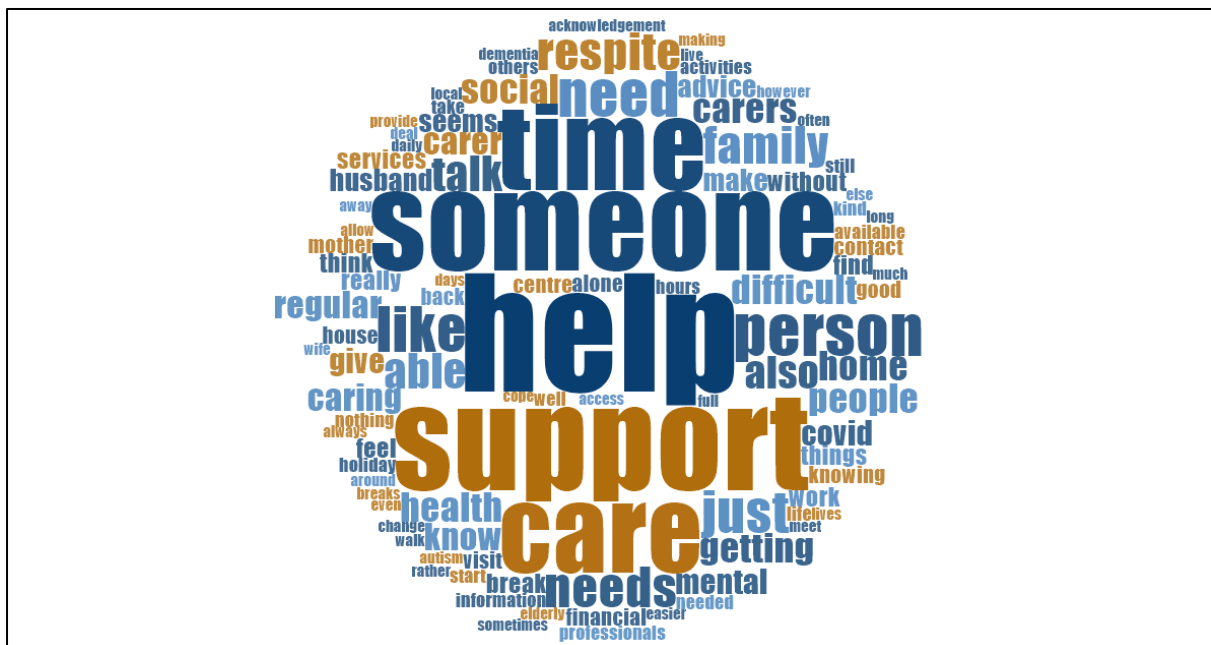
I would like a wage. I would like to be paid for every hour that I provide high-level nursing, administrative, managerial and other professional

¹ The Carer Passport is a document that identifies someone as a carer, which can help them access support, services, or other benefits. See <https://www.carersuk.org/news-and-campaigns/campaigns/carers-passport-scheme>

level skills. Not the insulting pittance of the 'carers allowance'. It would give me dignity, status, and - importantly - help me out of the state-enforced poverty that has been the greater part of my life. When I tell people that I am a carer, I am patronised, pitied and held somewhere on the social scale between a homeless person and a cleaner (female, aged 55-64, caring for 20 years or more)

Carers told us about many ways in which they would benefit from support. Figure 2 below illustrates some of the most common words they used to describe them.

Figure 2. Key support needs of carers



The main sources and types of support that carers talked about centred on (1) time and space for themselves (including short breaks or respite), (2) practical or specialist help with specific issues, and (3) personal or emotional support, including access to experienced individuals, greater recognition, and being included in the care of the person they looked after.

