

Healthwatch Hammersmith & Fulham – Carers Project

Part 1 – Main report



Contents

Section	Page number
Introduction and background	3
Key findings	12
Identifying as a carer	13
Carers Assessment	17
Physical health and wellbeing	20
Mental health and wellbeing	23
Financial impact	24
Quality of life	27
Accessing basic healthcare	29
Appendices	33



Introduction and background

About Us

Healthwatch Hammersmith & Fulham (HW H&F) is an independent consumer champion for local health and social care services. We help local people to voice their views and opinions about the services they use in order to improve them and enable them to meet service users' needs.

At HW H&F, we:

- Collect feedback from the public
- Produce reports that highlight good practice and make recommendations for improvement
- Present these reports to those involved in the commissioning, provision and scrutiny of health and social care services.
- Share the views of local people with Healthwatch England to help them carry out their work as the national champion.







Background

The growing number of unpaid carers and the significance of their contributions to health and social care has been acknowledged by both national and local government.

2008 - The UK Government published their National Carer Strategy, a 10-year plan to achieve universal recognition for carers and support them to live a well-balanced life between caring role and life outside caring.

2014 - The Care Act 2014 sets out local authorities' duties when assessing people's care and support needs. The Care Act gives clear guidance on the individual journey from the referral to the support plan, which includes screening, assessment and determination of eligibility.

2016 - The Department of Health conducted an evidence call-out through surveys, focus groups, and information gathering from relevant organisations and stakeholders to find out how support for carers can be improved. The report highlighted the need to:

- Improve the identification of unpaid carers
- Recognise the diversity of carers
- Provide information in a variety of formats
- Give consistent, good quality respite care
- Give carers the appropriate amount of financial support that recognises the time and effort put into their caring role.

2016 - Hammersmith & Fulham Council published Joint Strategic Needs Assessment (JSNA) 'Housing Support and Care: Integrated Solutions for Integrated Challenges' which acknowledged that only a minority of unpaid carers in H&F are known to the adult social care services and are therefore not having their needs assessed and addressed. It goes on to state that it is important that carers are supported for them to continue to provide unpaid care without impact on their own health and wellbeing.

2018 - The UK Government published the Carers Action Plan for 2018-20 that set out the plan to address the improvements needed.

2022 - Based on the acknowledgments of both the national and local governments that improvements are needed in the support provided to unpaid carers, Healtwatch Hammersmith & Fulham (HW H&F) set out to find out the following in order to identify local carers' needs specifically:

- How well the current carers assessment process in H&F works in identifying carers' needs
- How satisfied carers are with the outcomes
- How satisfied carers are with different aspects of their lives (physical and mental health and wellbeing; social life; work and life balance)

In addition to this, after having heard from local carers about their poor financial wellbeing and its impact on access to basic health care such as eye and dental care, HW H&F decided to investigate this further by asking local carers how affordable the following are:

- Eye care appointments
- Dental appointments
- Travel to health care appointments
- Repeat prescriptions

Methodology

Online Survey on Survey Monkey

- Responses collected over a period of 4 months (Jan-Apr 2022)
- Carers offered the option of filling in the survey over the phone or completing a paper copy and posting it back with a Freepost envelope.
- The survey was shared with:
 - Community and voluntary organisations such as Carers Network, Age UK H&F, Nubian Life Resource Centre, and ParentsActive
 - West London NHS Trust's Carers Council
 - Schools through the H&F Council's School e-bulletin
 - H&F Youth Council
 - HW H&F Social media accounts
- 141 online responses and 9 completed paper surveys

Methodology

One to One Interviews

- 9 structured interviews were conducted over the phone, online or face-toface.
- Questions included:
 - When did you first identify yourself as a carer
 - What kind of help would be most useful to help you maintain or improve your physical/ mental health and wellbeing
 - As a carer, have you ever struggled to afford basic health care services, such as dental or eye care appointments, or prescription medication
- The interviews were recorded and transcribed and some have been turned into lived experience narratives. Together with comments and quotes these have formed a 'Part 2' Report titled 'Carer Experiences'. This can be found on our website under the reports section.

Limitations

Low response rate from the following groups:

- Young carers (aged 24 or younger)
- Carers aged 25-49
- Male carers

A full breakdown of demographics can be found in Appendix 1.



Key Findings



The case for investing in carers

Half of the respondents we heard from said they care for 50 or more hours a week - these include respondents who reported spending either 50-100 hours or 100+ hours a week on caring duties

If carers were paid the minimum London Living Wage (£11.95), this would translate to **£597 per week per person** for someone who cares for 50 hours a week

In financial terms, it would mean that those 63 people who responded to our survey saying they look after someone for at least 50 hours a week are worth at least £1.9 million per year.

Recommendations

We recommend an annual carers registration awareness campaign.

We recommend a review of the carers assessment form in respect of individualisation/ personalisation.

We recommend a clear mental and emotional wellbeing support offer for carers

We recommend a clear and vocal offer of support to Carers around accessing benefits and gaining employment.

We recommend a clear and accessible offer is communicated around statutory rights/eligibility for both support and respite, and a local offer that goes above and beyond the minimum.

We recommend clear tangible measures are outlined for how carers aged 25-49 year olds can be better supported, in general, and specifically in accessing and paying for dental care, eye care, prescriptions, travel to health appointments.

The following slides detail each recommendation in turn, providing further information. Additional detail, and charts can be found in the appendices.

Key recommendation 1

Identifying as a carer does not come easily. It is a gradual process, often taking years. We recommend an annual awareness campaign communicated through primary care, hospital sites and local authority publications with a particular focus on underrepresented communities.

- The majority of carers have not had a carers assessment (59%) and almost half are not registered as a carer with the Carers Network or Hammersmith & Fulham Council (45%)
- People register as a carer late in their caring journey. As the patient, or carer's own health deteriorates with age, and the burden of caring increases over time, likelihood to have registered and had an assessment increases

Age	% registerd as a carer	% had a carers assessment
25-49	41%	27%
50-64	42%	37%
65-79	58%	42%

- Those from Asian/Asian British ethnic background are most likely to have registered as a carer (50%) and most likely to have had a carers assessment (75%)
- Those from White Other ethnic background are least likely to have registered as a carer (58%) and had a carers assessment (74%)
- Those with the highest number of caring hours each week were more likely to have registered and had an assessment

Caring hours a week	% registered as a carer	% had carers assessement
0-19	11%	28%
20-49	47%	37%
50-100	62%	38%
100+	66%	52%

- When asked why they have not had a carers assessment 47% of people said they did not know about it. Many indicated 'other' as a reason, and when probed, half of these said they were waiting for someone to contact them about the assessment.
- A significant number also reported not being able to find information about the Carers Assessment

Carers Assessment

Key recommendation 2

The Carers Assessment is helpful for those that have it and the Carers Network provide a compassionate service for Carers, supporting them through the assessment.

