

Oxfordshire Health & Wellbeing Board

Thursday, 16 March 2023

ADDENDA

10. Support for Carers - Developing a strategic approach (Pages 1 - 24)

3.15pm

The Health and Wellbeing Board is **RECOMMENDED** to:

- A. Develop and publish a new All-age Unpaid Carers Strategy for Oxfordshire, based on priorities expressed by carers of all ages
- B. Align workplans across Health, Education and Social Care to the refreshed All-age Unpaid Carers Strategy for Oxfordshire so that all services have procedures in place to identify and support unpaid carers, regularly review procedures, and seek ways to support and include carers
- C. Develop and keep updated a central public repository of information for carers so that carers and those supporting/advising them can easily find support
- D. Support the establishment of the overview arrangements necessary to ensure improvements are achieved across the system.

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Divisions Affected –

Public Health; Adult Social Care; Children’s Services

HEALTH AND WELLBEING BOARD

16 March 2023

REVIEW OF SUPPORT TO UNPAID CARERS

Report by Karen Fuller

RECOMMENDATION

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 - A. Develop and publish a new All-age Unpaid Carers Strategy for Oxfordshire, based on priorities expressed by carers of all ages
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 - D. Support the establishment of the overview arrangements necessary to ensure improvements are achieved across the system

Executive Summary

2. Local Authorities and Health organisations have statutory duties to support unpaid carers of all ages (see Background, below). The Survey of Adult Carers in England 2021/22 showed that, nationally and in Oxfordshire, unpaid carers’ satisfaction levels against all measures had fallen. Census 2021 showed that although the number of unpaid carers overall has fallen, the hours of care each generally provides has increased since Census 2011.

An action group set up to resolve carers’ reported issues and to engage more widely with carers found that many issues reported involved the wider Health, Education, Social Care and voluntary sector organisations, and especially communication between organisations. Carers and those supporting them found information hard to find. The issues reported followed the same themes as those reported in the national survey. The existing Oxfordshire Carer Strategy 2017-20 contained out of date information, particularly regarding young carers, and required refreshing; the adult carers’ main priorities remained the same. A review of support to young carers and engagement started later and

is ongoing, and the emerging themes mirror those of adult carers. Many improvement actions have been completed and work continues.

A review of support to adult carers in Oxfordshire was carried out, including listening to carers' stories and concerns through various methods, and agreeing goals and outcomes with them. Services for carers were evaluated to gauge whether they supported carers' three main priorities, which showed that more work is required, particularly to avoid carers having to constantly retell their stories.

Our findings showed that adult carers' priorities remain unchanged, that carers and those who support/advise them have difficulty finding information and support, and that organisations need to find ways of joining up to support carers. These findings are reflected in the recommendations above. Approval to develop the strategy was supported by Adults DLT (6/3/23) and Joint Commissioning Executive (9/3/23).

3. **Background**

The Care Act 2014 gives adult carers the right to receive support from their local authority if they have eligible needs. The Local Authority has a duty to assess carers when they come to their attention, provide carers with support to meet their needs according to national eligibility criteria, and a duty to provide information and advice, to promote wellbeing and to prevent people needing support, where possible. Young carers are those under 18 years old with caring responsibilities. Their rights to be assessed come mostly from the Children's Act 1989 and the Children and Families Act 2014, and as part of the whole family approach. The Health and Care Act 2022 places a duty on NHS Hospital Trusts to involve carers in discharge planning, ensuring that carers are involved in choices about discharge.

The Council's Strategic Plan 2022-25¹ states 'Support carers and the social care system' as one of its nine priorities. The Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board states in its Master Strategy Document² its ambition that carers experience a level of support that is seamless and consistent, including better access to support in a crisis, and that the health and wellbeing of carers is improved.