3.4.4.1 Time, space, and breaks from caring.

Many carers talked about the need for some time and space to themselves, either in the form of regular short breaks or occasional respite care. Those who had been carers for some time, or with considerable caring responsibilities, described experiencing physical and emotional strain, and often felt that caring deprived them of part of their own lives and freedom. Carers felt that, “respite is important, because that way it gives us a break”. They wanted an opportunity to relax, to do other, non-caring activities, or to socialise with friends without feeling guilty:

A complete day to myself - maybe once a month, when I would browse shops, meet a friend for coffee or lunch, without feeling guilty at leaving my husband alone (female, 65-74, caring for 5-9 years)

Carers recognised the benefits of time off for their own wellbeing and that it would help them look after the person they cared for:

I find having a change such as a short break away is really good. Even just looking forward to a change lifts your mood (female, 55-64 years, caring for 3-4 years)

To be able to have some personal time or a break, carers often said they needed more support in the home and with the person they cared for:

I know I need to take a break. I don't need someone to tell me that, but I do need someone to tell me who will care for my husband while I take that break. I just need a few hours in the day to catch up with housework and gardening. I don't want to go out anywhere or socialise as I am too exhausted to even think of that (female, aged 55-64, caring for 3-4 years)

3.4.4.2 Practical or specialist help

Carers said they wanted information and advice on the health condition of the person they cared for and how to deal with specific situations. Access to this kind of support helps them to understand the condition, know how best to look after the person, and to plan for the future should the person's condition deteriorate, or they are unable to care for them:

Information on how to support person with their nutrition, hydration and medical needs and how these are complicated by dementia ... Information on how to plan for the future e.g. where to live, increasing care needs (female, aged 55-64, caring for 3-4 years)

I am interested to know what help is available should it be needed and should I be ill. I am registered with the Emergency Carer network which is reassuring (female, aged 75-84, caring for 3-4 years)

Some people pointed out that at frequent points in a carer's 'journey' - especially at the beginning - they need specific online or telephone advice:

Because it is, for a lot of people in my situation, a first. I've never done this before. I've never been in this situation and people need help and guidance." It would be useful to have "a professional befriender whose job it is to know what's there and to steer you through it. Not to give you a load of phone numbers but to actually deal with it with you (female, aged 65-74, caring for 3-4 years)

For some, this also meant being included in decisions and care that affected the person they cared for. Not only would this help them as home carers but also by helping communication with health staff when the person they care for is unable to.

Many carers said they wanted more support for the person they cared for. They felt that by supporting their physical, mental, and social wellbeing it would

reassure them, take some of the pressure off caring, and give them some personal time and space. Social support could include in the home or at day centre services:

The biggest single help would be some kind of day care for a few hours a day so he could meet other people and do something other than sit in front of the tele while I am working in the next room (female, aged 55-64, caring for 3-4 years)

3.4.4.3 Personal support

We heard that carers wanted access to support for themselves, mainly in terms of counselling and emotional support to help them cope daily, greater recognition, and to feel valued. Younger or less experienced carers especially need personal support:

Any support groups or counselling would've been helpful. I was with young carers 4 years ago but as soon as I aged-out I was on my own (female, aged 18-24, caring for 5-9 years)

I think there needs to be more support out there for younger carers, like I'm in my 30s, there is no support groups out there for people of my age dealing with care for their partners (female, aged 25-34, caring for 5-9 years)

Several carers said they wanted to share their feelings and experiences with people who would listen and who understood. This type of support included talking therapies, support groups, social networks, and telephone helplines:

Just someone to talk to about my feelings (female, aged 55-64, caring for 10-14 years)

To have somebody to talk to as it is extremely isolating and unless you are in that position friends and family don't always understand. I get very lonely and feel extremely isolated being in a village and I don't drive. It would be nice if I had someone I could call once or twice a month to talk to who understands (female, aged 45-54, caring for 15-19 years)

3.5 People's experiences of the Carer's Assessment

In England, adult carers who are looking after another adult with a disability, illness, or who is elderly are entitled to a Carer's Assessment. The purpose of the assessment is to record the impact of caring on the carer and to consider what support or services the carer might need to make life easier for people with caring responsibilities. Carers should be offered an assessment, or they can request one from their local council.