The assessment delivers well on financial support, but we recommend a review of the assessment form in respect of individualisation/ personalisation and an improved offer around mental health and emotional support, respite, medical equipment, home care, and information on a range of key areas.

Carers Assessment

- Almost 3 in 4 people said that they found the assessment either 'helpful' (33%) or 'very helpful' (39%)
- Those who had the assessment via the Carers Network reported back more favourably than those who had it through Hammersmith & Fulham Council
- Positives of the assessment included having a good experience with the assessor; getting good guidance and advice on entitlements; receiving a better understanding of what it means to be a carer; receiving recognition for all their caring work; talking to someone who cares and genuinely listens
- Negative feedback on the assessment included dealing with a dismissive assessor and an "outdated" assessment form that did not address their specific needs. Poor communication when trying to book the assessment and get a copy of the assessment report were both reported.

Carers Assessment

- 82% who did the assessment, qualified for help
- The majority of help received as a result of the carers assessment was financial (74%)
- Further information and advice also featured substantially (23%)
- Other help recevied as a result of the carers assessment included mental health/emotional support, respite, medical equipment, home care, but this was all at much lower levels (all 3-6%).
- Carers want an individualised assessment, less box ticking, and identify the one-to-one aspect of the assessment as crucial to achieving this personalisation. A follow up call and check in would also be appreciated
- People would like more information on respite care, exercise, loneliness, relationships, rights and responsibilities, and accessing help

Physical health and wellbeing

Key recommendation 3

Many carers themselves suffer from a long-term health condition and report poor physical health and wellbeing.

Although questions in this section were around **physical** health, carers wanted mental and emotional help first and foremost. We recommend a clear mental and emotional wellbeing offer for carers.

In addition, we recommend that the services/support offer around physiotherapy, respite, help with caring duties, and access to a gym/help with exercise are all reviewed.

Physical health and wellbeing

- 48% of carers have a long-term health condition that they have to attend regular health appointments for.
- 56% take regular medication for a long-term health condition.
- 41% of carers are not satisfied with their physical health.
- Carers from 'Asian' ethnic backgrounds are most happy with their physical health.
- Carers from 'White British', 'White Other' and 'Black' ethnic backgrounds, report most dissatisfaction with their physical health (47%, 46% and 40% respectively).

 Carers aged 25-49 report the most dissatisfaction with their physical health.

Age	% unsatisfied or very unsatisfied with physical health
25-49 (n.22)	54%
50-64 (n.43)	40%
65-79 (n.12)	25%

Physical health and wellbeing

 When we asked carers what help would be most useful the top three themes were:

Most useful type of help	%
Mental health/emotional	25%
Physiotherapy/other medical	17%
Respite	13%

Mental Health and Wellbeing

Key recommendation 4

Carers struggle with their mental health and wellbeing and would benefit from therapy/counselling support.

We recommend the mental health support offer for carers is reviewed and additional funding opportunities and partnerships are sought to improve access to quality, regular and ongoing therapy/counselling support.

Mental Health and Wellbeing

- 36% of carers are either unsatisfied or very unsatisfied with their mental health and wellbeing (24% and 12% respectively).
- 31% are satisfied or very satisfied (25% and 6% respectively).
- Those aged 25-49 are most dissatisfied
- Those from the 'Asian' ethnic group are most satisfied
- When asked what support they want, the top answer was therapy/counselling (31%), followed by financial support (17%)
- When asked about anything else to enable a good quality of life, mental health/emotional support was second top answer.

Financial impact

Key recommendation 5

Many carers struggle financially and want financial support/ support with benefits and support with employment.

We recommend a clear and vocal offer of support to Carers around accessing benefits and gaining employment.

Financial impact

- 24% of carers we spoke to are unemployed
- 64% do not receive a Carers Allowance
- 39% of carers are unsatisfied or very unsatisfied with their financial situation
- 41% of those suggest that financial support/support with benefits would be most useful to them. This is closely followed by support to access employment (20%)
- By ethnic group, Asian/Asian British are most satisfied with their financial situation and White British and Black/Black British most unsatisfied
- By age, 65-79 are most satisfied with their financial situation and 25-49 most dissatisfied

Quality of life

Key recommendation 6

Carers struggle to balance their caring with work/ school/social life and would like more support and respite for the cared-for person to allow them to benefit from a reasonable quality of life.

We recommend a clear and accessible offer is communicated around statutory rights/eligibility for both support and respite, and a local offer that goes above and beyond the minimum.

Quality of life

- 45% of carers are unsatisfied with the balance of their caring role and work/school/social life
- 25-49 year olds are most dissatisfied
- There is dissatisfaction across the board for ethnic groups, with the exception of Asian/Asian British
- Over a quarter of carers want practical help and support for the cared for person to enable them to have a good quality of life

Accessing basic health care

Key recommendation 7

Some carers can't access basic healthcare because of the cost eg public transport to get to appointments, and dental fees. Impact is highest for working age carers (25-49) who are not eligible for age related support such as the Freedom pass and free prescriptions. Not being able to look after their own basic health, and access regular checks could impact their ability to care in the future.

We recommend clear tangible measures are outlined for how this age group of carers can be better supported to access and pay for dental care, eye care, prescriptions, travel to health appointments.

Accessing basic health care

- 43% of 25-49 year olds cannot afford to buy petrol or pay for public transport when travelling to health appointments.
- 25-49 year olds are the only age group that reported being unable to afford to pay for prescriptions (18%)
- 32% of the same age group report not being able to pay for dental services (vs 10% for 50-64 age group)
- 29% of the same age group report not being able to afford paying for eye care (vs 7% for 50-64 age group)

Accessing basic health care

- Overall many carers suggested that they do not struggle with paying for basic healthcare. However, this was predominantly seen in older age groups and is largely due to age related benefits such as the Freedom Pass, entitlements to free prescriptions, free NHS Dental care and free NHS eye Care.
- Given the findings for working age carers it is clear these benefits make a big difference for carers, and those who can benefit from them are at a great advantage, within what remains a challenging set of circumstances for unpaid carers.
- Other barriers to accessing healthcare and appointments included a lack of help with caring duties and just the daily sacrifice carers have to make, in putting the cared for first, often to the detriment of their own health.

For more information

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Appendices



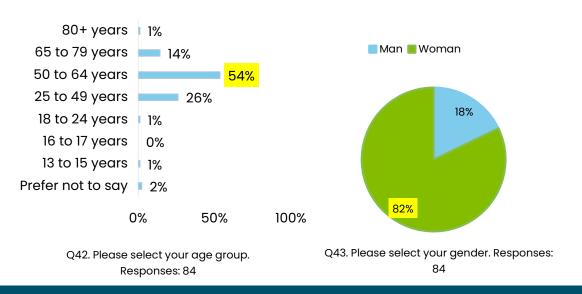
Appendix 1 – Equality Monitoring Data

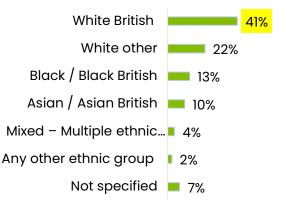
Majority of the responses came from

- Women (82%)
- People aged 50 or older (69%)
- White British (41%).