Oxfordshire County Council's Carer Strategy has been in place since 2017. Since its publication, the Covid-19 pandemic³ and cost of living crisis⁴ have impacted the population, with unpaid carers being particularly adversely affected financially and in terms of their wellbeing. The impact of the pandemic was reflected in the results of the Survey of Adult Carers in England

¹ [Our strategic plan 2022 - 2025 | Oxfordshire County Council](#)

² [7412dde8ee3fd572bf249ae0cb8058c2 Master BOB Strategy Document Draft vFINAL2.pdf \(amazonaws.com\)](#)

³

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/coronavirusandthesocialimpactsonunpaidcarersingreatbritain/april2021>

⁴ <https://www.economicsobservatory.com/how-is-the-cost-of-living-crisis-affecting-unpaid-care>

(SACE) 2021/22⁵ (which itself had been postponed for a year due to the pandemic) and showed lower performance than the previous survey across the five ASCOF indicators below, both nationally and in Oxfordshire.

- Carer reported quality of life
- I have as much social contact as I want with people I like
- Overall satisfaction of carers with social services
- The proportion of carers who report that they have been included or consulted in discussions about the person they care for
- The proportion of carers who find it easy to find information about services

The typical carer in Oxfordshire is a woman aged 65+ years living with the cared for person, providing 100 hours or more of care a week, and has been caring for over 5 years. This includes help with dealing with care services/benefits, personal care, making medical and other appointments, arranging transport and attendance with the cared-for person, collecting prescriptions, shopping, companionship, keeping an eye on them and other practical help including dealing with crises at short notice.

The main source of data about unpaid carers in Oxfordshire comes from the census. At the time of writing, data from Census 2021⁶ is being released. This tells us that both nationally and locally although the number of unpaid carers has reduced - in Oxfordshire to 52,674 from 61,000 in 2011 - the number of hours of care they are generally providing has increased.

In Oxfordshire the provision of unpaid care from 1-19 hours has decreased by 32%. However, there has been a 43% increase of people who provide 20-49 hours of unpaid care, and a 24% increase in those who provide 50+ hours of unpaid care. Again, this reflects the national trend.

Proportionally, Oxfordshire's residents provide fewer hours of weekly unpaid care than the rest of England and Wales.

The proportional rate of the population over 5 years old that provides:

	No care	Up to 19 hours unpaid care per week	20-49 hours unpaid care per week	50+ hours unpaid care per week
Oxfordshire	92.3%	4.3%	1.3%	2%
England & Wales	91.1%	4.3%	1.8%	2.7%
Difference	+1.2	0	-0.5	-0.7

Source: Census table TS039

⁵

<https://app.powerbi.com/view?r=eyJrIjoiNzI5ZDdmM2YtMDRiNC00MTY0LThlZjltYTE5ZjA3YTlxYWU4IiwidCI6IjUwZjYwNzFmLWJiZmUtNDAxYS04ODAzLTY3Mzc0OGU2MjllMiIsImMiOiJh9>

⁶ [Census | Oxfordshire Insight](#)

Oxford has the lowest proportion of the population who provide unpaid care across Oxfordshire. The population of Oxford which provide any weekly unpaid care is 2.20%. This is below the Oxfordshire average of 2.53%

Provision of unpaid care	Value	% of population
Cherwell	11,597	2.5%
Oxford	10,290	2.2%
South Oxfordshire	11,225	2.7%
Vale of White Horse	10,595	2.7%
West Oxfordshire	8,967	2.7%
Oxfordshire	52,674	2.5%
England and Wales	4,989,016	2.9%

Appendix 1 contains links to supplementary research and information. Annex 1 contains details of carers services currently provided in Oxfordshire

4. **Response to the results of the Survey of Adult Carers in England 2021/22**

The survey (SACE) was sent out in October 2021 to 1,600 carers registered with Oxfordshire County Council, of whom 465 (29.1%) responded. Interim results released from the survey in February 2022 showed:

- 62% were satisfied with the support they received; 16% were dissatisfied and 22% were neither satisfied nor dissatisfied
- 13% of carers said they had no time to do things they value or enjoy and 19% felt they were neglecting themselves; 19% felt socially isolated and 24% felt they had no encouragement or support in their caring role
- 20% reported that they had had to visit their GP as their health had been affected by their caring role
- Since 2012/13 there is a declining and statistically significant trend in the percentage of adult carers who have as much social contact as they would like (from 41.6% to 26.7%)⁷
- Nearly three quarters provide personal care (72.4%)

It was not clear from the comments that all carers actively wished to take on the role, but rather that they felt that they had to. Appendix 2 contains carers' comments from responses.