Our survey asked whether carers had received an assessment. Of 148 responses, only 40 (27%) said they had, 64% had not, and 9% were not sure. Most people who had not had an assessment said they had never heard of it (51%), while 42% said

they had not been offered one, and 15% said they did not want one. Other reasons included uncertainty about eligibility:

Have not until now considered myself eligible. I am unsure whether I would qualify (male carer, aged 65-74, caring for 5-9 years)

Other carers said they were not sure about the potential benefits of having an assessment or were more concerned about the wellbeing of the people they were caring for than themselves to fill one in.

People who shared their experiences of going through the assessment process were generally negative. The main problems they described were difficulties completing the form or being able to explain their specific situation and needs, being provided with information and advice that was not useful to them, or not being offered any support at all:

The new assessment form is really complicated and is not user friendly at all. I don't know how clients or people receiving the care can have the energy to stick with the form (female, aged 55-64, caring for 20 years or more)

Process was very difficult for me. I found it very upsetting and was disappointed that it did not provide me with anything that was helpful (female, aged 55-64, caring for 3-4 years)

People appreciated the help provided by voluntary organisations to complete the assessment. Others said they had benefitted from the process and had felt supported by it. Some were happy to have received useful information and advice, as well as financial assistance after assessment:

This was thorough & effective & made me feel supported. A large document I received has lots of information about sources of help & I am making some use of it, however none of the help for my husband is really currently available ... A £300 grant arrived quite quickly ... (female, aged 65-74, caring for 1-2 years)

3.6 The COVID-19 pandemic

Many carers told us how the COVID-19 pandemic had affected them and their ability to care, as well as the person they cared for. Very few people said they had not been adversely affected. Carers of people with dementia sometimes found it difficult to explain why they could not go outside or have visits from other people.

Many families experienced disruption to their support services, such as day centres and support groups, were unable to access GP surgeries and hospitals, and received fewer visits from external carers. Although many service providers put in place alternative forms of contact and support, such as telephone or online support, carers often found themselves having to carry the additional workload:

Day centre and respite stopped. Day centre has been restored part time but I have no respite so overall it has become much harder to get a break from caring (female, aged 55-64, caring for 20 years or more)

I have had to take on much more of the care work as one of the other carers worked in a home and didn't feel safe coming (she did contract Covid). Other carers have had time off self-isolating or quarantining after visiting their home county. Again, the mental health nurse has been a big source of support. My mum hasn't been seen by her doctor for some time now and so I feel her health is not being monitored (participant#90, female, aged 55-64, caring for 5-9 years)

Many carers described feeling vulnerable and said that the risk of infection, social restrictions, and disruption to support and health care had made them and their families feel considerable anxiety and fear. Others said the situation had made them feel lonely and isolated, all of which had affected their mental health:

Anxiety about either of us but particularly my husband catching the virus (female, aged 65-74, caring for 3-4 years)

Having to shield the person I care for was incredibly difficult for us all. The long stay at home without support nor breaks and dealing with extra health issues, that were arising, virtually (due to not accessing the hospital as usual) was incredibly straining on all our mental health (female, aged 35-44, caring for 10-14 years)

Carers told us that they received help from family, friends and neighbours who provided emotional support and practical help with shopping and other activities. Others were very appreciative of support from their GP and local pharmacy, and some said that their care agencies had continued to provide services and had been extremely professional:

The care agency has been superb in continuing to visit twice daily, taking the necessary precautions (female, aged 65-74, caring for 3-4 years)

It has been helpful to have the care agency staff visit my husband [every] morning and evening, and also sometimes in the afternoon to take him for a walk ... the carers are all excellent in their different ways (caring for 3-4 years, female, aged 85 or over)

4 Conclusions

The findings of the report reflect the challenges that unpaid carers face in Oxfordshire and nationally. The diverse impact that caring can have on carers' wellbeing is highlighted as is the burden that many carers carry beyond caring itself. The study supports other work that highlights the experiences of carers and the impact it can have on carers' physical, mental, and social wellbeing.