Our survey responses from minority ethnic groups collaborate and correlate the data on carers' ethnicities from the 2011 census¹. (See next page for demographics from the 2011 Census.)

It should also be noted that only around 57% (n.84-85) of the respondents answered the Demographic questions.



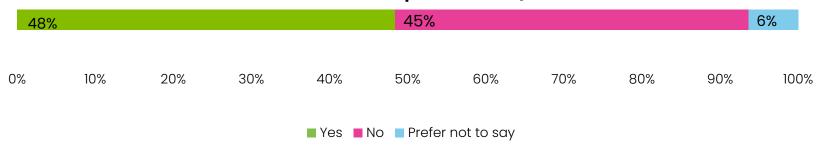


0% 20% 40% 60% 80% 100%

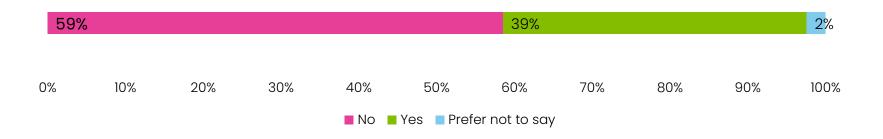
Q44. Please select your ethnicity. Responses: 85

Appendix 2 - Identifying as a Carer

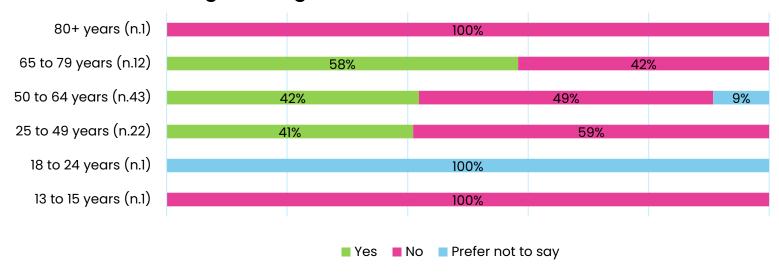
Q3: Are you registered as a Carer (i.e. with Carers Network or H&F Council? Responses: 126)



Q4: Have you had a Carer's Assessment? Responses: 126



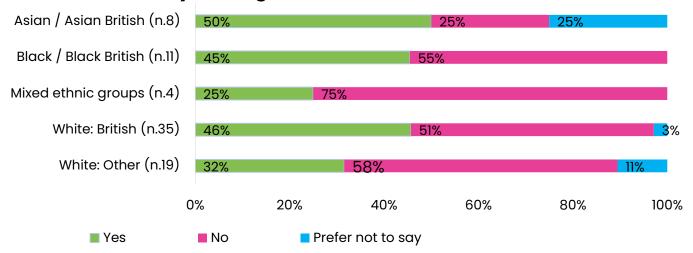
Age vs. Registered as a Carer



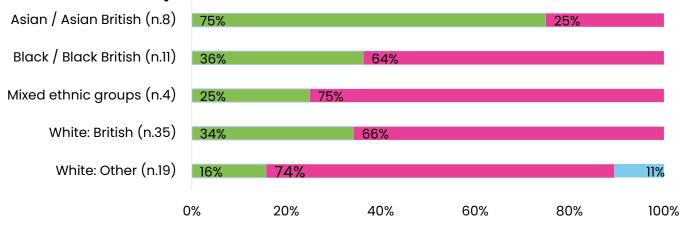




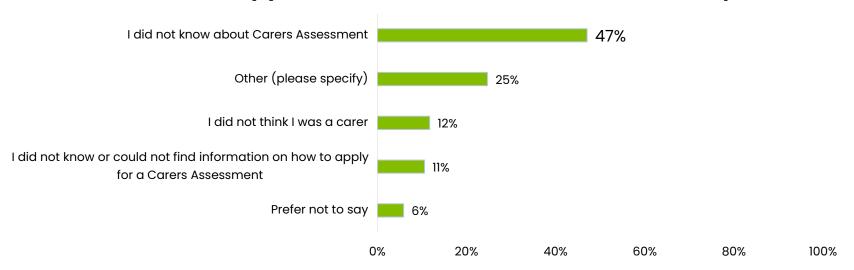
Ethnicity vs. Registered as a Carer



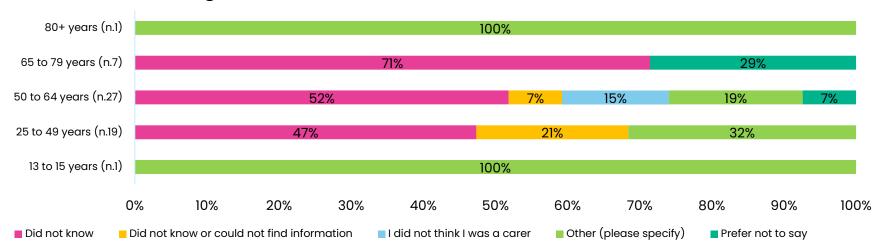
Ethnicity vs. Had a carers assessment



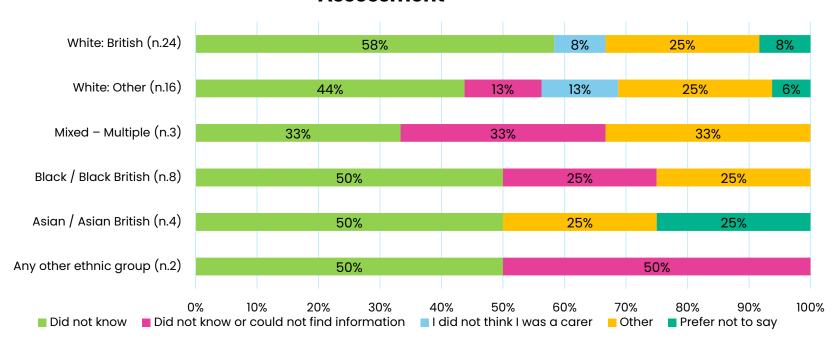
Q5: Why you have not had a Carer's Assessment (Responses: 85)



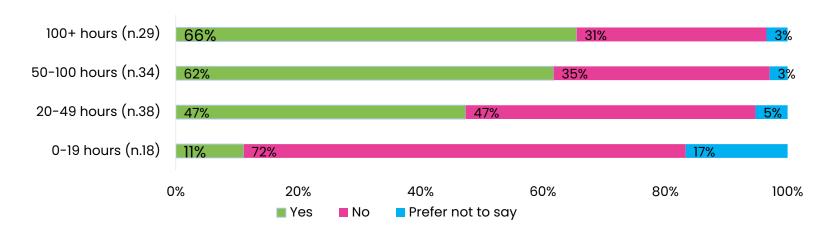
Age vs. Reason not had a Carers Assessment