A task group was formed comprising staff from the Commissioning, Adult Social Care, Finance, Customer Service, Direct Payment Advice, Quality Improvement and Quality Assurance Teams at the County Council and partners from the voluntary sector: Age UK Oxfordshire, Carers Oxfordshire, Dementia Oxfordshire, and Oxfordshire Specialist Advisory Service. The group devised an action plan to resolve issues raised in respondents' comments in the survey.

⁷ [Public health profiles - OHID \(phe.org.uk\)](https://phe.org.uk)

Progress on this work has been reported at People Overview Scrutiny Committee by the Interim Corporate Director of Adult and Housing on 12 January 2023. A summary of the work reported is in Annex 3; Annex 2 contains completed actions.

5. Carers Strategic Review

The work to this point showed that unpaid carers and those supporting them found it difficult to find information about services available, partly because multiple agencies were involved in their delivery and communication between those agencies was inconsistent, as indicated by 'communication' being the most referenced theme by carers. It was not possible to easily establish what was available to unpaid carers across all systems and where the gaps lay.

A stakeholder group was set up (with members from the County Council, Carers Oxfordshire, Rethink Mental Illness, Oxfordshire Family Support Network, Be Free Young Carers, Oxfordshire Parent Carer Forum, Age UK Oxfordshire, Dementia Oxfordshire, Oxford Health, Oxford University Hospitals, Buckinghamshire Oxfordshire and Berkshire West Integrated Care Board, Oxford City Primary Care Networks Social Prescribers and unpaid carers) to refresh the current Oxfordshire Carers Strategy and review services for unpaid carers. Adult carers were asked whether the three main priorities below from the current Oxfordshire Carer Strategy were still important to them, and for their experiences as carers. Lead Commissioners, Operational and Quality Improvement Leads across Health and Social Care, and voluntary organisations involved with supporting unpaid carers were asked to evaluate their services against the priorities and to provide stories of difference.

PRIORITY 1: To identify carers and effectively support them, improving their health and wellbeing and providing opportunities for a break from their caring role.

PRIORITY 2: To safeguard the most vulnerable carers who need more support to look after themselves, particularly during times of change and transition.

PRIORITY 3: To encourage and enable carers to have an active life outside their caring role, including fulfilling their education, employment, and training potential.

5.1 Services evaluation

Each of the questions within each service evaluation was rated as to how the service met the priorities above: Green – clear evidence, Amber – partial evidence or Red – no evidence. Overall, the evaluations rated - Red: 36.6% Amber: 22.1% Green: 41.3%. The gaps were predominantly around follow-up of referrals made to other organisations; identifying 'hidden' carers and/or exploring/recording reasons for not wishing to be identified as a carer; and lack of recent or planned initiatives or improvements for carers to services.

An area in which most services rated well or had identified changes they needed to make was in ensuring carers did not have to retell their stories at

each contact, about which carers have reported frustration. However, few of the services shared systems causing carers to have to reiterate when referred or signposted to another service.

5.2 Engagement with Unpaid Carers

Carers Oxfordshire carried out engagement work to facilitate and widen carer involvement in the review of the Oxfordshire Carers Strategy and services for unpaid carers, focusing on carers aged 18+, caring for adults and/or children; engagement with young carers is being undertaken separately by the Engagement and Commissioning (Start Well) Teams.

Contributions were collected from: attendance at the Carers Oxfordshire 'Listening Event', online surveys, direct media such as email and Zoom, visits to small groups including those in more rural areas, and individual telephone conversations.

Carers unable to use the online options were encouraged to use telephone or post options to have their voice heard. Oxfordshire County Council's survey was also made available in the top five most-translated languages in the county (Polish, Sudanese Arabic, Brazilian Portuguese, Kurdish Sorani and Spanish). To increase the reach to carers, Carers Oxfordshire worked with Oxfordshire County Council, Dementia Oxfordshire, Age UK Oxfordshire, Oxfordshire Family Support Network and Oxfordshire Parent Carer Forum. To date circa 300 adult carers have contributed and engagement continues.