The COVID pandemic has had a profound impact on many carers and those they care for, in terms of the direct effects of the virus on physical and mental health, disruption to support services, and access to health and social care. Although services have tried to continue providing services where possible, carers and those they are responsible for will continue to experience the effects well into the future. Local government and service providers must do as much as possible to minimise further disruption to essential services and that mechanisms are implemented urgently to support carers and their families in the long run.

The need for carer support is well-recognised and the various strategies, schemes, and services already go some way to helping people in their caring activities and to protect their physical, mental, and social health and wellbeing. However, unpaid carers still appear not to be sufficiently recognised and some feel undervalued and excluded. Our findings suggest that there is still an unmet need for help and support, which some find fragmented or confusing. Furthermore, coverage of the Carer's Assessment seems low, and many carers are either unaware of it or are not offered one. More coordinated work is needed to identify and support unpaid carers and to provide timely help and practical coordinated solutions that are tailored to their individual circumstances and needs.

At Healthwatch Oxfordshire, we recognise the need for more inclusive and participatory strategies to improve representation of people from marginalised and minority groups in our work. We have recently recruited a new team member to work more closely with these under-represented communities.

5 References

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6 Appendices

Appendix 1. A carer's Life (modern day Cinderella)²

March 2020

Coronavirus arrives. Lockdown.

To protect my family, especially my husband, I request the carers don't come, [so that] the two carers could look after other people who will find themselves isolated from their families.

I received time sheets stating care cancelled due to CV19.

13th May 2020

I receive an invoice from the Council for care provided between [March and April]. We are being charged for the hours cancelled. WHY?

I'm working still [and it] is extremely stressful at these times. I'm juggling my husband's care with work. My only get-out is my cycling, which I have to do on my own, because of lockdown and I am missing my friends to talk too. I've been up all night wondering what I should do.

June 2020

12th June: I contact care agency for carers to return for weekends only again, and mention my holiday in September will need covering. Also contacted council again.

Carers will return [in] June again. I'm still happy to care if any problems regarding staffing due to furlough or self-isolating.

We have discussed respite care for [husband], because care would be three times a day, and night time could be difficult for him alone.

For some reason at the moment I feel very alone.

July 2020

Respite care was too complicated to organise, too many different people to talk too.

Discovered we are now in the Oxon [] area, not Oxon [], so needed to explain again.

We have decided our kids will sleep over and the carers just need to come on three extra mornings that week.

Sores have appeared on the top of his left leg. Contacted the district nurse, but when she came over she only looked at []. Pointless. When I turned him for her she could see the sore. Told not to use this cream, but this one. A few days passed, needed to be re-looked at because carer was not happy with the sore. This time the DN decided you should be using this cream not that one. It makes me so angry. The DNs are now coming out once a week to check. This weekend the carers didn't change the dressing so back to stage 1, red and sore.

Also the carers the previous week have put a calf strap to hold his leg bag on the wrong way and the Velcro rubbed his leg and caused a blister, this is now needing to be dressed.

30th July 2020: Holiday cancelled (Easy-jet flight cancelled) So disappointing. This is all starting to stress me even more. I'm still working, the GP's have never contacted us about his illness and if he should self-isolate (thought we would get a letter like other people).

I still think the best way forward is a care home place.

August 2020

² Note: some words have been removed or changed (in square brackets) to protect people's identities.

Care going well. Husband still sore at top of leg. Also caught his foot on door, and now has a sore toe.

I really need help, terrible morning on 17th August. Just couldn't do it anymore. Cried so hard, it was hurting. I just don't know how to get help. It's making me ill.

