

Survey of Adult Carers Results 2016/17



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1. **Purpose:** to present an overview of the 2016-17 Carers Survey Results in Tower Hamlets, highlights of trends by equality groups and benchmarking against results for London and England.

2. Executive summary

The Carers Survey 2016/17 was sent to 754 Tower Hamlets carers who have received support from Tower Hamlets in the last 12 months, and was completed by 205. The Carer Survey is sent out every two years. The last survey took place 2014-15. This report includes an analysis of the results as compared with the last Carer Survey.

Satisfaction: carer satisfaction has increased significantly over the last three years with 64% of respondents stating they are extremely / very or quite satisfied with support or services (compared to 56% in 14/15).

Carers assessments: the majority of respondents stated that they agreed they were treated with respect (66%) and 88% reported that they found the assessment quite or very useful (an increase of 8% from 14/15).

Time spent caring: similar to the last survey results, most respondents have been caring for more than 5 years (62%, down 2% from 14/15) and 64% say they care for more than 50 hours a week.

Quality of life: as in previous survey results, there is a correlation between the number of hours spent caring each week and quality of life. Respondents caring for 20+ hours per week who state they have a good quality of life is 34%, compared to 21% for 50+ hours. Carers rated their overall quality of life in the survey as 33% reporting a 'good' quality of life (down 1% from 14/15), and 56% as 'alright' (up 2% from 14/15).

Aspects of quality of life: most carers reported that they cannot do enough of the things they value or enjoy with their time (58%), do not have enough control over their daily lives (61%), do not have enough social contact (51%) and do not have enough encouragement or support (55%).

Impact of caring: 61% of survey respondents reported that caring has a 'big' impact on their life (60% in 14/15).

Work and caring: 46% of carers report that they are not in work due to caring (an increase from 40% in 14/15) and 8% say they are in work and feel supported by their employer, however 3% say they are in paid work and do not feel supported by their employer.

Being involved in discussions: 53% of respondents reported that they are always / usually involved in discussions about support or services for the person they care for (up by 4%), and 7% say they never feel involved (down by 2%).

Support service used by carers: the most common forms of support used by carers are information and advice (59%, up 7%), carer groups / talking in confidence (40%, down 2% from 14/15) and a break for 24 hours or less (26%, no change from 14/15)

Information and advice: Survey results in 2017 show a 5% increase in the number of respondents who report that information and advice was easy for them to find and 64% of

respondents stated that information and advice they had accessed was helpful (up by 3%).

Health and ability to carry out daily tasks: Carers reported a range of health conditions with 27% stating they had a long term illness (25% in 14/15) and 15% a physical impairment or disability (9% in 14/15).

Trends:

- **Satisfaction:** Male, White ethnic group and older respondents report higher satisfaction levels.
- **Caring for 100 hours per week:** respondents from a White or Asian ethnic group are more likely to report this.
- **Quality of life:** Asian ethnic group respondents are less likely to report quality of life as 'very good /good'.
- **Impacts and 'things I do as a carer':** impacts on health tended to be slightly higher in most instances for White respondents, and slightly lower for Asian respondents. In terms of 'things I do as a carer' younger respondents were more likely to report 'offering emotional support', taking out' and 'personal care' as things they do, with older respondents more likely to report 'helping with paperwork', keeping company, and 'checking okay'.

3. Background

3.1. Carers survey: 205 Tower Hamlets carers who have received support from Tower Hamlets in the last 12 months completed a survey sent to them in December 2016. This represents a survey response rate of 27%. The survey seeks to understand people's quality of life and experiences of adult social care. The survey is sent to carers every two years, and this is the third time the survey has been carried out.

3.2 Profile of users and profile of respondent: the profile of the 205 people who completed the survey is mostly similar to the profile of the 754 people who received the survey, as can be seen in Figure 1.

Figure 1: equalities table

Equalities	People who received the survey	People who completed the survey
Female	70%	69%
Male	30%	31%
Under 65	72%	69%
Over 65	26%	22%
White	27%	39%
Asian	45%	42%
Other ethnic background/ unknown	28%	18%

4. Issues to consider when reading the results

- 4.1 Survey Methodology:** the questions within the survey and the methodology to carry out the survey are set out by the Department of Health. The Methodology asks that the survey be sent to all adults carers who have received support from Tower Hamlets over the last 12 months. The Carers Survey is carried out on a bi-annual basis and this year there were six additional questions added by Tower Hamlets Council to the questions set by the Department of Health.
- 4.2 Margin of error:** the survey has a margin of error around the results of no more than +/- 5%. This means that if, for example, 41 per cent of carers indicate that overall they are extremely or very satisfied with the services that they receive then we can be reasonably confident that the true figure for all eligible carers in Tower Hamlets will be between 36 per cent and 46 per cent.
- 4.3 Comparisons with annual Adult Social Care (ASC) Service User Survey:** the ASC Service User Survey is sent out every year to all service users who are in receipt of a long term social care support service. Some of the questions in the ASC Service User Survey are the same as those asked in the Carer Survey and therefore this report includes some comparisons across the two surveys. It should be noted that there are occasional variations in the phrasing of the questions and answers in the two surveys. These are referenced in the report.
- 4.5 Analysing the results:** the report sets out analysis of the responses from carers who have used Tower Hamlets services in the last 12 months. The report also includes an analysis of survey respondents based on gender, ethnic background, age and the “primary client group” of the cared for person.
- 4.7** This report uses local survey data which allows for some survey responses which are received after the final deadline to be included and for more detailed analysis by particular groups to be carried out. This means that there may be some minor differences in the results shown here (except for at 5.1 ‘ASCOF measures’ which shows nationally released figures) and those reported nationally.

4.8 There was very limited information available on sexual orientation, so this has been excluded from the analysis. Similarly, the numbers from some specific “groups” are too small to draw effective conclusions and have been largely excluded from the analysis. For other data, such as ethnic groups, results have been shown for groups where there is enough data to provide meaningful results.

4.9 Benchmarking: the Carers Survey results for England and London were published in Autumn 2017 and details have been added to Appendix A for all questions, as well as key comparisons being highlighted within the report. Results for the last Carer Survey 2014/15 have also been added to Appendix A and referenced in the report.

5 Adult Social Care Outcomes Framework (ASCOF)

5.1 The results of the bi-annual Carer Survey inform the Adult Social Care Outcomes Framework. The results for Tower Hamlets arising from this survey are set out below. Figure 2 below, shows a comparison between the results of the last Carers Survey and this year’s using the figures reported nationally

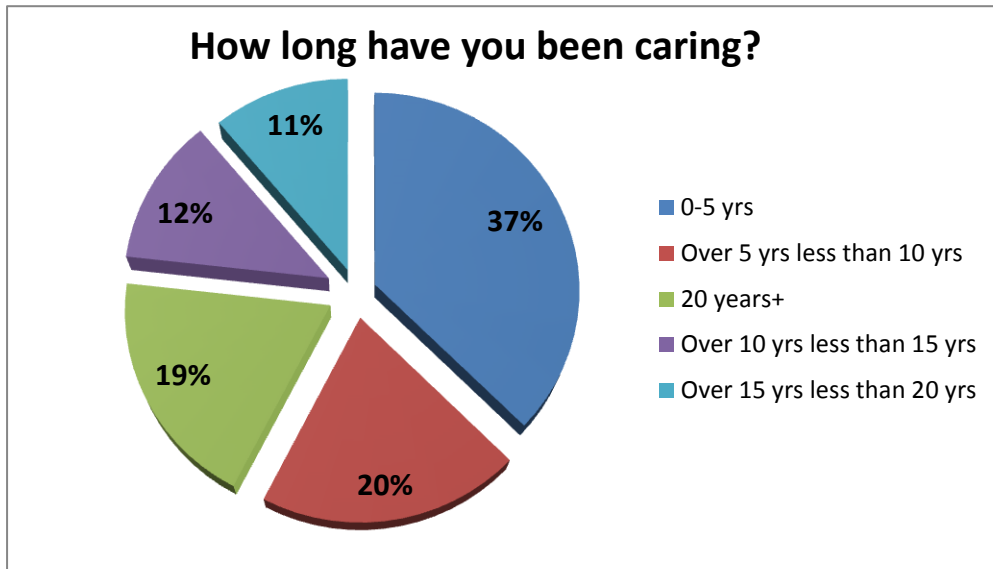
Figure 2: ASCOF Measures

ASCOF Measures		2014-15	2016-17
1D	Carer reported quality of life (score out of 12)	7.6	7.5
1L2	Proportion of carers who reported that they had as much social contact as they would like	36.2%	35.1%
3B	Overall satisfaction of carers with social services <i>This figure excludes those who answered “we haven’t received any support of services from Social Services in the last 12 months”</i>	32.1%	34.8%
3C	The proportion of carers who report that they have been included or consulted in discussions about the person they cared for <i>This figure excludes those who answered “there have been no discussions that I am aware of in the last 12 months”</i>	66.7%	69.2%
3D	The proportion of carers who find it easy to find information about services <i>This figure excludes those who answered “I have not tried to find information and advice in the last 12 months”.</i>	59.9%	66.0%

6. Carer Profile and needs

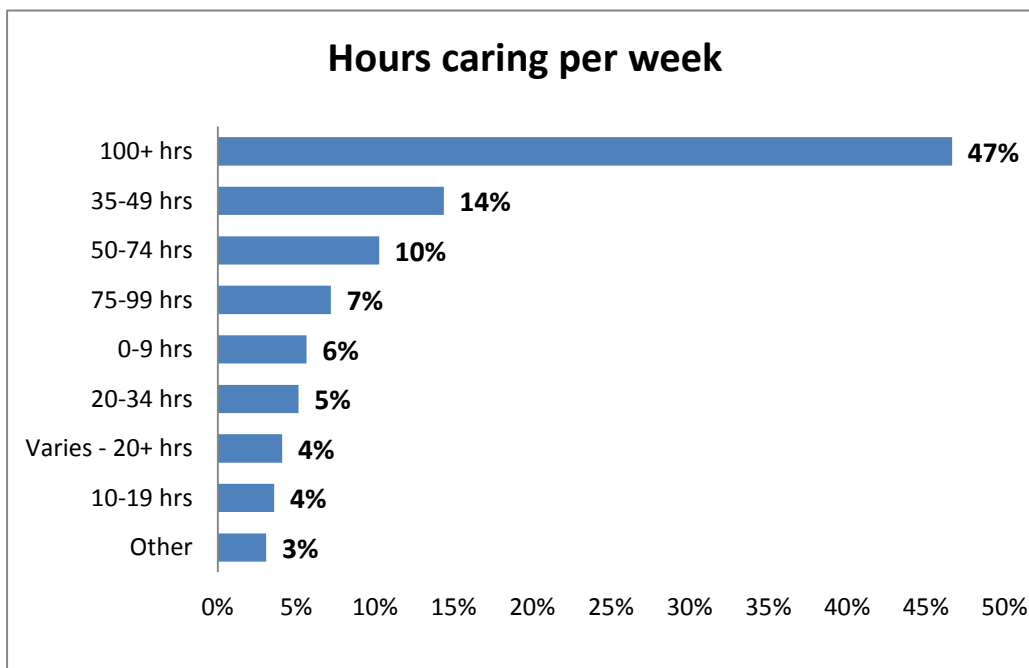
- 6.1 Time spent caring:** This year 62% of carers have said that they have been caring for more than five years, which is a decrease of 2% from the last survey finding of 64%. Many carers have been caring for far longer than this, with 11% reporting they have been caring for over 15 years, but less than 20 years, and 19% reporting that they have been caring for 20 years or more.