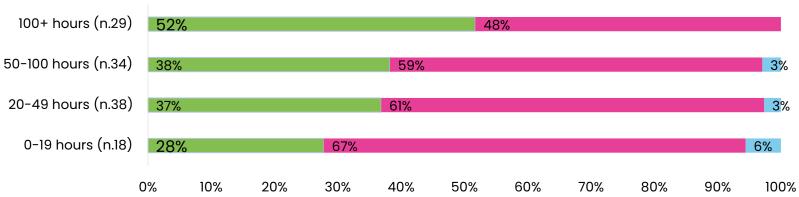
Ethnicity vs. Reason why they have not had a Carers Assessment



Q2. Hours spent caring vs. Q3. Registered as a Carer



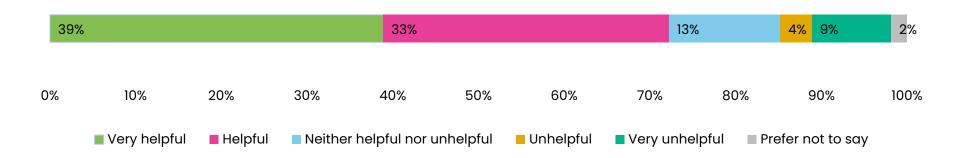
Q2. Hours Spent caring vs. Q4. Had a Carers Assessment



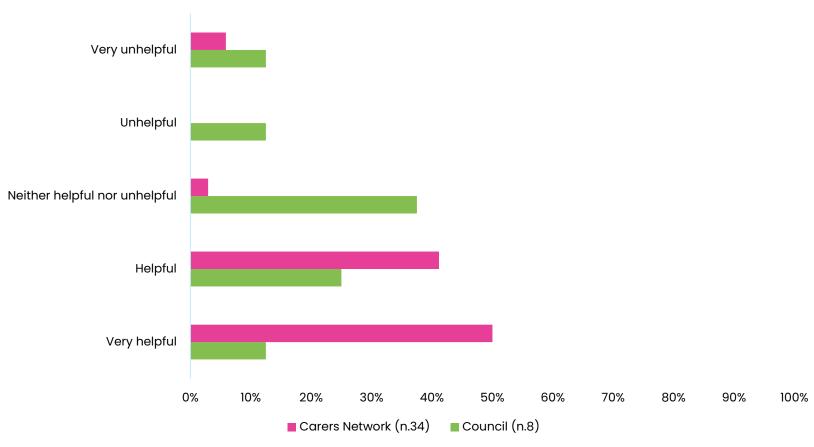
Appendix 3 - Carers Assessment

This section of the survey was directed to those respondents who reported having had a carers assessment (n.54). It should be noted that less than a third of the total number of respondents to the survey completed this section.

Q7: Overall, how did you find the Carer's Assessment?



Assessment conductor vs. Satisfaction level



Theme	%
Understanding Assessment Conductor	28%
Guidance/Advice	22%
Support	22%
Better Understanding of Role	11%
Understanding of specific needs	11%
Recognition of Work	8%
Didn't address specific needs	8%
Dismissive	8%
Poor Communication	8%
Outdated	8%

As a follow up to the previous question, we asked the respondents to provide further details on why they had found the assessment helpful or not helpful. 36 people gave us further information and below we have included some positive and negative themes.

Positives:

- + A good experience with the assessor
- + Guidance and advice on what they are entitled to and how to overcome problems
- + A good way to clarify and understand what is involved in the role of a carer
- + Important to get recognition for the work they do
- + someone who genuinely listens to their needs

Negatives:

- Did not address their specific needs
- Person conducting their assessment was dismissive towards their circumstances
- Assessment outdated
- Poor communication when trying to get a copy of the assessment report or booking an assessment in the first place

Quotes

Positive Themes and Selected Comments

Understanding Assessor

"I feel that the advisors at The Carers Network go a long way to build and maintain a rapport with their clients. I have been registered with them for about seven years, so I have known them for several years. It is almost as if they are family. So, this makes my assessment much more comfortable than if I were speaking to someone I barely know."

Guidance and Advice

"The Carer's Network Support Worker who carried out my Carer's Assessment was very helpful and supportive. She assisted with my application for a Personal Budget and explored the possibility for my parents to apply for Pension Credit."

Supportive

"Because they're in regular contact with me they know exactly my caring role. And they know me well. And it is good to have somebody that understands and is so supportive and shows so much empathy and compassion."

Better Understanding of role

"It was helpful as an introduction to being an unpaid carer - and made me realise the extent of the situation I am in - caring for my Mum."

Negative Themes and Selected Comments

Didn't address specific needs

"It was marginally helpful, but not very practical as it did not cater for young women or middle-aged dynamic woman. I have ongoing issues with care."

Dismissive

"[...]During the carers assessment I was not listened to, and both my needs and my fears were dismissed by the assessor. I cried for 4 hours after the assessment: this was the first time I had had to explain my situation in detail to a stranger, and what I had to describe was having my entire career and social life take away from me - the assessor reacted as if this was a perfectly normal and manageable situation and indeed expressed incredulity that I was devastated not to be able to be active any more in the career I love (at one point she said, "oh well, it's only a job - and after this meeting we can pop you on benefits, don't worry!). [...] All in all it was a very disturbing experience which had very negative effects on my mental health at an already distressing time."

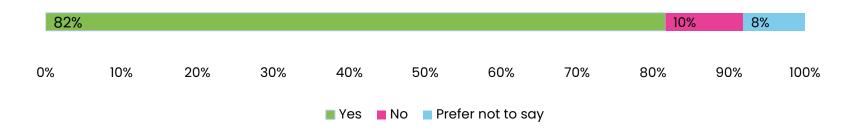
Outdated

"My carer's assessment was many years ago and I did not have any particular needs at the time. Things have changed over time and I am more constrained by my caring responsibilities now and feel the assessment is out of date."

Poor communication

"It took me 2 years to get a Carers Assessment. Carers Network had a backlog & couldn't conduct one & I was passed to Hammersmith & Fulham to do it instead who told me that they didn't do them & it was Carer's Network. After going back & forth - H&F eventually did one after 2 years."

Q9: In your Carer's Assessment, did you qualify for help?



Q15. Please list the help you were offered based on your Carer's Assessment?

Theme	%
Financial help	74%
Further advice & information	23%
Mental Health/Emotional Support	6%
Respite	6%
Medical Equipment	3%
Home Care	3%

Quotes

We asked respondents to share any suggestions or ideas on how the carers assessment could be improved. In total, 11 people shared their ideas.

"As long as Carers network are doing the assessments it needs to be personalised and they need to understand and know you and the person you're caring for. Not just a form it's about the one-to-one they give you."

"Be less a case of box ticking and more individual."

"Better trained social workers, who understand the needs of a child changes as they get older."

"There could be more information about rights and responsibilities that you might not have thought about, maybe a booklet with information/ useful telephone numbers etc; how to access help if your circumstances change."

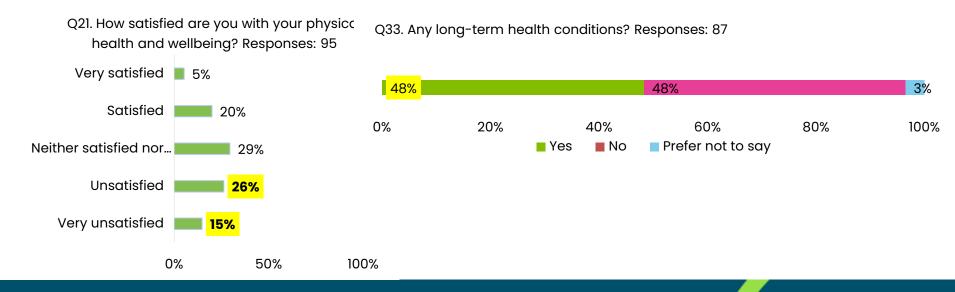
"[...]Maybe a follow up call would be good - as at the time of the assessment - was in a bit of a state - sorting things out - and adjusting to the situation."

Appendix 4: Physical Health and Wellbeing

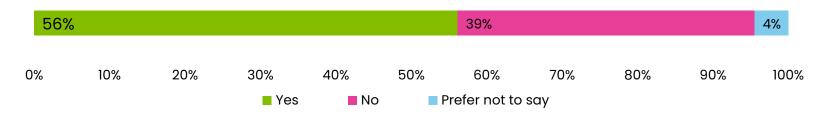
In this section of the report, we will explore how satisfied carers are with different aspects of their lives. We also asked the respondents to tell us in their own words, what kind of help would be most useful to them. During our analysis, we identified key themes from the respondents' answers and included the six most identified themes. This means that the percentages do not necessarily add up to 100% if there were more than six themes identified.

Overall majority of the respondents reported being **unsatisfied with their physical health and wellbeing** with 41% of respondents saying they are either *'Unsatisfied'* or *'Very unsatisfied'*.

Nearly a half (48%) of the respondents said they have a long-term health condition that requires them to attend regular health appointments.



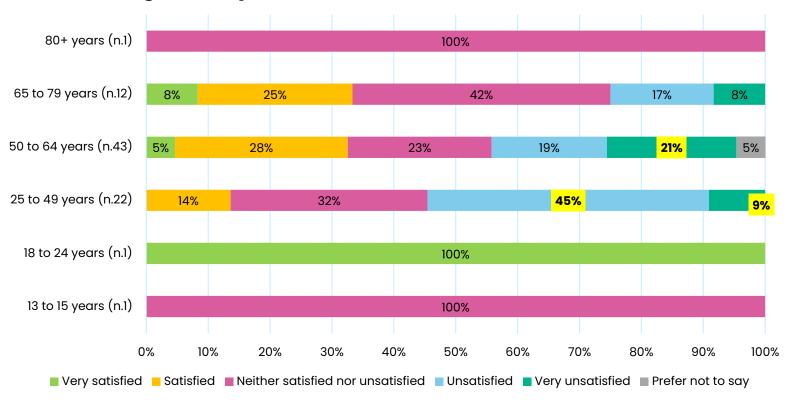
Q35. Do you have any long-term health conditions that require you to take medication regularly?



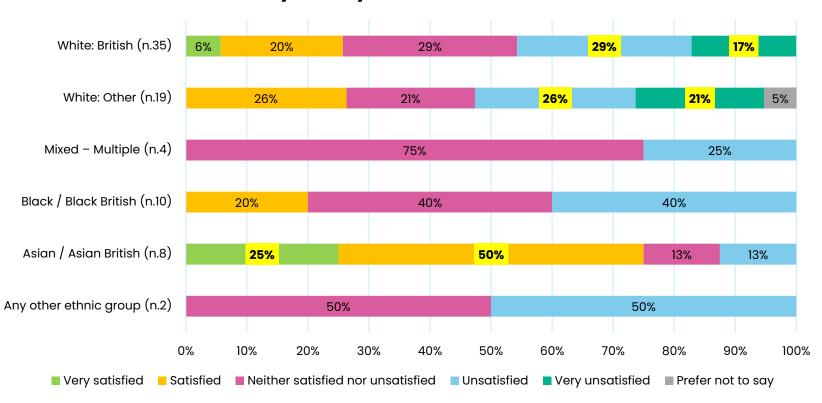
Q22. What kind of help do you think would be most useful to you?

Theme	%
Mental Health/Emotional	25%
Physiotherapy or other medical help	19%
Respite	17%
Help with caring duties	13%
Information&Advice	10%
Gym/Help with exercise	8%

Age vs. Physical Health Satisfaction



Ethnicity vs. Physical Health Satisfaction



Quotes

Themes and Selected Comments

Mental/Emotional Help

"I would like therapy that would enable me to talk about things that affect me daily & would like a group that can allow younger carers an outlet to socialise."

Physiotherapy or other medical help

"But own physical health we have to explain constantly to every profession. So not only have we had to look after someone that is ill and in poor health mentally or physically. We have to literally fight for absolutely everything. I'm quite often our own health suffers because we do not time or energy. We should automatically get an occupational therapist and be checked for and physical health as a priority. If we are ill who cares for the person we care for."

Respite

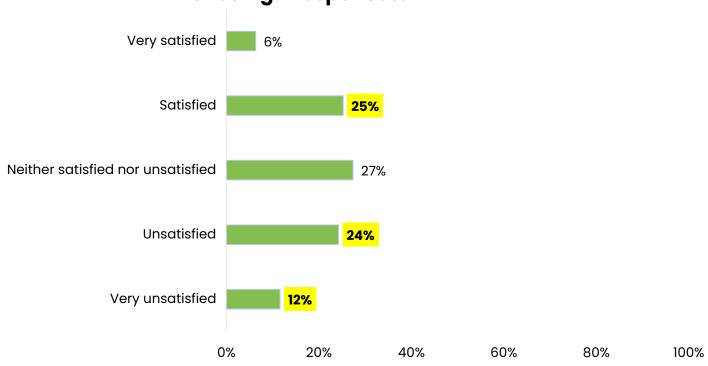
"Being able to socialise with other teenagers like me who care for family members. Having breaks where I am not providing support but being a teenager."

Help with caring duties

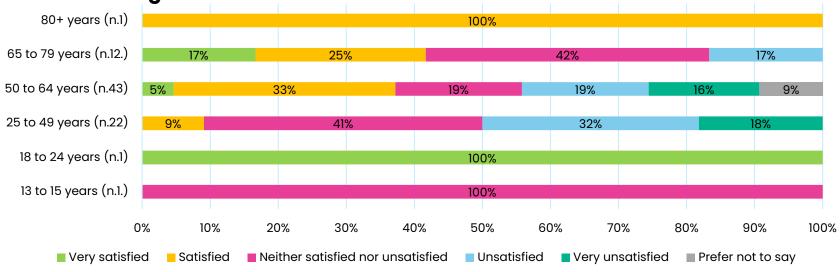
"Help with cleaning and looking after my mum when things get a little more tough for her ."

Appendix 5: Mental Health and Wellbeing

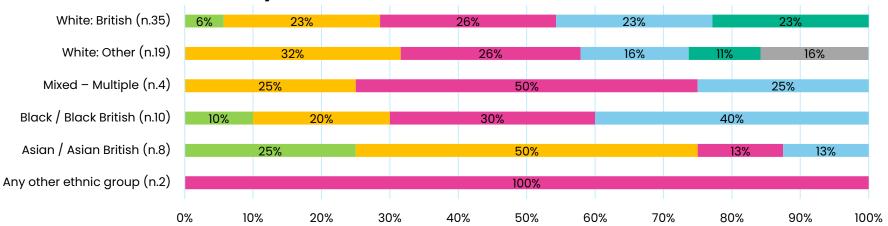
Q23. How satisfied are you with your mental health and wellbeing? Responses: 95



Age vs. Mental Health Satisfaction Level



Ethnicity vs. Mental Health Satisfaction Level



Q24. What kind of help do you think would be most useful to you? Responses 42

Theme	%
Therapy/Counselling	<mark>31%</mark>
Financial support/concessions	17%
Respite	10%
Someone who listens	10%
Activities/courses	10%
Help with caring duties	7%

Quotes

Themes and Selected Comments

Professional Help

"I would like to have some sessions with an experienced therapist."

Financial support/concessions

"As a carer paid or not paid we are not recognised as a profession just somebody invisible. Even with concessions on an adult education course to give us a little time out. And do something completely different from what we do seven days a week constantly. Is out of the question due being a carer you normally on a very low income. To go to the hairdressers get our nails done give ourselves an hour. Just to feel better in ourselves and more relaxed. Unable to cope again we don't get any discounts so that is out of the question as a luxury. Hammersmith and Fulham council don't value Carers."

Respite

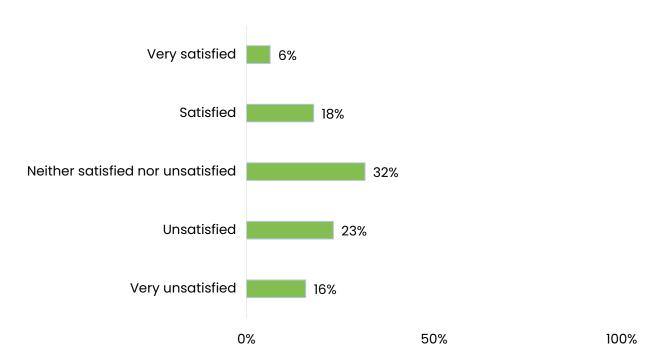
"I look after my severely disabled parents who require round the clock care. I have no assistance, respite or opportunity to take a break. I am exhausted and severely sleep-deprived due to having to administer medication at various intervals at night. Opportunity for free wellbeing sessions such as fitness or exercise (Yoga, Pilates or free swimming lessons for those who are unable to swim) would be really useful. I know that some provision exists for the elderly, but younger unpaid carers are left out. Opportunity for a "breather" through access to activities supporting wellbeing would be invaluable."

Someone who listens

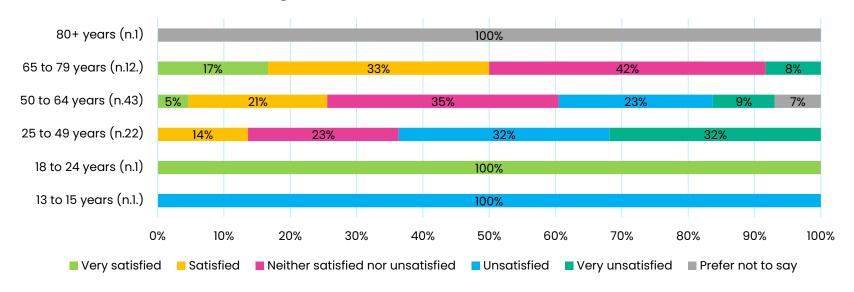
"The ability to talk to others about the responsibilities of being a carer. Some practical help with the 24/7 of being a carer."

Appendix 6: Financial Situation

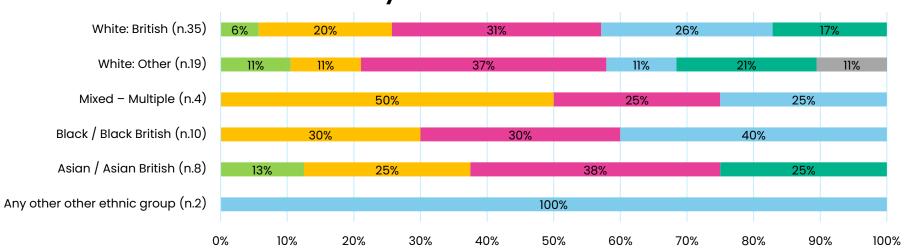
Q25. How satisfied are you with your financial situation? Responses: 95



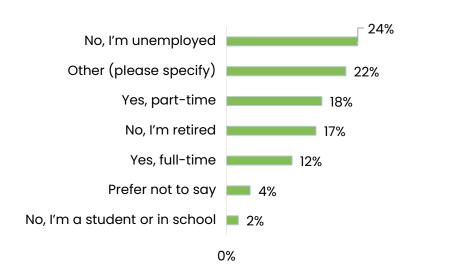
Age vs. Financial Satisfaction Level



Ethnicity vs. Financial satisfaction levels



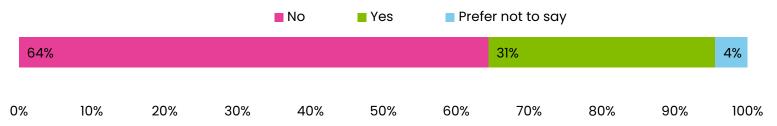
Q32. Are you currently employed? Responses: 90



100%

Q30. Do you receive Carer's Allowance? Responses: 90

50%



Q26. What kind of help do you think would be most useful to you? Responses: 44

Theme	%
Financial support (Benefits)	41%
Employment / to work more hours	20%
Information and Advice	9%
To be recognised as a worker	7%
Practical help	5%
Help managing finances	2%

Quotes

Themes and Selected Comments

Financial Support (benefits)

"As a carer I need to be around for my son. Due to my own issues I am unable to work enough to bring in enough money so it's a constant struggle so help with bills and transportation is vital for those in my position."

Employment / Ability to work more hours

"For me it's hard to find a job that is flexible around my caring responsibility and studies, I'm not sure how carers network could help with this."

Information and Advice

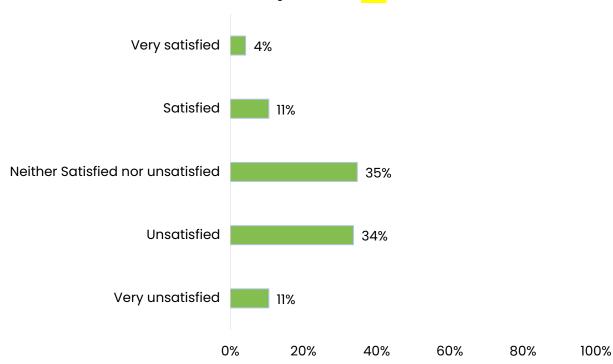
"Would be useful to have guidance on what sort of support is available for carers and for the person receiving the care too.

To be recognised as a worker

"[...]Unpaid carers in receipt on Carer's Allowance only are not entitled to any other help and are excluded from the provisions of the minimum living wage despite the enormous economic contribution we make in society. Given the economic contribution by unpaid carers with seriously demanding caring roles such as mine, what would really help would be parity with the rights and provisions granted to other benefit recipients who do end up with considerably higher income which exceeds the Carer's Allowance, and yet are entitled to free prescriptions, eye and dental care as well as subsidised travel card. Unpaid carers desperately need meaningful recognition and should be recognised with a provision for the minimum living age."

Appendix 7: Quality of life

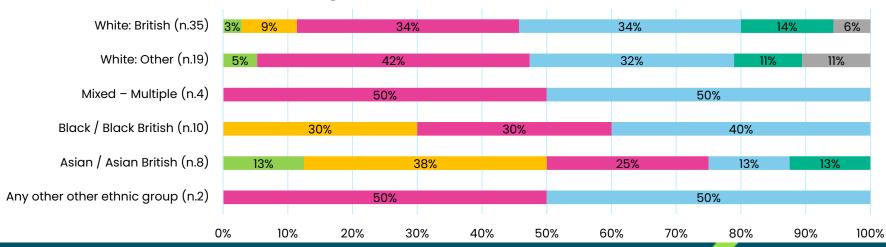
Q.27 How satisfied are you with your ability to balance your caring role with your work life / school life / social life? Responses: 95



Age vs. Work/School/Social Life Balance



Ethnicity vs. Work/School/Social Life Balance



Q28. What kind of help do you think would be most useful to you? Responses: 46

Theme	%
Support for the cared for person	39%
Respite	30%
Financial support	2%
Information&Advice	2%
Flexible working	2%
Emotional support	2%

Q29. Is there anything else that has not already been mentioned that you feel would help you to have a good quality of life? Responses: 40

Type of help	%
Practical help/ Support for the cared for person	28%
Mental health/emotional support	15%
	100/
Respite	13%
Recognition	10%
D = = = = = = = = + = = = + = = = = =	00/
Peer support/activities	8%
Financial support	8%

Quotes

Support for the cared for person

"I need someone to keep my husband who I care for happy and occupied sometimes so I can have some space to go out alone. I've tried to access help but it has been difficult during the pandemic."

Respite

"Currently working from home - but really have no real time to myself or for socialising. Have to try and get a family member to come and stay with Mum - but proves difficult sometimes. I am trying to follow up respite care for me with social services - but this is proving hard - and with so many calls to make - is very frustrating. Each time you are told something different - so not really sure of my rights."

"I'd like to meet other Carers but would need to take my husband with me. It would be fantastic if there was a meeting place for people with dementia and their carers with experts to entertain those with dementia so the carers could spend time together."

Mental health/emotional support

"Support for myself to listen to me and how caring for my daughter affects me as a carer."

Practical help/Support for the cared for person

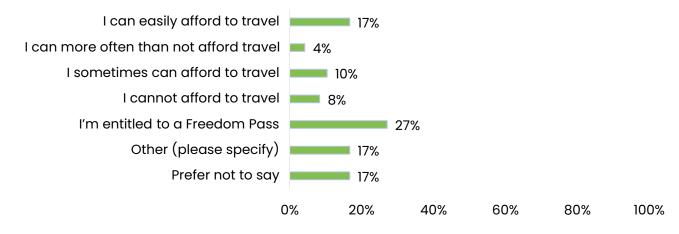
"Creating sustainable and secure living arrangements that I can afford to pay for/ help with accessing educational and career opportunities for my child."

Recognition

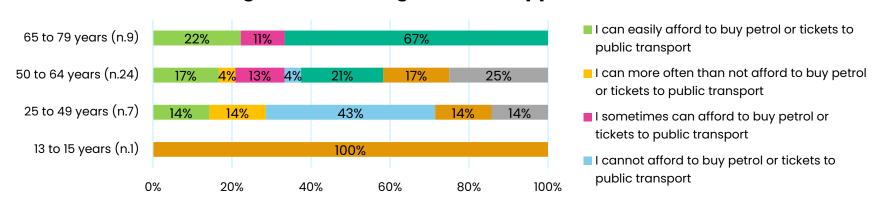
"To be recognised throughout the borough. And when dealing with the benefits that is all recognise that you are a carer and you have your own health issues. I seem to spend my life explaining and filling out forms and justifying my role and my health."

Appendix 8: Accessing basic health care

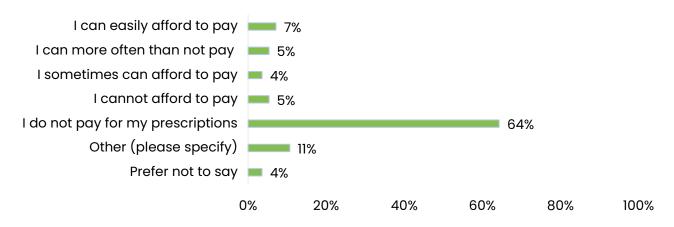
Q34. How easy or difficult it is for you to travel to health appointments? Responses: 48



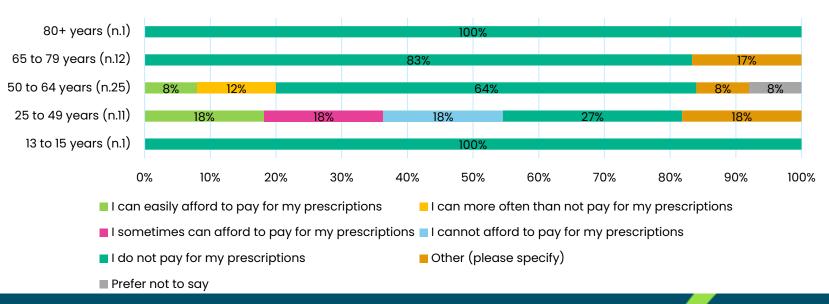
Age vs. Travelling to Health Appointments



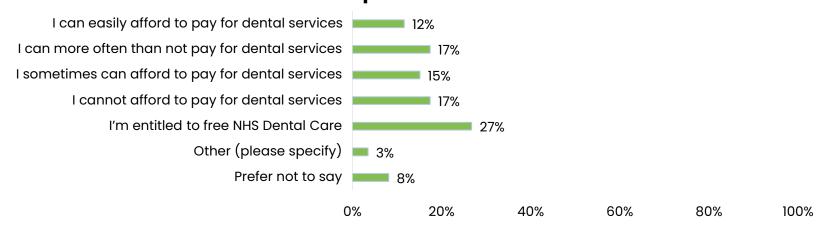
Q36. Can you tell us how easy or difficult is it for you to collect your repeat prescription? Responses: 56



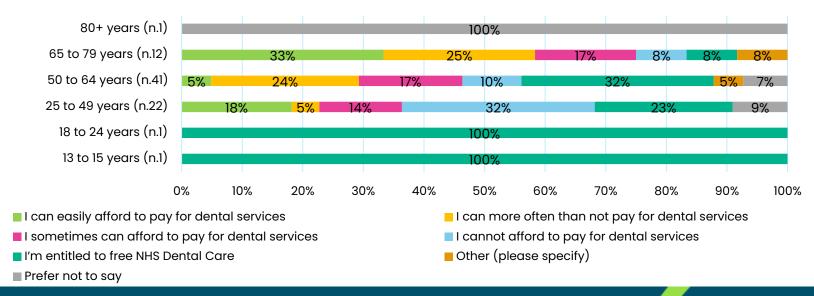
Age vs. Paying for Prescription Medication



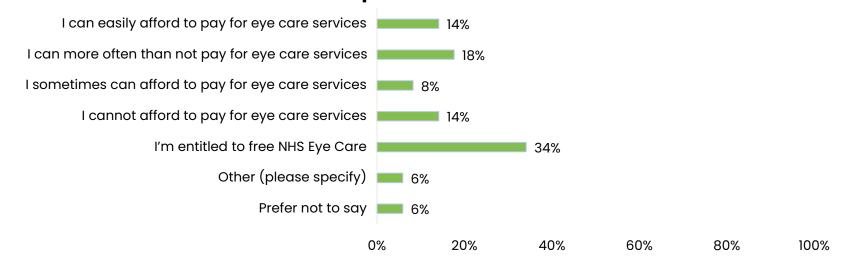
Q37. How easy or difficult is it for you to access dental services Responses: 86



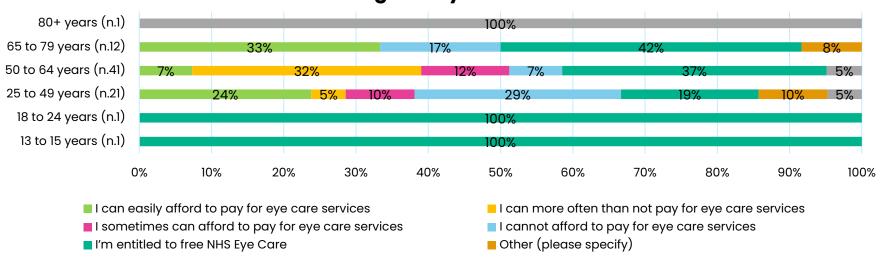
Age vs. Dental Appointments



How easy or difficult is it for you to access eye care services? Responses: 85



Age vs. Eye Care



Q39. Please tell us if there are any other ways that your caring role has made it difficult or stopped you from accessing any health care services that you have needed? Responses: 32

Theme	%
Lack of help with caring duties	16%
Putting cared-for first	16%
Financial difficulties	13%
Lack of time	9%
Covid	3%
307.G	3.0
Peer support	3%

Q40. If your caring role has made it difficult or stopped you from accessing any health care services, what help would you find most useful (i.e., Carers Travel Pass; Expanding free prescriptions, dental and eye care to those who receive Carer's Allowance)? Responses: 33

Theme	%
Dental care	20%
Eye care	16%
Carer travel pass	16%
Financial support	14%
Free presciptions	14%
Respite	9%

Q41. Finally, we would like to ask if there is anything that you have experienced as a carer that has not been mentioned in this survey but you feel would be helpful for us to know? Responses: 45

Theme	%
Better support from social services	29%
Better/More Information & advice	11%
Better support from GP practices	9%
Social isolation	7%
Recognition as a worker	7%
Training	4%

Quotes

Better support from social services

"I think that the social services, child services, GPs have no knowledge about how to support carers and their families. Again, until now I wasn't aware that any carers support was in place. Sadly, I think that this survey will not produce any positive changes."

Better/More information and advice

"I had to do a lot of research to find out what might be available to me and my mum in terms of care and support, e.g. -blue badge -lifeline fall detector -carers assessment -respite care etc. I went several months having no idea about any of it but over time starting googling it all out of necessity and desperation. If I can tell you anything it's this: when someone gets sick, their medical team or GP should ask if they have a carer and then furnish that carer with all available information at the very beginning. It's bad enough having your life turned upside down so any help as early as possible would be well received.

Better support from GP practices

"I previously tried to register as a carer with my GP and was shut down by the receptionist who led to believe this was not an option. It would be helpful if the first people can contact are versed in the services offered by the medical professions and do not gatekeep in a way which prevents eligible people accessing the help they need. Because of this I was initially unable to register as a carer and have my needs assessed."

Social isolation

"It can be an extraordinarily lonely, arduous and often frightening role. Carers need support for all of this and more." "Because your whole world is centred around the person you care for. Their physical and mental health. And it's so unpredictable. Quite often you forget your own appointments for your own medication. Or you have to cancel at the last minute."

"I would definitely benefit from having a carers free travel pass as this would enable me to travel around more often with the person I care for to hospital appointments and shopping trips etc."

"What support seems to be available in the borough seems to be aimed mostly at carers who – to put it bluntly – have already given up hope. For those of us who desperately want and need to be part of the big outside world – there seems very little. This is reflected in the activities offered by Carers' Network. I totally accept that it is a volunteer organisation, they are doing their best, and I imagine they provide great support and amazing comfort to some carers. But I sort of want you – and them – to know that, when I explained that I am a professional writer with a good career but I am unable to take up offers of work because of my caring duties, and that that was causing me great distress, the person from Carer's Network offered, in response, to help me fill in a form so I could sign up for a session where a volunteer could help me write a poem about my feelings. And I want you to know that that moment was the closest to suicide I have come in this horrible process. I would love to participate in a current affairs discussion group that helped me learn more about, say, what's going on in Ukraine, or have the opportunity to learn a new skill or language – to be honest, to take up anything that would be a genuine challenge. As soon as you become a carer, it feels everything available to you assumes you are of limited intelligence, capability, ambition or curiosity. That is not only not true – it is desperately psychologically damaging.

"Just to say thank you for the support the Carer's Network has given. It really made a difference to my life and I'm going to continue working on looking after myself. I know that is essential for me to help care and support my son."

"1) It's good to have social & financial supports for carers. It may be more beneficial also to provide some carers' training course enabling carers to provide right care for both carers and those they care for. 2) To organise / encourage ex-carers to pass on their own experience to those new."