September 2020

Carers are lovely on Sat & Sun mornings. Still sore at top of leg, but toe much better. Oxfordshire Healthwatch still not contacted me regarding a group. Council still have not contacted me regarding reviewing finances. Would like to work out if paying for full time carers would be better. Still finding it very hard.

November 2020

During the past 4-6 weeks, caring is becoming a struggle. Trying to communicate with anyone regarding his care is so hard you just give up.

During the first lockdown this year, we cancelled the care to reduce people visiting and to free up the carers for someone else. I took on his care with no break and worked. At the end of lockdown, I had an invoice from the council for payment for the hours I'd worked. Apparently, the care providers had claimed. Why do the council just make payment before checking with us that the care was supplied? It is a nightmare to claim back refunds because the council paid the providers.

Trying to find help when I'm struggling is impossible. I was given the opportunity to go for a few days to the [forest] with friends. We needed cover, which was being required because of holiday [abroad] before cancellation. So when I contacted the council about respite care, what a nightmare - the care providers just didn't have the staff to cover for a week. So, in the end my daughter covered the hours and the carers came as usual plus two days.

We have help at the weekends for half an hour on Saturday and Sunday mornings. I do the rest of the weekend, and week.

Contacting the council is now impossible. The last time I called we had moved from Oxfordshire [], to Oxfordshire []. I tried to explain to a lady over the phone what I required, and could she tell me how much it would be for full time care at home. She kept stating that we would pay £x for the whole week. I told her that is what we pay currently for the hour over the weekend. She insisted that is all we would pay for the whole week's care. She didn't understand my question "How much would we need to pay for the whole week?" I tried to ring Oxfordshire [] on a different number, but as usual it's too stressful and I give up.

GPs impossible just don't bother.

District Nurses lovely people, but why don't they contact us before they arrive? I could then get home and be there when they arrive. They don't use overhead hoists and expect my husband to do it himself. It's very dangerous and there will be an accident one day. Whenever I return home after a district nurse has been, he's usually not sat in his wheelchair safely.

4 times in the last 7 days, I've need to change his stoma bag, first thing in the morning, the bag leaked all over the bedding. We just don't know how to get a review on the type of bag he should be using, because the current bag is not suitable. When he was first ill, a team was set up for his care. How do we contact anyone?

Appendix 2. Looking after my wife - a carer's story³

I have attended to my wife's every need since mid-2019 as her full-time Carer. The Corona Virus Pandemic has not impacted our lives because we have been shielding throughout. I have learnt how to support my wife and we try and follow a schedule each day with washing at 09:00 (a lovely Carer comes three times a week). Then coffee at 10:00 followed by lunch at 12:30. As I am not a cook, we have relied on wholesome and nourishing prepared meals. Fruit is important, and particularly blueberries. Supper at 18:30 is always a savoury selection, also with fruit.

During the night, incontinence pants have improved our sleep pattern although the recent re-commencement of chemo has upset this. Every activity including moving around the cottage and WC visits require constant support. NHS equipment has been invaluable (commode, WC frames, zimmer, walker). My wife is able to come downstairs on most days and we have added extra wooden handrails to increase safety. Getting into and out of bed, sometimes four times in the night, requires my support. I am always beside her and never leave. We have weekly cleaners to keep our home tidy and that has allowed me to put 100% focus on my wife's care. Of great importance is the Support Bubble assistance of our daughter and son who visit separately to oversee her climbing the stairs.

The most important issues for me as my wife's Carer is to ensure that she is always warm (her condition attacks when it's cold), has a nourishing diet and is physically comfortable. Our GP has travelled this two-year journey with my wife and keeps in constant touch. We are so lucky to have incredible NHS medical support. Luckily, we do not have financial concerns and we seem to cope with the stresses that her condition brings.