Common themes recurred through the evidence submitted from the groups and studies outlined above. Whilst these themes are all distinct, it is important to note that they are interrelated. This was particularly clear during the first carers voices event where carers were separated into groups that were allocated a theme to discuss their experiences around yet found it difficult to discuss one theme in isolation.

Based on responses received to date, the themes remained consistent with the national survey responses. They have been re-worked below to show goals and outcomes required to meet statements describing what carers say is important to them. It is important also to facilitate a means of measurement and accountability.

5.3 Goals and outcomes agreed with carers

Having a quality of life should not be lost because you are a carer.

- Having a break from your caring role is essential.
- Different options for respite are important i.e. day care, family days out.
- Improved provision and access to residential respite.
- Access to support when at work or studying.
- Wellbeing opportunities need to be increased e.g. counselling.

Services, provision, and support needs to improve.

- Better communication including carers being listened to, responded to and involved.
- A joined-up approach between services. (NHS, Social Care and the voluntary and community sector)
- Quality of care needs to improve. (Timeliness, access to services e.g. GPs)
- Increased specialist service provision and training for services (SEND provision & Adult Social Care).

Information & advice needs to be easily accessible.

- Information is available when needed.
- Available in different formats and languages.
- Easily understandable and accurate.
- In one place.
- With explanations of services.

Carers should be valued

- Treated as partners/experts in supporting the cared for person.
- Involved in decision making and planning.
- Understood and acknowledged for the important contribution they make to society.
- Provided with increased support to manage caring role. (Carers Assessment, Support Plans, Direct Payment).
- Recognised as having their own diversities, disabilities, abilities and needs.

Strategy priorities must be measurable and reported on.

- Effective, meaningful measures.
- Reporting back on strategy progress and outcomes.
- Transparency.
- Communication.

6. Monitoring progress

To deliver the improvements required, the following are necessary:

1. developing a common framework/strategy;
2. agreement from all of the partners to the strategy to implement within their own organisations the aligned workplans;
3. monitoring and review of progress against agreed areas for improvement overseen by the Health & Wellbeing Board in partnership with experts by experience.

7. Conclusions

The review indicates the priorities within the strategy remain unchanged for adult carers, however, the current strategy does not include how to implement required changes, nor having a central source of information, nor how organisations can join up. Additionally, for young carers, the services have

since been brought in-house. For all of these reasons, a new All-Age Unpaid Carers Strategy is required, to:

- Achieve the system engagement and commitment to meet the needs of unpaid carers across health and social care throughout Oxfordshire.
- Ensure the outcomes developed in the strategy form part of how we monitor implementation and impact across health and social care settings. Focusing on simplicity, consistency, value for money and accessibility.
- Set expectations that individual organisations either develop or adapt unpaid carer service plans in line with the strategy when it is concluded.

It is clear from all engagement with adult carers that they cannot concentrate on their own wellbeing while they have concerns about the person/people they care for, so unpaid carers must be included and engaged in all services relating to the person/people they care for.

The review of the young carers' offer began at a later stage than that for adult carers and will require more time for review, analysis and planning and would inform the refreshed All Age Unpaid Carers Strategy for Oxfordshire. Emerging themes from engagement with young carers tend to mirror those of adult carers in that they do not necessarily identify as carers, are unsure of what support is available for them, and do not find information easy to find.

Corporate Policies and Priorities

8. Carers are identified in our strategic policies including the [Oxfordshire Joint Health and Wellbeing Strategy](#), the Council's Corporate Plan, and NICE guidelines.

Financial Implications

9. There are no new or additional implications. Improvements required will come from the current allocated funds available to the Health & Social Care system. Through the review we have identified pockets of good practice and development of the proposed strategy seeks to strengthen integration between organisations.

Equality & Inclusion Implications

10. An equalities impact assessment will be completed as part of the delivery of the final strategy.

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Annex 1

Carers services currently provided in Oxfordshire:

Description of Service	Service includes:
<p>Carers Oxfordshire Our principal commissioned support to unpaid adult carers in Oxfordshire. OCC is the lead commissioner which is a partnership between Action for Carers, Rethink and the council's Customer Services Centre funded by the council and Oxfordshire Clinical Commissioning Group – now BOB ICS</p> <p>The current contract started on 1st April 2021</p>	<ul style="list-style-type: none"> • Information, advice and support online, over the phone and face-to-face • Carers' assessment, support planning and review • Mental health carers' support service • Peer support, training and befriending services • Care Matters, a quarterly newsletter for people who look after family members, friends or neighbours • Practical support with housework/gardening etc.
<p>Respite services Commissioned from care providers such as StyleAcre and the Order of St John for example and breaks for carers</p>	<ul style="list-style-type: none"> • Short Breaks • Sitting service • Cared for Short stay respite
<p>Oxfordshire County Council Directly provided services for adult carers</p>	<ul style="list-style-type: none"> • Carers joint assessments. 2,045 people have been assessed jointly with individuals they care for between April-Nov 2022. • Provide personal budget payments to enable carers to take a break. • Carers' wellbeing payments (administered by Carers Oxfordshire on behalf of the Council). 1,623 carers have received direct payment of up to £300 to support their own wellbeing. Carers have used these payments on a wide variety of things e.g. purchase of new orthopaedic mattress, days out, carers holiday and driving lessons.
<p>Oxfordshire County Council Directly provided services for young carers</p>	<ul style="list-style-type: none"> • Initially Young Carers needs are assessed and subsequently categorised. • Those who have been identified with level 2-4 needs and who would benefit from Early Help, a Strengths and Needs form or C&FA and Child Development Checklist is completed to determine the intervention required and supports the

	<p>development of an outcome-focused Team Around the Family Plan</p> <ul style="list-style-type: none"> • This prevents the need for a statutory assessment (managed by MASH) • A Young Carer's strengths and needs are identified through the Early Help process. This is a whole family, multi-agency process led by the professional who has identified that a family or young person could benefit from early help. • The council's Locality and Community Support Service and Targeted Early Help teams support Young Carers and their families to access support within their communities and also help co-ordinate the "Team Around the Family" multi-agency process, which seeks to support families to build on their strengths and make positive changes to family life. This process helps identify and resolve issues at an early stage to prevent potential escalation where statutory services may be required. • When a Young Carer is identified as having more complex needs, where Statutory Services may be required, they are supported by the Multi-Agency Safeguarding Hub (MASH).
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The NHS also provides extensive support to unpaid carers through its services including Primary Care, Oxford University Hospitals and Oxford Health NHS Foundation Trust.

Annex 2

Carers Survey 2021-22 – Action Plan – Completed Actions

Workstream	Deliverables	Action Completed	Completed By
Communications			
Financial	Review financial circumstances forms and letters	- Design of combined and simplified forms and initial contact letters trialled successfully.	Adult Social Care (ASC) Teams
	Improve signposting and support opportunities	- New Carers Oxfordshire website with links to specialist services. - Direct Payment support service fully operational, including help line.	Carers Oxfordshire OCC Direct Payment Advice Team
	Maximise uptake of eligible benefits	- Care Matters newsletter August 2022 edition included section on understanding benefits - Carers Champions in each ASC team provided with information on eligible benefits - A practice note on benefits available to Carers produced for ASC teams including signposting to specialist advice services	Carers Oxfordshire Oxfordshire Specialist Advice Service
	Inform about eligibility for free equipment	- GP Surgeries provided with Live Well Oxfordshire brochures and re-order information - ASC Operational staff deliver information at home visits	Carers Oxfordshire ASC Ops Team
Non-Financial	Information for ASC teams to ensure carers and cared for understand the home care offer	- Some improvements made to the website to make it more user-friendly.	Quality Improvement Team
	Assistance in completing carers assessment forms	Carers Oxfordshire provides assistance in completing carers assessment/review forms by phone or in person	Carers Oxfordshire
	Improvements in information available to Carers and for those whose first language is not English	- Services Handbook for carers and business cards additionally made available in the 5 most translated languages in the county - Contact made with groups with more diverse backgrounds	Carers Oxfordshire Customer Services Team/Carers Oxfordshire

Workstream	Deliverables	Action Completed	Completed By
		- Links made with food banks to widen reach to lesser heard voices	
	Training on signposting for OCC Customer Services Team	- Induction and training schedule for CS staff now includes information and signposting for carers, provided by Carers Oxfordshire	OCC Customer Services Team
Digital Exclusion	Availability of paper-based comms	- Live Well brochure distributed to GP practices, hospitals, libraries etc. GPs have requested extra copies - Care Matters newsletter and Services Handbook available in hard copy as well as online	OCC Commission Team Carers Oxfordshire
	Partnership working	- Partnership event organised - Feedback from Voice of the Customer meeting circulated	RUC Carers Oxfordshire
Timeliness	New telephony system for ASC to address calls not answered/returned	- Installation will be completed by end March 2023	ASC Teams
	ASC Staff/Business Support voicemail messages to be updated	- Standardised voicemail message now in use	ASC/Business Support Teams
	Quality Assurance Team completing case audits focusing on Carers	- Audits looked at whether the Care Act is being met - Audits completed and review scheduled to establish main themes	OCC Quality Assurance Team
	Review progress of LAS checks	- Data cleansing completed	Carers Oxfordshire
Quality of Life	Addressing isolation/loneliness	- Creative consultation work in progress by Carers Oxfordshire - Mapping and model of all Carer support groups across the County completed to scope and reduce duplication of support	Carers Oxfordshire
	Ineligibility for blue badges	- Blue badge criteria are from DoT and ineligibility reasons are notified to applicants	OCC CSC Team
	Parking issues	- OUH Carers passports give free parking at hospitals to Carers. Carers notified during assessments and at Listening Events	OUH Carers Oxfordshire

Workstream	Deliverables	Action Completed	Completed By
Quality of Care	Self- funders and DP recipients require more support and information	- New DP support service now in place, Carers updated on DP support improvements at Listening Events	DP Advice Team and Carers Oxfordshire
	Addressing reports of poor care and support from Home Care providers	- Quarterly contract meetings are held with providers, issues are dealt with under Standards of Care/Serious Concerns meetings and information is shared with CQC and Adult Safeguarding Team	Quality Improvement Team

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Annex 3

Summary of the work on the Unpaid Carers Action Plan reported to the People Overview Scrutiny Committee on 12 January 2023 by the Interim Corporate Director of Adult and Housing

The comments from responses to the Survey of Adult Carers in England 2021/22 and resulting actions fell under five main themes:

- Communication (including financial communication and digital exclusion)
- Timeliness
- Quality of Life
- Quality of Care
- Finances

Service improvements had begun before the survey had taken place and/or the interim results received but were included in the action plan as carers had commented upon them. These were:

- NHS hospital trusts in England must ensure that unpaid carers are involved as soon as possible when plans for a patient's discharge after treatment are being made.
- A carer assessment looks at how caring responsibilities affect the carer, physically and emotionally. It will identify whether the carer is willing or able to carry on caring, what they wish to achieve in their daily life, what support they need, and what support they are eligible for. It focuses on the carer, not the cared for person.
- Under the new contract with Carers Oxfordshire (a partnership between the charities Action for Carers (Oxfordshire) and Rethink Mental Illness), the service took over carer assessment processes previously carried out by the Customer Services Team and enhanced them by using strengths-based conversations to create carer support plans, carry out reviews, and distribute payments to support carer wellbeing.
- The relaunch of the Carers Oxfordshire website where carers can access online assessments, opportunities for short breaks, and other support and information, including groups and events.
- Creation of Direct Payment Advice Team, providing support and guidance by telephone and email to residents and professionals around direct payments, as well as streamlining and speeding up the process. Carers had fed back how onerous and lengthy the process had previously been, adding strain by delaying them getting the assistance they needed to support those they cared for by weeks/months.
- Review and simplification of financial assessment correspondence, which carers had found convoluted and complex.
- The adoption by Adult Social Care Teams of the Oxfordshire Way to reform delivery of Adult Social Care has reduced waiting times for care needs assessments, reducing the time that unpaid carers are managing alone. Unpaid carers are also referred for assessment and support if there is likely to be a delay in care needs assessment for those they care for, so that they are supported as early as possible.

A key objective of the action plan was to ensure that actions would make a difference to carers' quality of life.

Annex 2 contains details of actions completed on the plan

Appendix 2 contains a selection of the carers' comments, arranged by theme.

Appendix 1

Supplementary information and research

The Survey of Adult Carers in England 2021/22 responses for Oxfordshire should that adult carers: feel tired (78%) and stressed (63%) over their caring role. One in 5 had seen a GP in the last 12 months because of the stress of caring, this had dropped from 33% from previous surveys. For just under a half (43%), their caring has caused financial hardship. Half of the people they care for have a physical disability, 38% have a long-standing illness and 35% have dementia.

- We need to better understand the Census 2021 data – could the apparent reduction in unpaid carers have been caused by the change of wording of the question?
[Health and unpaid care question development for Census 2021 - Office for National Statistics \(ons.gov.uk\)](https://www.ons.gov.uk/health-and-unpaid-care/question-development-for-census-2021)
- Protected characteristics Census 2021 data released on 13 February 2023 includes young carers data.
- Research shows status changes in and out of the caring role; this needs to be taken into account when engaging with carers and reinforces the need for engagement and review to be a continuous process: Petrillo, M., Bennett, M.R., and Pryce, G. (2022) Cycles of caring: transitions in and out of unpaid care. London: Carers UK.
<https://centreforcure.ac.uk/publications/cycles-of-caring-transitions-in-and-out-of-unpaid-care/>
- Research shows that unpaid carers save the UK £billions each year, but often then have poor health and financial outcomes themselves because of their caring role. Budgetary pressures on Local Authorities since 2010 have resulted in a decrease in support for unpaid carers. <https://www.nuffieldtrust.org.uk/files/2022-10/nuffield-trust-unpaid-carers-web-final.pdf>
- The impact on young carers of Covid has been particularly acute:
<https://carers.org/what-we-do/our-survey-on-the-impact-of-coronavirus-on-young-carers-and-young-adult-carers->
<https://www.childrenscommissioner.gov.uk/2022/03/16/the-big-ask-voices-shining-a-light-on-young-carers/>

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Appendix 2

Some carers' comments from SACE 22/22, arranged by theme

Communication

"Felt like there was a lack of communication as we were often left in the dark as to what was happening. Also, every time someone left we had to start over from beginning. This seemed to be a waste of time and resources".

"Finding a care agency and negotiating a set price, a time-consuming and stressful process"

"There was definitely a lack of communication between all parties (hospital/care home/social care/family) particularly during this time. Thankfully we are all well and the person I care for came home safely, unlike a lot of others but it was an extremely worrying time, and it will take a long time for those scars to heal"

"Our s/worker was incredibly helpful. All my support came from my s/worker. Who worked so hard and communicated so well and supported us brilliantly. Our previous social workers were brilliant too"

"Difficult to know which teams to contact in S/S. Website needs to be clearer / updated. I found out about 'Move into adult team' by word of mouth. Oxfordshire Family Support Network have facilitated online information sessions which have been useful"

"I was told the Carers' Break Service no longer exists"

"The areas of activity and responsibilities of the many, many sources are just a fog. Practitioners in some of these have told me they don't understand the system either. What chances have I? A simple - if possible - multi-source list."

"Lack of communication between all parties (hospital/care home/social care/family) during the COVID lockdowns"

"We have had to 'drive' all communications. When you have a self-directed support budget, you are just 'left to get on with it' which is fine until things go wrong - then a support network is needed"

Timeliness

"Passed from one organisation to others and 3 hrs queuing on phones. Given advice with wrong problems, not got enough time to listen and understand me."

"Getting/making GP appointments was near impossible to get, long waiting time when making initial calls"

"There has been no follow-up visit from OT to help change bed height / measure for a suitable chair for his disability"

"The time that it took for a social worker to be allocated, for assessment to take place and for a Direct Payment to be put in place took 7 months"

Quality of Life

"There are massive problems in the care services. One box does not fit all. S/S give no help whatsoever to anyone needing help if they live with family. I feel alone, neglected, unworthy and unappreciated by any services. It's pointless even writing anything here because no one will read it or care. But the unpaid family carers are the unsung heroes! It's such a shame there is no recognition for them as they save the government £1000s upon £1000s every single year!"

"We do have a private carer who comes in the mornings but in the last few weeks they are also coming in the evening to help my husband to bed. This is helping me enormously

"Since looking after my husband my whole life has changed. There are days when I feel I can't cope"

"Do regular benefit and health checks to make sure the carers don't have to become cared-for"

"I have no control over my daily life - I have 2 adult sons with Autism and my husband has Parkinson's"

"I have to care for my grandchildren (usually 5 of them as well as Dad) This is something I want to do but leaves little quality time"

"This survey has made me realise the strain we are feeling and I have taken advice to reach out to the Alzheimer's society and Contacted OCC to see if her support plan can be renewed. I have also got a phone call with her GP next week which has made me feel less helpless and more in control. This survey has galvanised me into action. Thank you!"

"Taking my mum to appointments has encroached on my work time"

"The stress, strain and depression and worry from all this made me just cancel care even though my husband was newly out of hospital and incontinent. I've never felt worse"

Quality of Care

"My mother has complex needs and although we have had a live in carer, over the last 12 months, these have constantly change as carers are not used to dealing with the level of care mum needs. That either means I am constantly re-training people,

having to be on hand or concerned whether they are caring for mum in the way she needs. It is also stressful having different people in your home with you. I am grateful for the support, but it is not without it's challenges for mum or I"

"2nd carer left so 8 days a month they cannot cover. They just have no one else. They had a month while the other carer worked his notice out. Did they bother to train or advertise for someone - no. that's why we're in this mess."

"Following a week in hospital he received excellent care in an NHS Hub bed in a care home. The physio kept me fully informed and visited our home before my husband was released from the care home"

"I just think that the medical profession does not give old people any backup or support. Impossible to get a GP to visit or contact"

"My husband went to a care home from respite care and the worse decision ever made. He came out with COVID – 8 weeks of hell. I was mentally and physically exhausted, not a good experience"

Finances

"Because of my age (83) and arthritis, I find it hard to shower my husband and care prices are very high. It seems I don't qualify for a carer's allowance (I have had 1 payment of 300, but that's a one off)"

"I'm a full-time carer for my wife for 39 hrs. I get only £67.60 pw. That's all I have to live on"

"My husband is now in a care home. because of COVID-19, I had 1 hour pw for fresh air or a very quick shop. Also after caring for so long was told that I wasn't entitled to carer's allowance. The payments for carer's was not explained to us. We received, out of the blue, 4 invoices. it took every penny we had in the bank to pay them"

"I received a Social Services carers grant of £300 last winter and appreciate this, as it helped me to have a much-needed holiday in a hotel with my husband."

"In many ways were fortunate we have insurances and so financially we have been able to convert our property and undertake works required. I do feel it's slightly insulting, I don't qualify for carer's allowance just because I go to work one morning a week (frankly, for my mental health and retain independence). I cannot earn enough money per hour to cover the cost of extra care (D has to have 2 carers at a time). As it is we are paying just under £1,000.00 pm privately for carers Mon-Fri, 1 hr in the mornings"

"We struggle financially day-to-day as we have a one wage family"

"I cannot earn enough money per hour to cover the cost of extra care"

"I shall be retiring so financial circumstances will change for the worse. We will have to review the amount of private care provision we can afford"

"I also live with mum meaning I would be without a home once mum sadly passes. I have made the decision to give up a good / well paid job in order to care for mum full-time myself. This is going to be a difficult financial period for me but feel there is little option"

"24/7 without ANY BREAK! I am 77 yrs. old caring for an 80yr old with Dementia and multiple health problems. I will continue to care for him because of the cost of any help"