Figure 3: time spent caring



- 6.2 Hours caring per week:** the majority of survey respondents (47%) reported that they care for over 100 hours per week, which is a significant increase from the last survey (35%), following this the most common response was 35-49 hours (14%, down from 19% in 14/15).

Figure 4: hours caring per week



6.3 **Trends:** This year the results show that respondents of a White ethnic background (49%) and those of an Asian ethnic background (49%) are more likely to care for more than 100 hours per week. Respondents of an Asian background are also more likely to have cared for more than 20 years. Similar to last year, people caring for someone with a learning disability and older people are more likely to report having cared for a longer period of time.

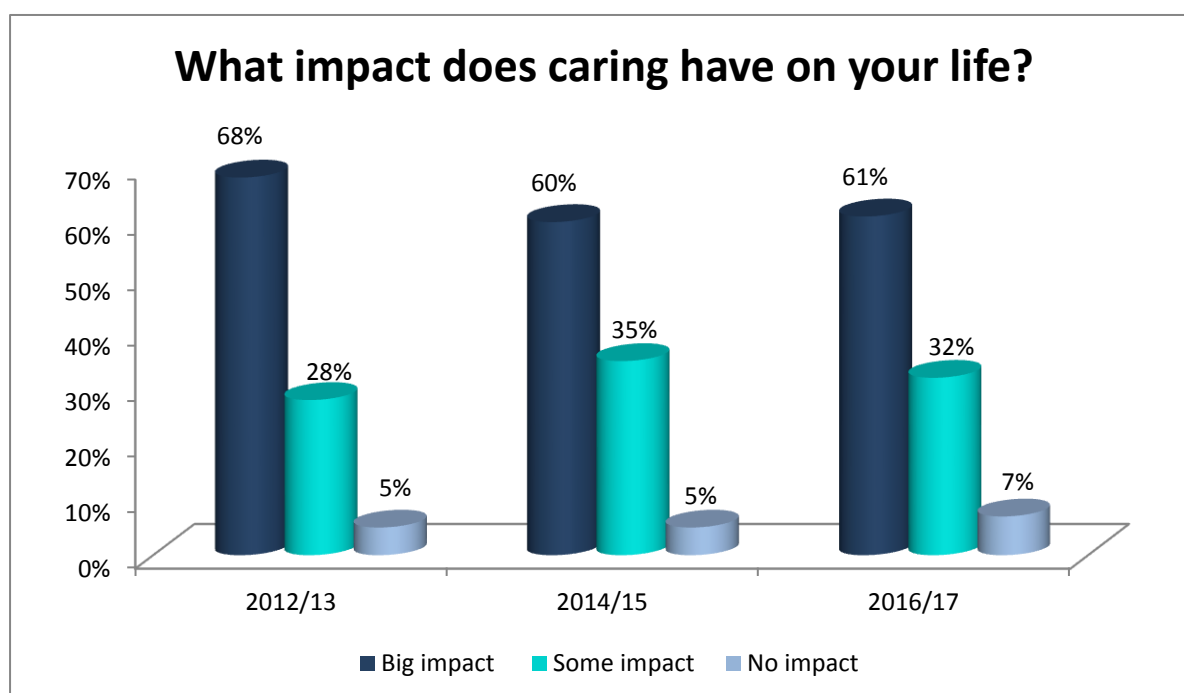
6.4 **Time spent caring and quality of life:** similar to results from the last survey there is a noticeable correlation between the numbers of hours per week spent caring, and the quality of life carers report. Figure 5 below sets out the results when bringing this data together and generally speaking, the more hours of care provided, the lower the quality of life being reported.

Figure 5: time spent caring and quality of life

Number of hours of care per week	-20 hours	20+ hours	50+ hours	100+ hours
I have a good quality of life	56%	34%	21%	30%
I can look after myself well enough	46%	50%	29%	45%
I have enough social contact	54%	39%	24%	33%
I get enough encouragement and support	23%	34%	35%	35%
I spend enough time doing things I value & enjoy	33%	19%	18%	27%
I have enough control over daily life	38%	24%	6%	26%

6.5 **Impact of caring and caring responsibilities:** figure 6 below shows the results to this question over the last three surveys, with very little change between 14/15 and 16/17. 61% of respondents said that caring had a big impact on their life, compared to 60% in 14/15, and sustaining the decrease from 68% in 2012/13.

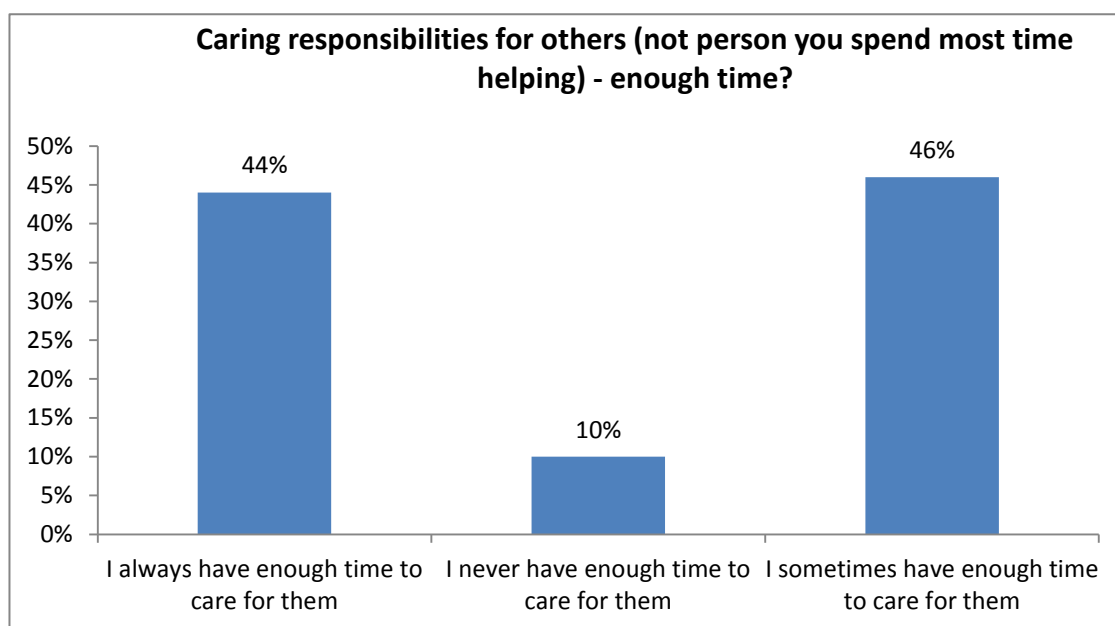
Figure 6: impact of caring – results of last 3 surveys



6.6 **Trends:** respondents of a White ethnic background and (in general) older age groups are more likely to say caring has a big impact on their lives (age group 75-84, 65%) and those of an Asian ethnic background are less likely to state this (52%).

6.7 **Caring responsibilities for others:** survey results show that after removing responses that stated 'I do not have caring responsibilities for anyone else' (28% of all respondents). 44% of the remaining respondents report that they always have enough time to care for the other people they have caring responsibilities for, 46% state that they sometimes have enough time and for 10% they never have enough time.

Figure 7: caring responsibilities for others



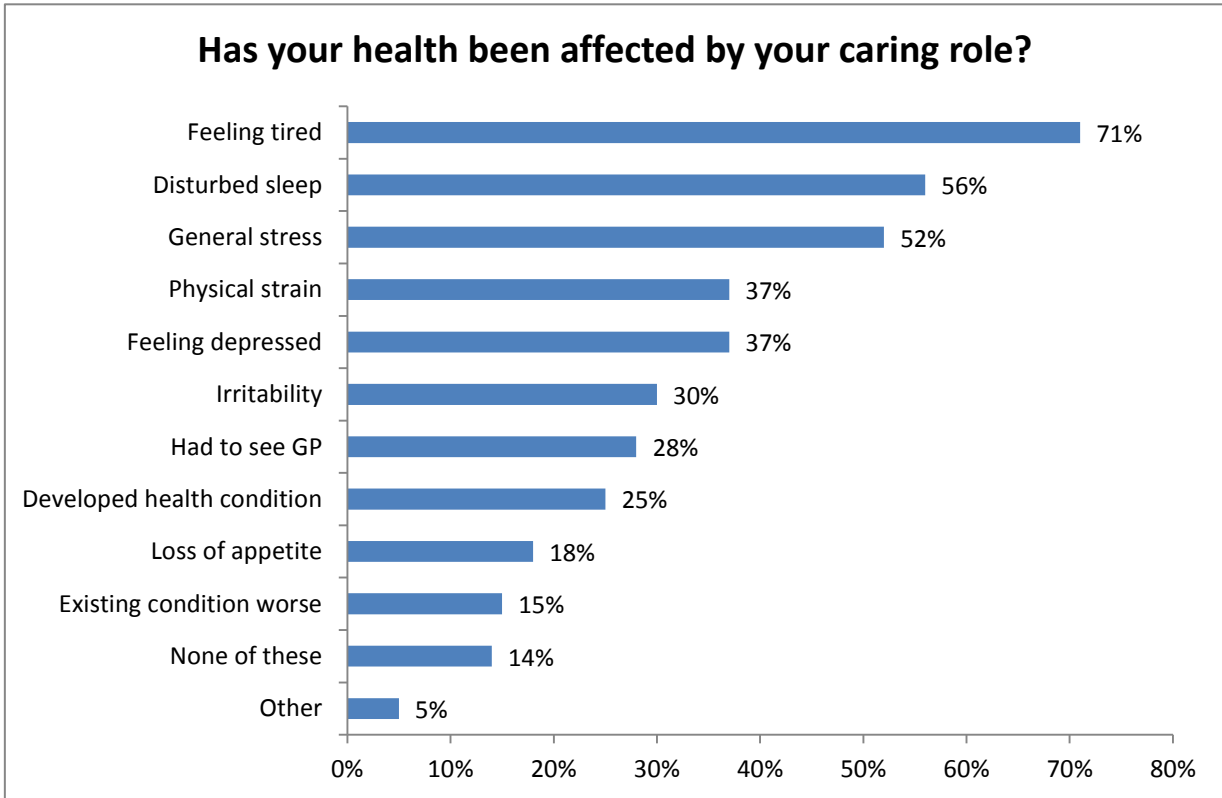
6.8 **Health of carers:** figure 8 below shows the percentage of survey respondents reporting the listed health issues, from the last two surveys. It shows some increases for 'physical impairment or disability' and 'sight & hearing loss', alongside small decreases for 'mental health problem' or 'illness' and 'learning disability or difficulty'.

Figure 8: health of carers 2014/15 and 2016/17

Health problem	% of all respondents 2014/15	% of all respondents 2016/17
A long standing illness	25%	27%
A physical impairment / disability	9%	15%
Sight or hearing loss	8%	12%
A mental health problem or illness	11%	9%
A learning disability or difficulty	6%	5%

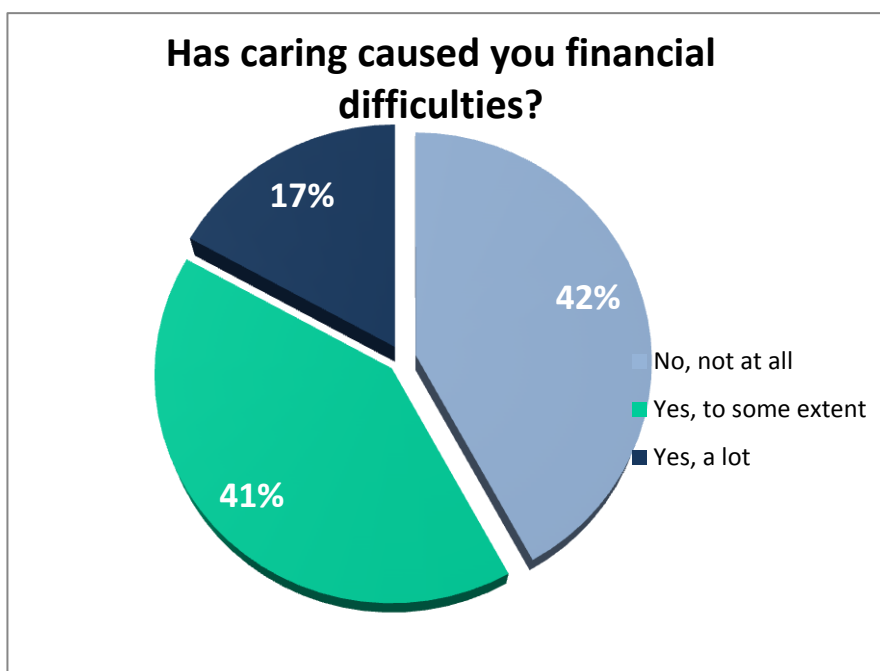
6.9 **Health affected by caring role:** the survey asks respondents a range of questions about how their health may have been affected by their caring role. The results are set out in Figure 9 below and show the most commonly reported impacts are 71% of respondents saying they 'feel tired', 56% say their 'sleep is disturbed' and 52% feel 'general stress'. This was a new question for 2016/17.

Figure 9: has your health been affected by your caring role?



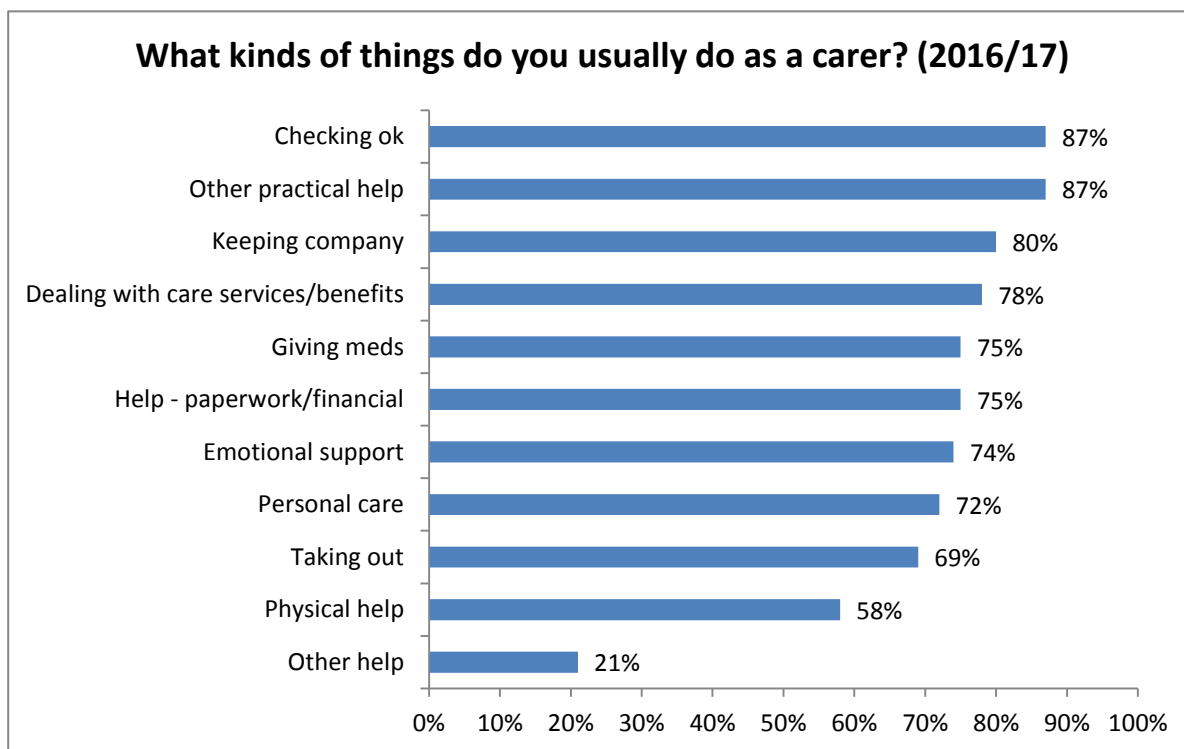
6.10 **Financial difficulties:** as can be seen below in Figure 10, when asked if caring had caused them any financial difficulties, 41% reported 'to some extent' and 42% stated 'not at all'. This was a new question for 2016/17. Results for London show 12% reporting 'a lot' of difficulty, and 10% for England, both lower than in Tower Hamlets at 17% for this response.

Figure 10: has caring caused you financial difficulties?



6.11 **Type of care being provided:** survey respondents reported that they do a wide range of things as a carer with high percentages for most of the response options shown in Figure 11 below. Results for 2014/15 were very similar for most options but there are increases this year for general checking / making sure person is okay (up from 59% in 14/15), personal care (up from 66% in 14/15) and helping with dealing with care services and benefits (up from 76% in 14/15).

Figure 11: what kinds of things do you usually do as a carer?



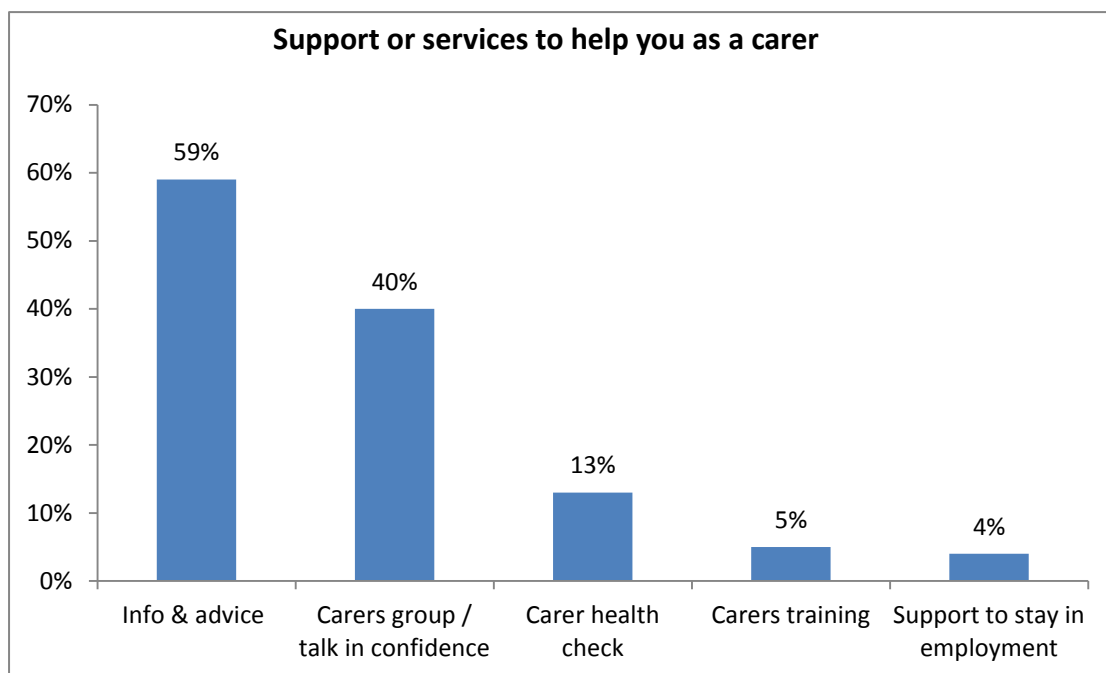
- 6.12 **Trends:** the age group 55-64 was more likely to report experiencing 'disturbed sleep and 'general feelings of stress', whilst people caring for someone with a mental health problem reported higher levels of health impacts in general. Asian respondents reported slightly lower levels of health being affected in general, and levels were slightly higher than 'overall' rates in most instances for White respondents. In regard to what they do young age groups are more likely to report 'offering emotional support', taking out' and 'personal care' as things they do, and older respondents are more likely to report 'keeping company, and 'checking okay'.
- 6.13 **Work and caring:** this year, the options were changed to differentiate carers who are self-employed and retired – with 39% stating that they are not in paid work due to being retired or 'other reasons' in 2016/17, and 3% reporting they are self-employed (part or full time). The number of carers that said they are not in work due to caring responsibilities increased from the last survey by 6%, returning to the level of 2012/13.

Figure 12: work and caring

Work and caring	2012/13	2014/15	2016/17
Not in work due to caring	46%	40%	46%
Not in work for other reasons (e.g. Retired)	N/A	N/A	39%
In paid work and feel supported	7%	10%	8%
In paid work and not supported	2%	6%	3%
In paid work and I don't need support	3%	4%	2%
Self-employed and can balance caring responsibilities	N/A	N/A	2%
Self-employed and unable to balance caring responsibilities	N/A	N/A	1%

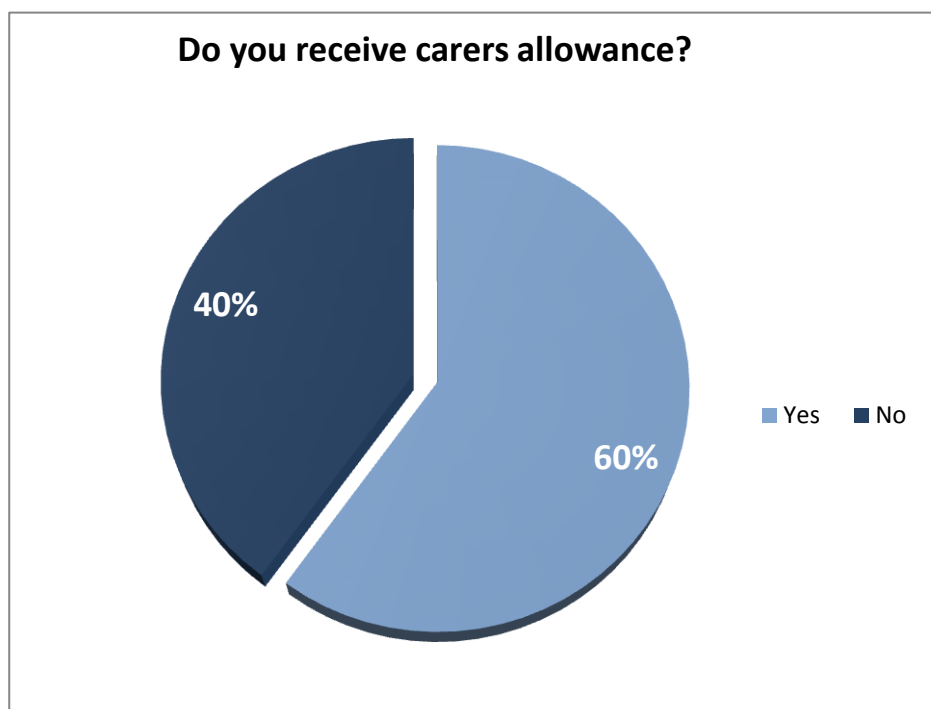
- 6.14 **Trends:** similar to last year, respondents of a White ethnic background are more likely to be retired (42%) whilst Asian respondents are a lot more likely to be unemployed due to caring or other responsibilities (67%, compared to 46% overall). The profile in Tower Hamlets is quite different to London and England survey results. Those reporting they are retired is lower locally (26%, compared to 48% for London, 58% for England), and the percentage not in paid work is higher (34%, compared to 24% for London and 21% for England).
- 6.15 **Support to help carers:** survey respondents reported the most commonly used support or services to help carers as 'information and advice' (59%, up from 52% in 14/15), support from a carers group / talking in confidence' (40%, down slightly from 42% in 14/15) and carers health check which has gone down significantly this year, from 23% in 2014/15 to 13% for 2016/17.

Figure 13: support to help carers



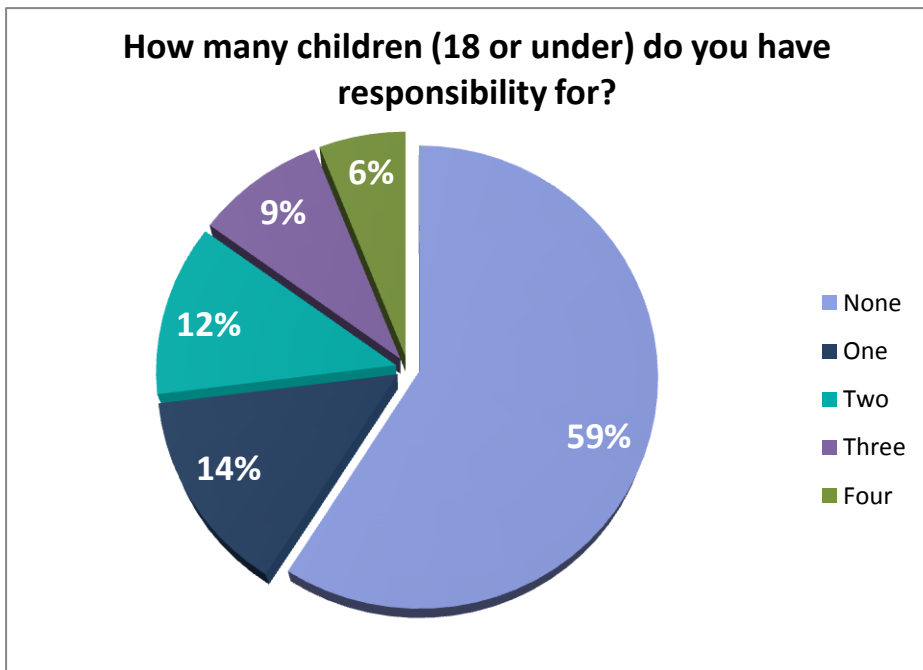
6.16 **Carers allowance:** the majority of survey respondents (60%) stated that they do receive carers allowance. This question is new for 2016/17 and is added to the local questionnaire only.

Figure 14: carers allowance



6.17 **Responsibility for children under 18:** it should be noted that 31% of survey respondents did not answer this questions and Figure 15 below shows the results after removing these responses. This question is new 2016/17.

Figure 15: responsibility for children under 18



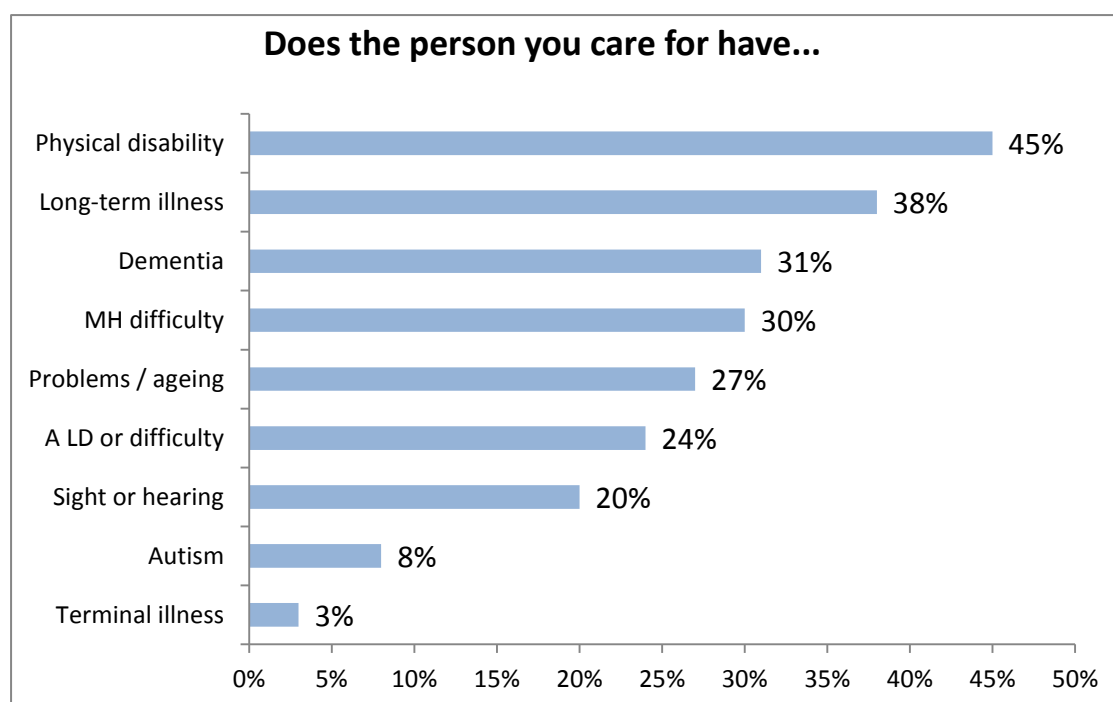
6.18 **Trends:** The results are similar to last year, with respondents of a White ethnic background more likely to access information, advice and group support or talking in confidence. This year, carers of people with a mental health problem are also more likely to have accessed these types of support – information and advice (69%), support from carer groups or talking in confidence (47%).

7. Profile of the people being cared for

7.1 **Age and needs of the people being cared for:** just over half of the people being cared for are over 65 (54%), 24% are aged 18 to 44, and the remaining 22% are aged 45 to 64. The age profile is older for both London and England (Over 65's – 64% and 67% respectively).

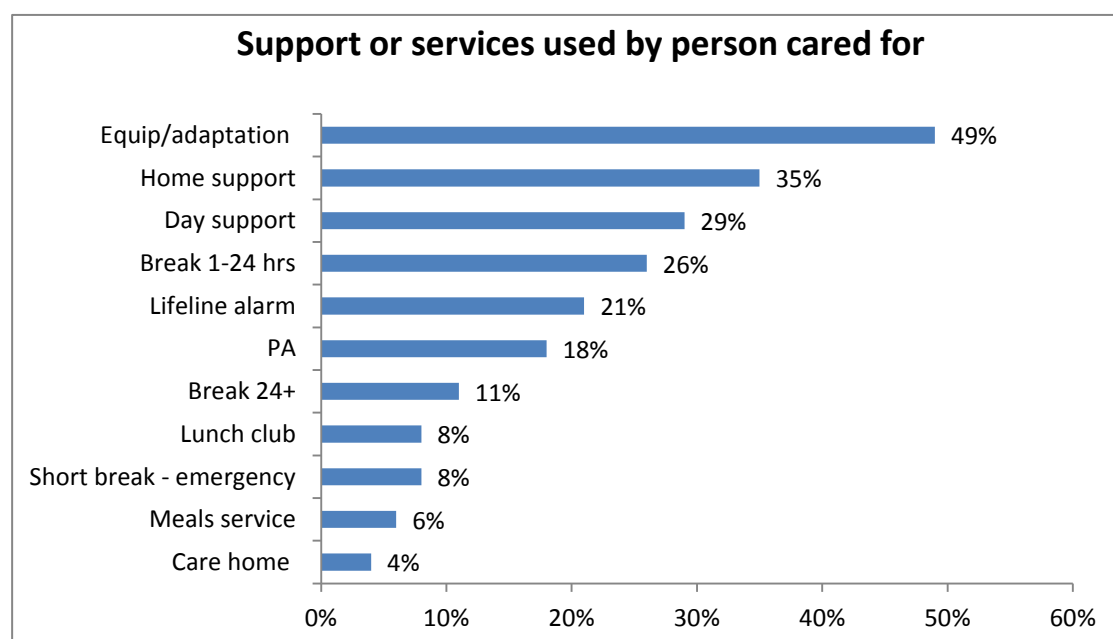
7.2 **Health of person being cared for:** responses to the options given for the question 'Does the person you care for have' are shown in Figure 16 below. The most common response was a physical disability (45%), long term illness (38%) and dementia (31%). These results compare very closely with those for 2014/15.

Figure 16: health of person being cared for



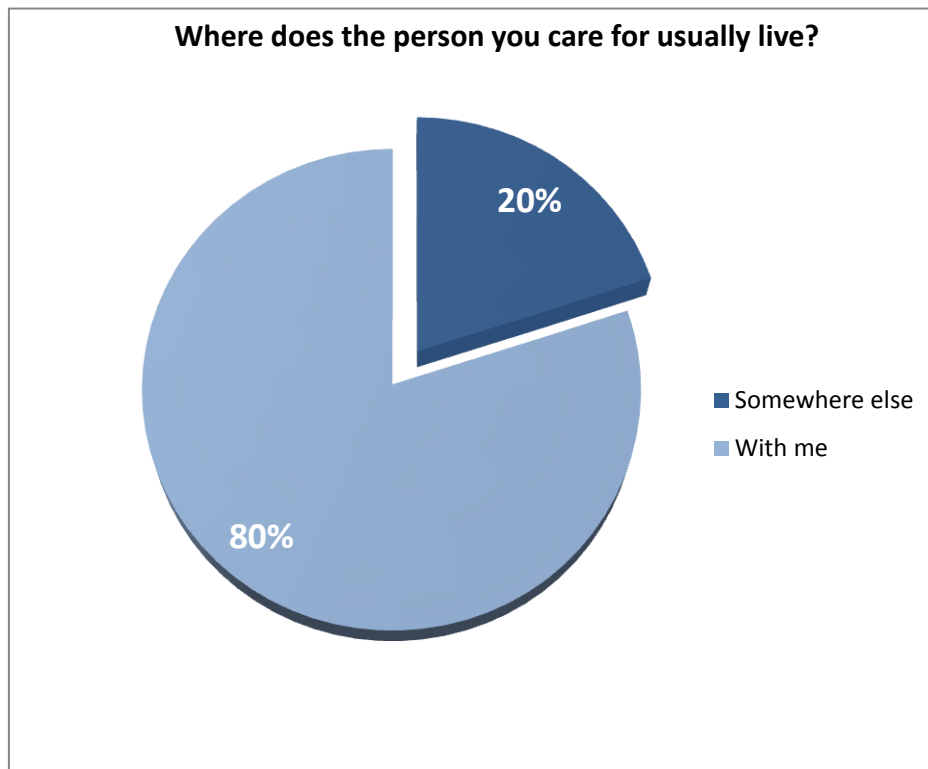
7.3 **Support used by the person cared for:** Figure 17 sets out the support or services used by the person who is cared for over the last 12 months, as reported by survey respondents. The most commonly used support or service was equipment / adaptations (49%, almost unchanged from 50% in 14/15), home care / home help (35%, down from 40% in 14/15) and day centre / day activities (29%, also almost unchanged from 28% in 14/15). The percentage reporting use of support services to take a break are higher for London and England with 'break for 24+ hours' at 18% for London and 21% for England, compared to 11% in Tower Hamlets.

Figure 17: support used by person cared for



7.4 **Living arrangements:** as Figure 18 shows above, survey respondents reported that the majority of those they cared for lived with them (80%), and 20% lived somewhere else. Results are almost identical to the last survey in Tower Hamlets but the percentage living 'somewhere else' is higher for London (26%), and England (25%) survey results.

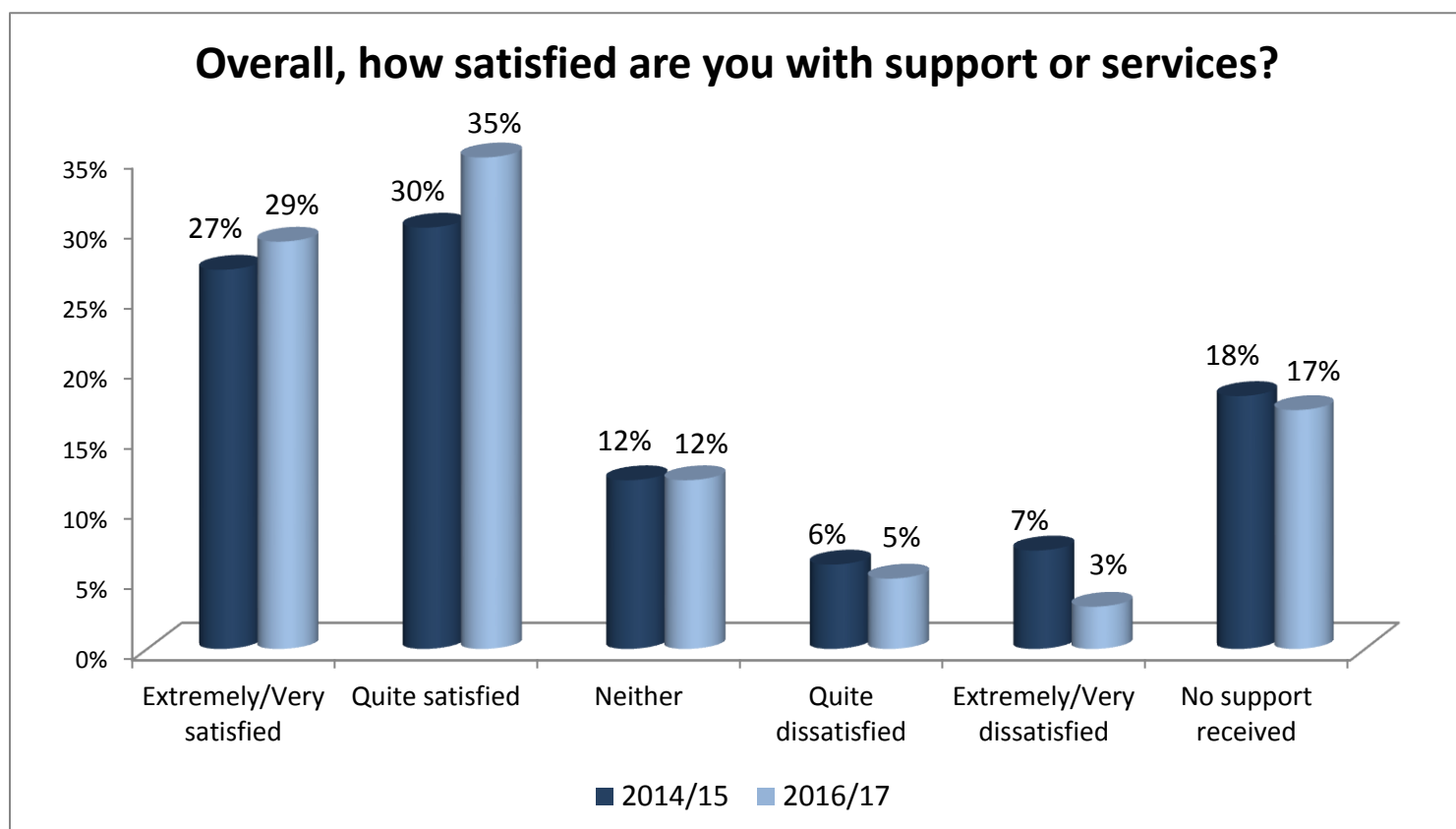
Figure 18: living arrangements



8. Satisfaction with care and support services

8.1 Overall satisfaction: figure 19 below shows results from the last two surveys when respondents were asked how satisfied they were with support or services. There is a significant increase in 2016/17 for the percentage of respondents who are extremely, very and quite satisfied (64% in 16/17, up 7% from 56% in 14/15).

Figure 19: overall satisfaction with support or services



8.2 Carer and service user satisfaction: an overview of satisfaction levels (for 'extremely or very satisfied') from several surveys is shown in figure 20 below. A similar question on satisfaction is included in the annual Service User Survey, but it is important to note that it does not include the option "no support has been received the last 12 months". The table below sets out the results of carer and service use survey results once this option has been removed.

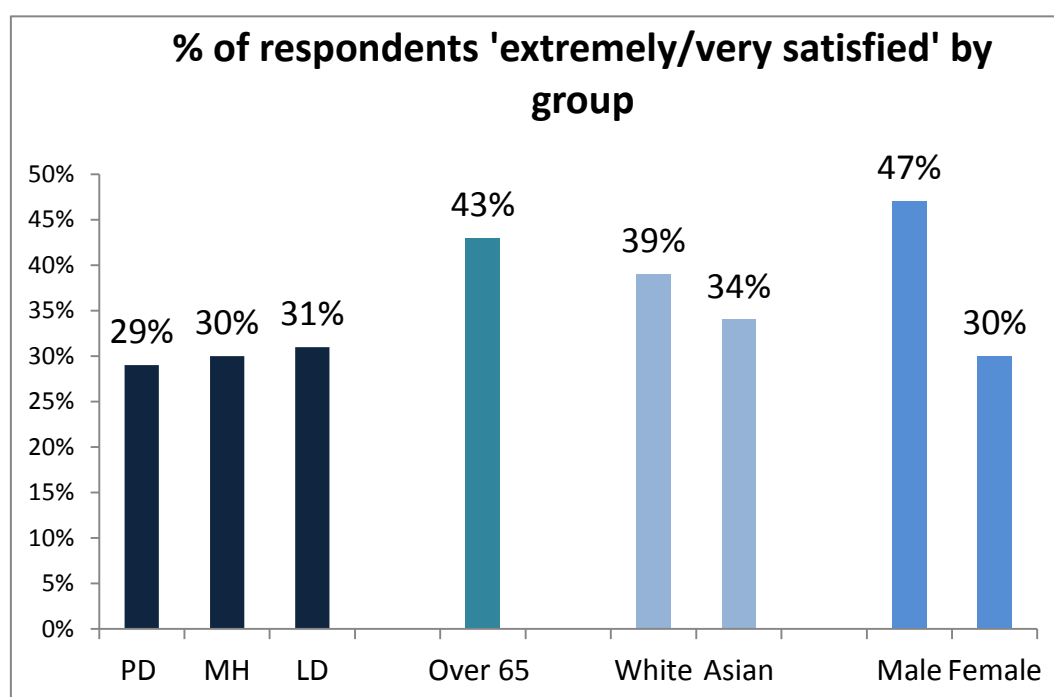
8.3 Figure 20 shows that while carer satisfaction has increased significantly over the last three years, it does remain much lower than the service user satisfaction levels. It is interesting to note that the carer survey question covers both the support provided to them and the person they care for due to the way the question is phrased – it is not possible to separate out the two. Carers have written comments in the Carer Survey which gives some indication as to how carers feel about support services both for themselves and the people they care for. Please see Section 10.

Figure 20: carer and service user satisfaction – survey comparisons

	Service User 2016/17	Carers 2012/13	Carers 2014/15	Carers 2016/17
Extremely or very satisfied	62%	28%	32%	35%

8.4 Trends: this year; men, older respondents and respondents from a White ethnic background report higher satisfaction levels. The table below sets out the results in more detail.

Figure 21: levels of satisfaction by group (with those who have not received a service removed for results by ethnic group and gender)



8.5 **Satisfaction and carer support services:** carers who have accessed information and advice, group or confidential support or a carer health check report higher than average satisfaction levels. The results in figure 22 below show a comparison between this year and the previous year.

Figure 22: satisfaction comparisons

Type of support accessed	% extremely/ very satisfied 2014/15	% extremely/ very satisfied 2016/17
Information and advice	34%	41%
Group or confidential support	39%	39%
Carer Health Check	37%	38%

8.6 Satisfaction levels compared to other responses: overall there is a positive correlation between satisfaction levels and responses in other areas.

- 76 per cent of those who are extremely/very satisfied also feel that they are treated with respect by people carrying out their assessment. (The average is 66 per cent).
- 54 per cent of those who are extremely/very satisfied say they have a good quality of life. (The average is 33%)
- 31 per cent of those who are extremely/ very satisfied say they spend enough of their time doing things valued and enjoyed. (The average is 24%)

8.7 Being treated with respect: This year most of the respondents agreed that they were treated with respect by the people who carried out their assessments, although there was an increase in those stating ‘neither’ as their response. It should be taken into account that this year the options “strongly agree” and “strongly disagree” have been replaced with just the options ‘agree’ or ‘disagree’ instead. Figure 23 below sets out the results compared with the last two Carers Survey and ASC Service User Survey.

Figure 23: being treated with respect survey results



8.8 Usefulness of carer assessments: the survey asked respondents “How useful did you find the carer assessment you had?” This year 88% of respondents said they found it useful, which was an increase of 8%. It should be noted that an additional response option was added this year of ‘I haven’t had a carers assessment in the last year’ – these responses were removed from the percentages below to allow comparison with previous years. Figure 24 below sets out results from the last three surveys.

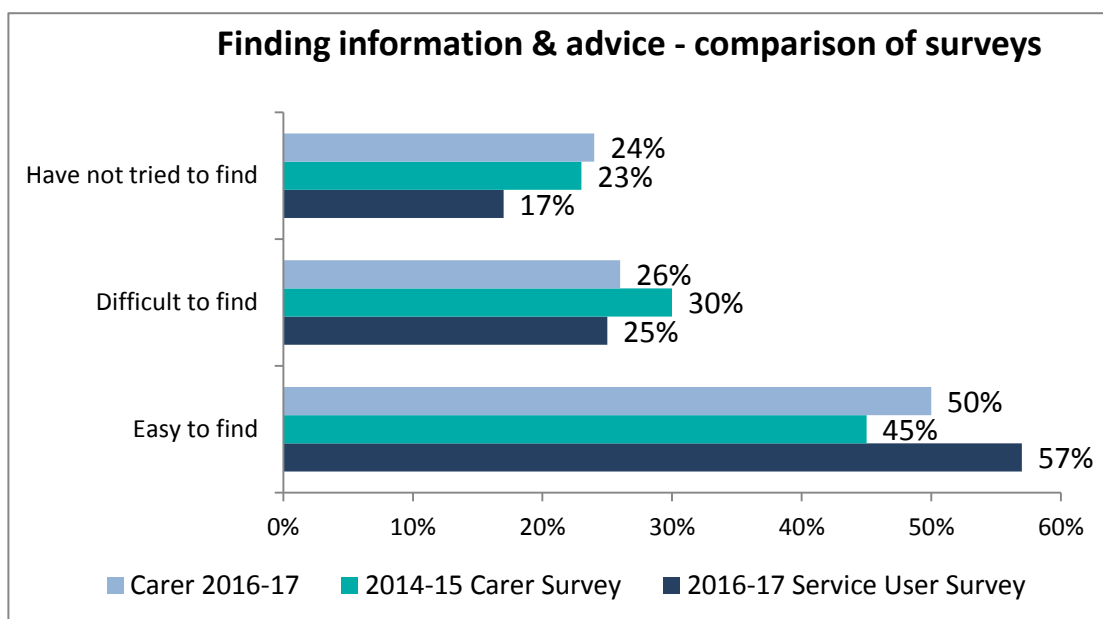
Figure 24: usefulness of carer assessments

Usefulness of carers assessments	Carers 2012/13	Carers 2014/15	Carers 2016/17
Very useful	34%	26%	32%
Quite useful	46%	54%	56%
Not useful	20%	20%	12%

8.9 Trends: This year, Asian respondents report a more positive experience compared to White respondents. 12% of White respondents have not found carers assessments useful, compared to 8% of Asian respondents (results with those who have not had an assessment removed). Respondents aged 45-64 are also more likely to report that their assessment was ‘very’ useful, as do carers of people with mental health problems. It is interesting to note that there is no correlation between overall satisfaction levels and how useful carers found their assessments to be.

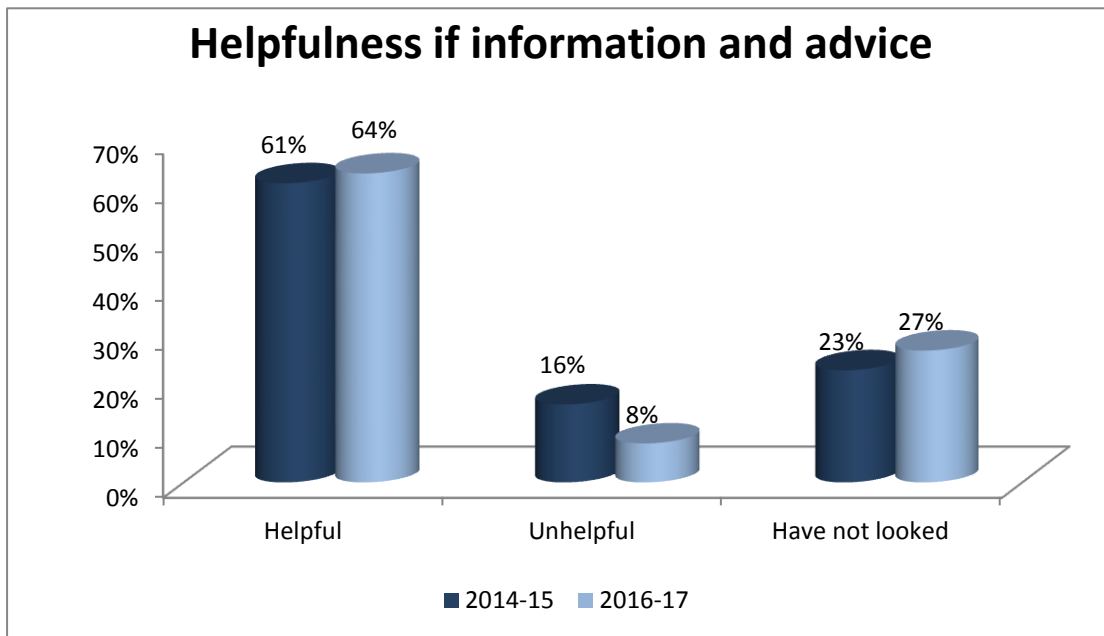
8.10 Finding information and advice: comparisons of carer and service user surveys; figure 25 below sets out the results for this question within the last two Carer Surveys and the ASC Service User Survey. Service users (who may or may not also be carers) appear to find it easier to find information and advice, however carers seem more likely to ‘have not tried to find’ information and advice over the last year.

Figure 25: finding information and advice – survey comparisons



8.11 **Helpfulness of information and advice:** when asked how helpful information and advice was, 64% of respondents said that the information and advice they received was helpful (61% in 14/15) and just 8% said it has been 'unhelpful' (16% in 14/15).

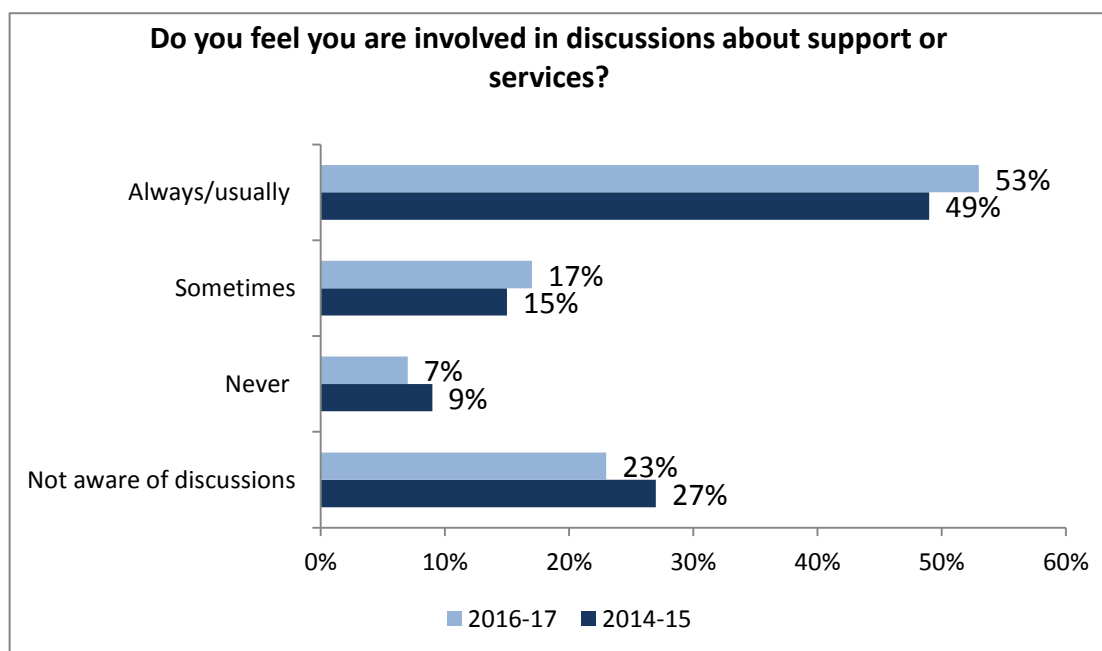
Figure 26: helpfulness of information and advice



8.12 **Trends:** respondents caring for someone with a learning disability (53%) report lower than average experiences in ease of finding information and advice. However, when it comes to how helpful the information and is respondents caring for someone with a learning disability (90%) and respondents from an Asian ethnic background (88%) are more likely to say that information and advice was helpful (results with those who have not received information and advice removed). More people appear to try and find information or advice in the borough as those stating they have not tried are at 33% for London and England, compared to 24% locally.

8.13 **Being involved in discussions:** carers were asked how involved or consulted they feel in discussions about the support or services provided to the person they care for. This year 53% of respondents report that they are 'always' or 'usually' involved in discussions, which is up from 49% in 2014/15.

Figure 27: being involved in discussions



8.15 Trends: Respondents from an Asian ethnic background (74%) and respondents caring for someone with a physical disability (69%) report the most positive experiences in this area (results are with those where discussion has not taken place removed). Older age groups are less likely to report that they ‘never’ feel consulted, and those caring for someone with a mental health problem or a physical disability are slightly more likely to say they ‘never’ feel consulted.

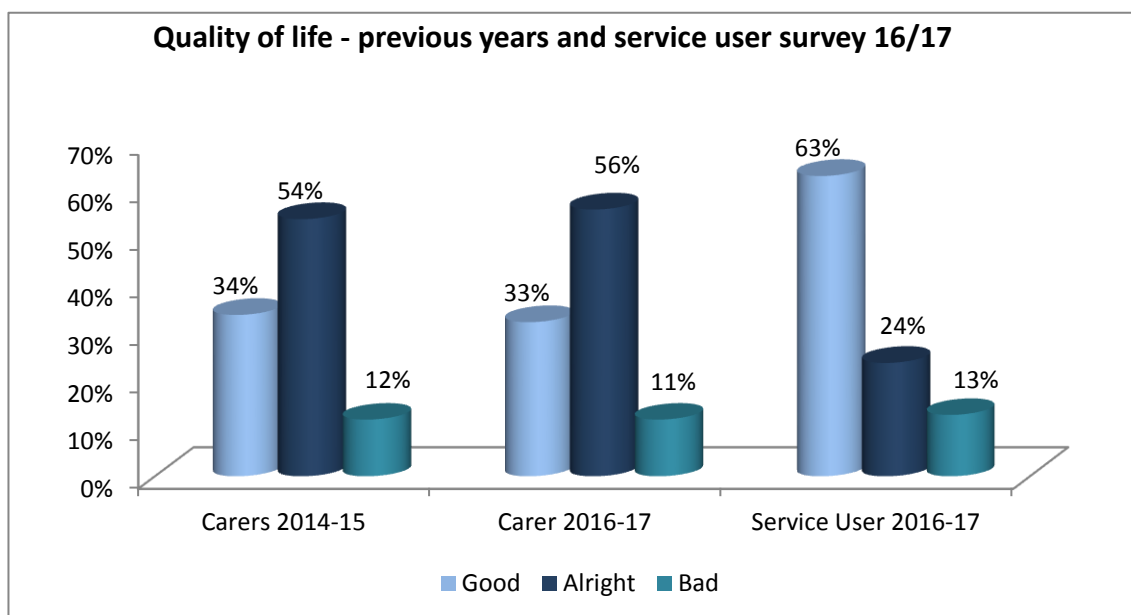
9. Quality of life

9.1 Overall quality of life: the survey asked respondents to rate their quality of life overall. As per Figure 29 below, this year 33% rated their quality of life as “very good / good” and 56% of respondents rated their quality of life as “alright”. The remaining 11% rated their quality of life as “bad / very bad”. These results are almost identical to the last survey results. Figure 29 also sets out the results for ASC Service User Survey.

9.2 Compared to the previous year, results are very similar with a small increase in the number of carers that report their quality of life as “alright”. Comparing the results from the Carers Surveys with the ASC Service User Survey there is a generally poorer quality of life reported by carers.

9.3 The reasons behind this can only be speculated on, however, there is a noticeable correlation between the number of hours spent caring and the overall quality of life carers report. Generally speaking, the more hours of care being provided the lower the quality of life being reported. More details on this are presented in section 6.4.

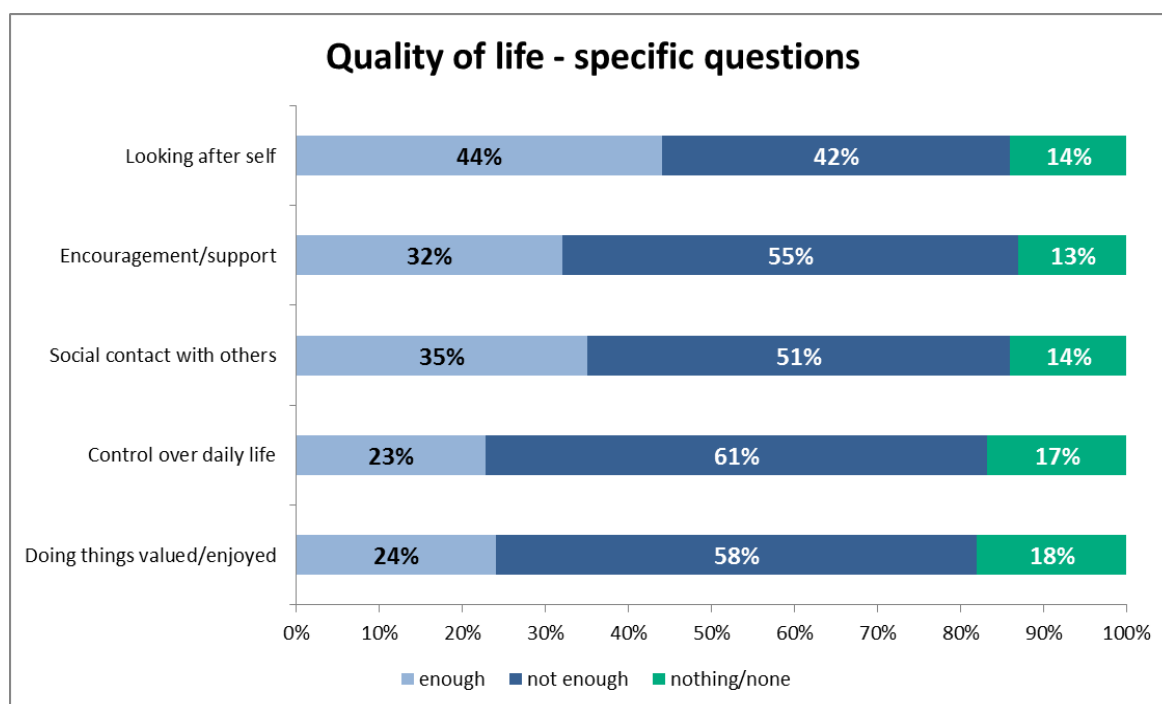
Figure 29: quality of life – comparison of surveys



9.4 **Trends:** Asian respondents are less likely to report quality of life as ‘very good / good’ (29%). Women (34%) and respondents caring for someone with a learning disability (35%) report slightly higher than average experiences in this area (33% for all respondents).

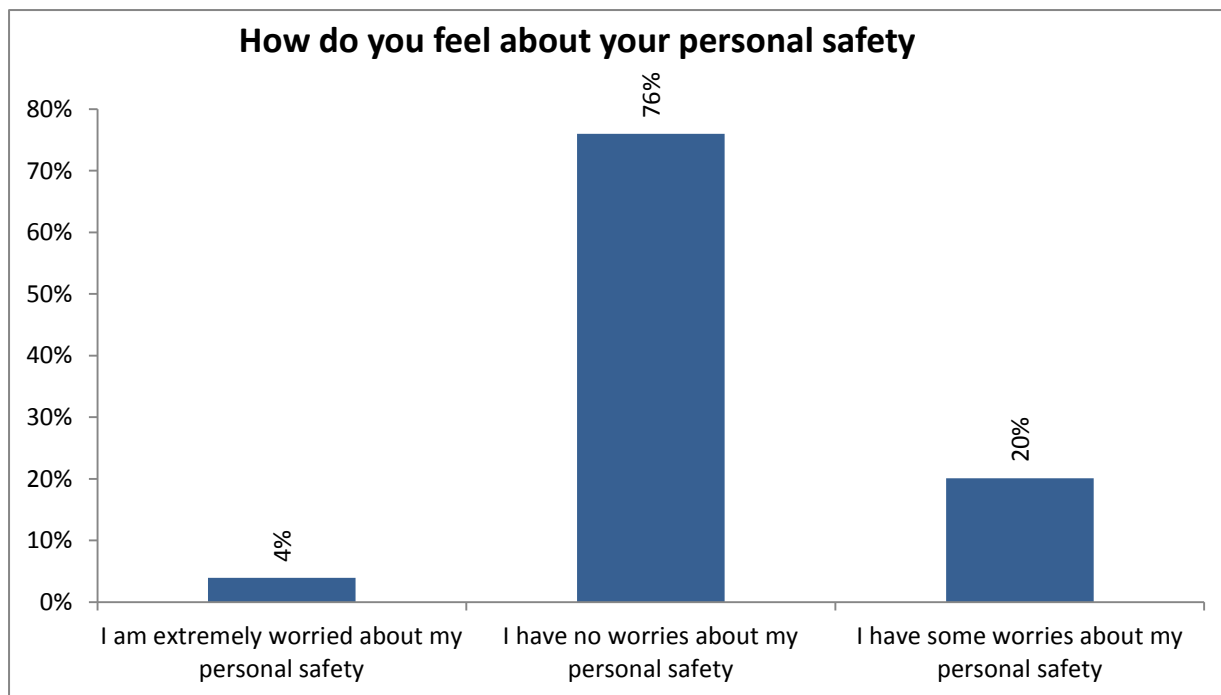
9.5 **Aspects of quality of life:** figure 30 below sets out carer quality of life in more detail, looking at five key areas. The majority of respondents reported that they felt they cannot do enough of the things they value or enjoy with their time (58%, up slightly from 56% in 14/15), do not have enough control over their daily lives (61%, up from 56% in 14/15), do not have enough social contact (51%, almost the same as 50% in 14/15) and do not have enough encouragement or support (55%, up from 50% in 14/15).

Figure 30: aspects of quality of life



9.6 Feeling safe: in 2016/17 the majority of respondents reported that have no worries about their personal safety 76%, which is the same as in 2014/15 and other results for the question have also remained at the same level.

Figure 31: feeling safe



9.7 Trends: Men, White respondents and older age groups report the most positive feelings of safety.

10. Feedback from Carers

10.1 Comments about carer experiences

The summary of feedback in this table was from comments made in response to the space within the survey to *'describe any other experiences you would like to tell us about, or to write any other comments you would like to make?'*

Many respondents described impacts and pressures they experienced as carers, including feeling tired, feeling depressed, financial impacts and impacts on their health. There was also reference to feelings of guilt and concerns about what would happen 'if I were to fall ill'

The challenges that can exist around finding and accessing information and support were mentioned, this included:

- Difficulties in managing forms and 'red tape' when a carer is also working
- Multiple points of contact can be confusing
- Experiences of long waiting lists

Several respondents referenced the need for breaks and holidays, how difficult this can be but how important it is due to the levels of stress and other challenges experienced.

Some respondents talked about how important information and support has been to them, especially from the voluntary and community sector, describing it as a 'lifeline', 'an opportunity to become more fully involved in my community', and 'makes it possible to take a break'.

Some survey respondents noted that not everyone may know about the information and support that is available and how important it is to ensure it is well promoted.

There were references to whether the role and responsibilities that carers undertake is understood and appreciated by everyone, this included comments such as feeling part of a 'forgotten army', that some do not feel recognised for their 'vital role', 'people providing unpaid care are a valuable resource' and the challenges of trying to meet commitments on restricted budgets.

The benefits of occupational therapy were mentioned and how the right equipment has 'made life easier'.

Some described the challenges of caring for someone who can experience 'rage and frustration' and that the need for support in managing these circumstances.

10.2 Comments about finding information and how helpful it was

The summary of feedback within this table was from comments made in response to the following questions:

- *If you found it difficult to find information and advice, please tell us why and what we can do to make it easier for you*
- *If you found the information and advice you received unhelpful, please tell us why and what we can do to make it more helpful for you*

Some reported that they could find information and advice, including online, but many others also said they did not know what was available or where to look find information and advice.

It was noted how valuable and important support from the voluntary and community sector was, however there may be a need to ensure more people know about this.

Some mentioned that language barriers still exist when trying to access information and advice.

The challenges from living in a different area to the person with care and support needs, and not always knowing where to then go for support, were mentioned.

Issues around the varying sources of information and advice were referenced, some described them as 'not co-ordinated, nothing is in one place' and 'very fractured' as well as 'websites are confusing'.

Some respondents expressed a desire to have a nominated social worker, or referenced the difficulties that staff changes, and trying to reach people can create.

Some felt that a more proactive approach to getting information to people would be helpful, with comments such as 'provide the information, rather than having to seek it out'.

Appendix A: Full Table of Results

Please note: figures for 2016/17 (Tower Hamlets) are from local survey data in order to allow inclusion of some survey responses received after the national deadline and more detailed analysis by particular groups. Any differences between the figures here and nationally released figures are minor.

1. How old is this person	2014/15	2016/17	London 16/17	England 16/17
18-44	22%	24%	21%	17%
45-64	27%	22%	16%	16%
Over 65	50%	54%	64%	67%

2. Does the person that you care for have...?	2014/15	2016/17	London 16/17	England 16/17
Dementia	27%	31%	34%	35%
Physical disability	52%	45%	52%	53%
Sight/hearing loss	25%	20%	28%	30%
Mental health problem	37%	30%	22%	21%
Problems connected to aging	26%	27%	34%	35%
Learning disability or difficulty	18%	24%	23%	19%
Long-standing illness	42%	38%	39%	40%
Terminal illness	6%	3%	5%	5%
Alcohol or drugs dependency	1%	1%	2%	2%
Autism (<i>option on 2016/17 local survey only</i>)	/	8%	/	/

3. Where does the person you care for usually live?	2014/15	2016/17	London 16/17	England 16/17
With me	81%	80%	74%	75%
Somewhere else	19%	20%	26%	25%

4. Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
Extremely satisfied	8%	9%	9%	12%
Very satisfied	19%	20%	20%	19%
Quite satisfied	30%	35%	25%	25%
Neither satisfied or dissatisfied	12%	12%	14%	12%
Quite dissatisfied	6%	5%	6%	5%
Very dissatisfied	3%	1%	3%	2%
Extremely dissatisfied	4%	2%	3%	3%
We haven't received any support or services from Social Services in the last 12 months	18%	17%	20%	22%

5. Has the person you care for used any of the following support services in the last 12 months. All % shown as for 'Yes' responses	2014/15	2016/17	London 16/17	England 16/17
Support/services allowing a break from caring at short notice or in an emergency	10%	8%	14%	15%
Support/services allowing a break from caring for 24 hours +	12%	11%	18%	21%
Support or services to allow you to have a rest from caring between 1- 24 hours	26%	26%	23%	23%
Personal Assistant	18%	18%	17%	14%
Home care	40%	35%	38%	35%
Day centre or day activities	28%	29%	29%	27%
Lunch Club	2%	8%	4%	4%
Meal Services	4%	6%	5%	4%
Equipment or adaptation	50%	49%	53%	56%
Lifeline alarm	25%	21%	29%	34%
Permanently in a care home	9%	4%	9%	10%

6. Have you used any of the following support or services to help you as a carer in the last 12 months <i>All % shown as for 'Yes'</i>	2014/15	2016/17	London 16/17	England 16/17
Information and advice	52%	59%	47%	52%
Support from carers groups / talk in confidence	42%	40%	30%	31%
Training for carers	3%	5%	7%	6%
Support to keep you in employment	3%	4%	4%	3%
Carer health check (<i>option on local survey only</i>)	23%	13%	/	/

7. Which of the following statements best describes how you spend your time? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I'm able to spend my time as I want, doing things I value or enjoy	22%	24%	22%	20%
I do some of the things I value or enjoy with my time but not enough	56%	58%	62%	66%
I don't do anything I value or enjoy with my time	22%	18%	16%	15%

8. Which of the following statements best describes how much control you have over your daily life? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I have as much control over my daily life as I want	29%	23%	26%	25%
I have some control over my daily life but not enough	56%	61%	60%	61%
I have no control over my daily life	15%	17%	14%	14%

9. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I look after myself	48%	44%	49%	55%
Sometimes I can't look after myself well enough	33%	42%	34%	29%
I feel I am neglecting myself	20%	14%	16%	16%

10. Thinking about your personal safety, which statement best describes your present situation? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I have no worries about my personal safety	76%	76%	79%	84%
I have some worries about my personal safety	21%	20%	19%	15%
I am extremely worried about my personal safety	3%	4%	2%	1%

11. Thinking about how much social contact you've had with people you like, which of the following best describes your present situation? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I have as much social contact as I want with people I like	36%	35%	36%	36%
I have some social contact with people but not enough	50%	51%	47%	48%
I have little social contact with people and feel socially isolated	13%	14%	17%	16%

12. Thinking about encouragement and support in your caring role, which of the following statements best describes your current situation? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I feel I have encouragement and support	38%	32%	35%	36%
I feel I have some encouragement and support but not enough	50%	55%	46%	44%
I feel I have no encouragement and support	13%	13%	19%	20%

13. Thinking about the other people you have caring responsibilities Which of the following best describes your current situation? (<i>new question for 2016/17</i>)	2014/15	2016/17	London 16/17	England 16/17
I always have enough time to care for them	/	32%	31%	28%
I sometimes have enough time to care for them	/	33%	28%	26%
I never have enough time to care for them	/	8%	11%	8%
I don't have caring responsibilities for anyone else	/	28%	30%	38%

14. In the last 12 months, has your health been affected by your caring role in any of the ways listed below? (new question for 2016/17)	2014/15	2016/17	London 16/17	England 16/17
Feeling tired	/	71%	72%	76%
Feeling depressed	/	37%	40%	43%
Loss of appetite	/	18%	13%	13%
Disturbed sleep	/	56%	57%	64%
General feeling of stress	/	52%	56%	59%
Physical strain (e.g. back)	/	37%	35%	33%
Short tempered / irritable	/	30%	36%	42%
Had to see own GP	/	28%	28%	29%
Developed my own health conditions	/	25%	23%	23%
Made an existing condition worse	/	15%	19%	20%
Other	/	5%	4%	3%
No, none of these	/	14%	13%	10%

15 In the last 12 months, has caring caused you any financial difficulties? (new question for 2016/17)	2014/15	2016/17	London 16/17	England 16/17
No, not at all	/	42%	50%	54%
Yes, to some extent	/	41%	38%	36%
Yes, a lot	/	17%	12%	10%

16. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
Very easy to find	13%	13%	11%	11%
Fairly easy to find	32%	37%	31%	32%
Fairly difficult to find	19%	17%	16%	16%
Very difficult to find	11%	9%	9%	8%
I have not tried to find information or advice in the last 12 months	23%	24%	33%	33%

17. In the last 12 months, how helpful has the information and advice you have received been?	2014/15	2016/17	London 16/17	England 16/17
Very helpful	21%	24%	19%	21%
Quite helpful	40%	40%	37%	37%
Quite unhelpful	13%	6%	7%	6%
Very unhelpful	3%	2%	3%	3%
I have not received any information or advice in the last 12 months	23%	27%	35%	33%

18. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? ASCOF related	2014/15	2016/17	London 16/17	England 16/17
I always felt involved or consulted	27%	26%	25%	28%
I usually felt involved or consulted	22%	28%	22%	22%
I sometimes felt involved or consulted	15%	17%	18%	15%
I never felt involved or consulted	9%	7%	7%	5%
There have been no discussions that I am aware of in the last 12 months	27%	23%	29%	30%

19. In addition to your caring role, please tell us which of the following also applies to you?	2014/15	2016/17	London 16/17	England 16/17
Retired	25%	26%	48%	58%
Employed full-time	8%	8%	11%	9%
Employed part-time	8%	6%	11%	10%
Self-employed full-time	1%	1%	3%	2%
Self-employed part-time	2%	2%	4%	3%
Not in paid work	33%	34%	24%	21%
Doing voluntary work	5%	5%	7%	6%
Other	18%	18%	9%	6%

20.Thinking about combining paid work and caring, which of the following statements best describes your current situation?	2014/15	2016/17	London 16/17	England 16/17
I am not in paid employment because of my caring responsibilities	40%	46%	25.8%	21.0%
I am not in paid employment for other reasons (e.g. Retired)	22%	39%	47.6%	55.7%
I am in paid employment and I feel supported by my employer	10%	8%	11.3%	10.5%
I am in paid employment but I don't feel supported by my employer	6%	3%	5.0%	3.8%
I do not need any support from my employer to combine my work	4%	2%	4.9%	4.2%
I am self-employed and I am able to balance my work and caring	/	2%	3.6%	3.3%
I am self-employed but I am unable to balance my work and caring (response options for self-employed different for 2016/17 and not comparable)	/	1%	1.8%	1.4%

21.About how long have you been looking after or helping the person you care for?	2014/15	2016/17	London 16/17	England 16/17
Less than 6 months	0%	2%	1%	1%
6 months to a year	4%	3%	3%	2%
1 to 3 years	18%	15%	12%	15%
3 to 5 years	13%	17%	16%	17%
5 to 10 years	24%	20%	22%	24%
10 to 15 years	13%	12%	13%	12%
15 to 20 years	10%	11%	9%	8%
Over 20 years	17%	19%	25%	21%

22.About how long do you spend each week looking after or helping the person you care for?	2014/15	2016/17	London 16/17	England 16/17
0-9 hours per week	3%	6%	6%	6%
10-19 hours per week	4%	4%	8%	7%
20-34 hours per week	7%	5%	8%	7%
35-49 hours per week	19%	14%	9%	8%
50-74 hours per week	9%	10%	7%	7%
75-99 hours per week	7%	7%	8%	8%
100 or more hours per week	35%	47%	33%	36%
Varies – under 20 hours per week	2%	0%	3%	3%
Varies – over 20 hours per week	4%	4%	7%	7%
Other	10%	3%	12%	12%

23.Over the last 12 months, what kinds of things did you usually do for the person you care for?	2014/15	2016/17	London 16/17	England 16/17
Personal care	66%	71%	68%	69%
Physical help	61%	58%	55%	58%
Helping with dealing with care services and benefits	76%	78%	83%	85%
Helping with paperwork or financial matters	74%	75%	82%	85%
Other practical help	88%	87%	90%	93%
Keeping him/her company	78%	80%	82%	83%
Taking him/her out	68%	70%	71%	76%
Giving medicines	81%	75%	74%	76%
Keeping an eye on him/her to see if he/she is alright	59%	87%	88%	91%
Giving emotional support	82%	74%	81%	84%
Other help	24%	21%	20%	17%

24. Do you have any of the following?	2014/15	2016/17	London 16/17	England 16/17
A physical impairment or disability	9%	15%	18%	21%
A sight or hearing loss	8%	12%	13%	17%
A mental health problem or illness	11%	9%	7%	9%
A learning disability or difficulty	6%	5%	4%	3%
A long-standing illness	25%	27%	27%	29%
Other (option not included in 2014/15)	/	13%	15%	12%
None	51%	39%	43%	40%

Local Questions – 25 to 30

25. Thinking about the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?	2014/15	2016/17
Very good	7%	7%
Good	27%	26%
Alright	54%	56%
Bad	8%	10%
Very bad	4%	2%

26. On average, what impact does your relative or friend's condition have on your own life?	2014/15	2016/17
It has a big impact	60%	61%
It has some impact	35%	32%
It has no impact	5%	7%

27. How useful did you find the carer assessment you had?	2014/15	2016/17
Very useful	26%	23%
Quite useful	54%	39%
Not useful	20%	8%
I haven't had a carer assessment in the last year (<i>option not included in 2014/15</i>)	/	29%

28. Did you get a copy of the carer assessment you had?	2014/15	2016/17
Yes	36%	27%
No	26%	19%
I can't remember	38%	30%
I haven't had a carers assessment in the last year (<i>option not included in 2014/15</i>)	/	25%

29. Do you agree that you were treated with respect by the people who carried out your assessment?	2014/15	2016/17
Agree (Agree / Strongly agree – 2014/15)	79%	66%
Neither agree or disagree	17%	29%
Disagree (Disagree / Strongly disagree in 2014/15)	4%	5%

30. Do you receive carers allowance? (<i>new question for 2016/17</i>)	2014/15	2016/17
Yes	/	60%
No	/	40%

31. Did someone help you complete this questionnaire?	2014/15	2016/17	London 16/17	England 16/17
Yes	19%	42%	15%	9%
No	81%	58%	85%	91%

How many children aged 18 or under do you have parental responsibility for? (<i>new question for 2016/17</i>) *no response' returns removed from these figures	2014/15	2016/17	London 16/17	England 16/17
0	/	59%	77%	83%
1	/	14%	13%	9%
2	/	12%	7%	5%
3	/	9%	2%	1%
4 or more	/	6%	1%	1%