I do need help as an Unpaid Carer in the form of visits for washing and moral support through our children's support bubble visits. Fortunately, my own health has been good throughout (aged 76). I follow the advice of Medics to look after myself, physically and mentally, so that I can look after my wife.

The spring and summer of 2020 were spent happily in our Oxfordshire cottage and garden with a live-in Carer for three months of recuperation and a support Carer helping thereafter for an hour three times a week. My wife's NHS Consultant said that her condition is very rare and that a new course of chemo is required. The chemo commenced in January 2021 and involves a number of three-week cycles...The side effects are mostly fatigue and feeling shattered, and apprehension and worry.

³ Note: some words have been removed or changed (in square brackets) to protect people's identities.

Appendix 3. Survey questionnaire on unpaid caring in Oxfordshire



Unpaid caring in Oxfordshire - looking after someone you know either in your home or theirs

If you are aged 18 or over and you help an adult family member, friend, or neighbour in their home because of their age or an illness, disability, mental health problem, or addiction, we would like to hear from you. Even if you only help them for a few hours or you don't see yourself as a 'carer', your views are important. We want to hear your experiences and about any support you get or that would help you.

Healthwatch Oxfordshire is an independent charity set up to hear the experiences of people who use health and social care services. What you tell us will help those who make decisions about health and social care understand your views.

Please tell us about your experiences of caring during 'normal' times – there is a question at the end of the survey about COVID-19 (Coronavirus).

We may use a translation service for questionnaires that are completed in any language other than English but will ensure that your information is treated confidentially. If you need help to fill complete this questionnaire, please call Healthwatch Oxfordshire on 01865 520520. Or you can email us at hello@healthwatchoxfordshire.co.uk.

Action for Carers Oxfordshire gives free specialist support to unpaid family carers looking after a loved one, friend or neighbour living in Oxfordshire. Please telephone the Carersline if you are looking for advice and support: 01235 424715.

1. Your consent: This survey is anonymous. This means you don't have to say who you are, and you cannot be identified. Healthwatch Oxfordshire uses people's comments and stories in reports and on our website with their permission. We need to know if you are happy for your anonymous comments to be used in this way. Please choose Yes or No: *

Yes, I am happy for my direct comments to be used in reports

No, I don't want my direct comments to be used in reports

2. How many people do you care for?

1

2

3 or more

3. How old are they? (if it is more than one person, please select all their age groups)

18-24

25-34

35-44

45-54

55-64

65-74

75-84

85 or over

4. Who do you care for? (please select all that apply)

A disabled person

Someone with a long-term illness (e.g. arthritis, chronic pain, diabetes)

Someone with Dementia

An elderly person

Someone with problems seeing or hearing

Someone with a mental health condition

- Someone with a learning disability or difficulty
- Someone with a terminal illness
- Someone with an alcohol or drug dependency
- Other (please tell us):

5. How long have you been caring for them? (If it is more than one person, tell us about the person you have been caring for the longest)

- Less than 6 months
- More than 6 months but less than a year
- Between 1 and 2 years
- Between 3 and 4 years
- Between 5 and 9 years
- Between 10 and 14 years
- Between 15 and 19 years
- 20 years or more

6. How many hours a week do you usually spend doing caring activities? (if you are not sure, please estimate)

- Between 0 and 9
- Between 10 and 19
- Between 20 and 34
- Between 35 and 49
- Between 50 and 74
- Between 75 and 99
- 100 hours or more

- Varies – less than 20
- Varies – more than 20

7. Who else provides care for the person you care for? (select all that apply)

- Nobody, I do the caring on my own
- Family members who live with me
- Other relatives
- A friend or neighbour
- A private or agency carer(s) paid for by me or the person I care for
- A private or agency carer(s) paid for by the Council
- Other (please tell us):

8. Has being a carer affected your health and wellbeing? (this can include physical, mental, or emotional effects)

- Yes
- No
- Don't know

If Yes, please tell us about it:

9. Who is aware that you are caring for someone? (please select all that apply)

- Nobody
- Family or friends
- GP or other health professional
- Social worker
- Oxfordshire County Council
- Local voluntary group or charity
- Other (please tell us):

10. In the past 12 months, have you as a carer received any advice or support? (please select all that apply)

- Information or advice for carers (e.g. getting benefits, looking after yourself)
- Support from other carers or experienced people at a local group or online
- Advice or help with employment (e.g. starting a job, getting time off for caring)
- Advice or help with education or training (starting a course, flexible study)
- Time off from caring (e.g. to go out or do personal things)
- Longer breaks from caring (e.g. respite care)
- Training (e.g. about the health condition of the person you care for, first aid, lifting safely)
- Counselling or emotional support for you
- No, I have not received any support (If no, please go to Q12)
- Other help or support (please tell us):

2. Advice or support you get as a carer

11. Please tell us about the advice or support you mentioned above, including who provided it, when, and what is helpful about it:

3. Reasons you don't get support as a carer

12. If you have not received any help or support in the past 12 months, please tell us the reason (select all that apply)

- I didn't/don't want support
- I haven't asked for any
- I didn't know that support was available for me
- I didn't know how or where to find support
- Nobody has offered me any help
- I have been offered support but have not received it yet
- Other reason (please tell us):

4. Other help and support for you as a carer

13. What other help or support would make the biggest difference to you as a carer?

14. Unpaid carers are entitled to a 'carer's assessment' from the local council to see what might help make your life easier. Have you had one?

- Yes (if yes, please go to Q16)
- No

Don't know

If yes, please tell us about your experience of the assessment (when you had it, how you felt about it, what was recommended):

5. Reasons for not having a carer's assessment

15. If you have not had a carer's assessment, please tell us the reason (please select all that apply)

- Never heard of it
- I have not been offered an assessment
- I have been offered an assessment and am waiting for it
- I don't want an assessment
- Other reason (please tell us):

6. Other aspects of caring

16. Some people with long-term complex health needs can get free social care arranged and funded by the NHS. This is called NHS continuing healthcare or CHC. If you or the person you care for receive continuing health care, please tell us about it:

17. How has Coronavirus affected you as a carer? Tell us what has been most difficult and about any help or support you have received:

18. Is there anything else you would like to say about being a carer?

19. Please tell us where you found out about this survey (e.g. Parish newsletter, social media, Healthwatch Oxfordshire poster):

7. About you

20. Are you:

- Male
- Female
- Non-binary
- Prefer not to say

21. Please tell us your age group

- 18-24
- 25-34
- 35-44
- 45-54

- 55-64
- 65-74
- 75-84
- 85 or over

22. Please tell us the first part of your postcode (e.g. OX4)

23. Please tell us your ethnicity

- Indian
- Pakistani
- Bangladeshi
- Chinese
- Any other Asian background
- African
- Caribbean
- Any other Black/African/Caribbean background
- Arab
- White and Black Caribbean
- White and Black African
- White and Asian
- Any other mixed or multiple ethnic background
- English/Welsh/Scottish/Northern Irish/British
- Irish
- Gypsy/Irish Traveller

Any other White background

Other (please specify):

Or tell us your own definition:

24. If you would like to speak to us anonymously or in confidence, please leave your details below, or email us at hello@healthwatchoxfordshire.co.uk and we will contact you - or just phone us on 01865 520520 to speak to our friendly staff.

We are also keen to hear from you if you would like to share your experiences or your 'story' in more depth, or be part of a 'focus group' discussion with others about being a carer in Oxfordshire. Your voice is important.

Please select any you are interested in:

Yes, I would like to speak to you in more depth about my experience

Yes, I would like to share 'my story' with you in more detail

Yes, I would like to take part in a 'focus group' discussion with others to give my views

If you answered Yes, please leave your name and details. We will not keep these and will only use them to contact you for the reason you state above: