

Personal Social Services Survey of Adult Carers in England (SACE)

England 2018-19

Published 25 June 2019

This report contains findings from the Survey of Adult Carers in England, 2018-19 (SACE). This national survey takes place every other year and is conducted by Councils with Adult Social Services Responsibilities (CASSRs). The survey seeks the opinions of carers aged 18 or over, caring for a person aged 18 or over, on a number of topics that are considered to be indicative of a balanced life alongside their unpaid caring role.

Key findings



38.6% of people who had received services said that they were very or extremely satisfied with the support and services received. 7.2% said that that were extremely or very dissatisfied



The majority of carers (65.4%) have been carers for over five years. Almost a quarter (23.5%) have been caring for 20 years or more



60.6% of carers reported that caring had caused them feelings of stress, compared with 58.7% in 2016-17. This was a significant increase



53.4% of carers reported that their caring caused them no financial difficulties. 10.6% of carers said that caring caused them a lot of financial difficulties, which is a significant increase from the 2016-17 figure of 9.6%

Contents

Key findings	1
Introduction	4
Data presentation	4
About the Carers	6
Eligible population and respondents	6
Individual question analysis	12
Overall satisfaction with services	12
Financial difficulties	14
Social contact, social isolation, support and control	16
Quality of life	19
Further information	20

This is an Official Statistics publication



**This document is published by NHS Digital,
part of the Government Statistical Service**

All official statistics should comply with the UK Statistics Authority's Code of Practice for Statistics which promotes the production and dissemination of statistics that inform decision making.

Find out more about the Code of Practice for Statistics at www.statisticsauthority.gov.uk/assessment/code-of-practice

These statistics provide useful insights into the lives and experiences of the members of our communities who provide informal care. They will be of use not just to people who plan, provide or use carers' services, but also more widely to all those who take an interest in the vital support that unpaid carers provide.

Introduction

This report contains England-level findings from the Personal Social Services Survey of Adult Carers in England (SACE). Surveying carers gives vital information about the impact of people's caring responsibilities on their quality of life. This enables greater understanding of the impact of carer support services and can inform service development.

The eligible population for the SACE is all carers aged 18 and over, who are caring for someone aged 18 or over. Carers are included regardless of whether they have received an assessment or review in the previous year.

The survey asks carers questions about their caring responsibilities around the following themes:

- Information about the carer
- Information about the cared-for person
- The impact of caring and quality of life
- The quality of any information and advice received
- The carer's needs and experiences of support
- Carers' involvement in arranging services for the cared-for person

This report presents only key findings from the survey. More detailed information including an interactive Power BI report, summary tables and a record-level csv dataset can be found at <https://digital.nhs.uk/pubs/psscscarerssurvey1819>

Responses collected for the carers survey are also used to populate five of the measures within the Adult Social Care Outcomes Framework (ASCOF), these are:

- 1D: Carer-reported quality of life (Q7-12).
- 1I2: The proportion of carers who reported that they had as much social contact as they would like (Q11).
- 3B: Overall satisfaction of carers with social services (Q4).
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for (Q18).
- 3D2: The proportion of carers who find it easy to find information about support (Q16).

Data presentation

Percentages are rounded to one decimal place; the percentages given for each question may therefore not add up to 100%. The proportions have been calculated by weighting the response data, with eligible population figures, to estimate the proportion of the population who hold these views. Further information on how the weightings are calculated is available in the Methodology and Further Information document¹.

As these questionnaire responses are estimates the figures quoted in relation to the number of 'carers' or 'people' are rounded to the nearest 10. The known figures, such as the eligible population, are rounded to the nearest five.

Surveys are generally used to produce estimates of population proportions as it is usually not possible to ascertain the true values for a whole population. The variation,

¹ <https://digital.nhs.uk/pubs/psscscarerssurvey1819>

or margin of error, present in the sampled data can however be used to produce a range of values, or a confidence interval, within which the true value is likely to sit for each measure. Further information on margins of error and how these are presented on the charts is provided in the 'Methodology and further information' document².

When comparing two estimates, where confidence intervals do not overlap, the difference between the estimates can be considered as statistically significant. The statistical tests are used to identify where differences are statistically significant but cannot be used to imply cause and effect. Further information on the statistical tests used is provided in the 'Methodology and further information' document².

Where response options are quoted from the SACE, these are presented with speech marks either side, for example "So good, it could not be better".

² <https://digital.nhs.uk/pubs/psscarersurvey1819>

About the Carers

Eligible population and respondents

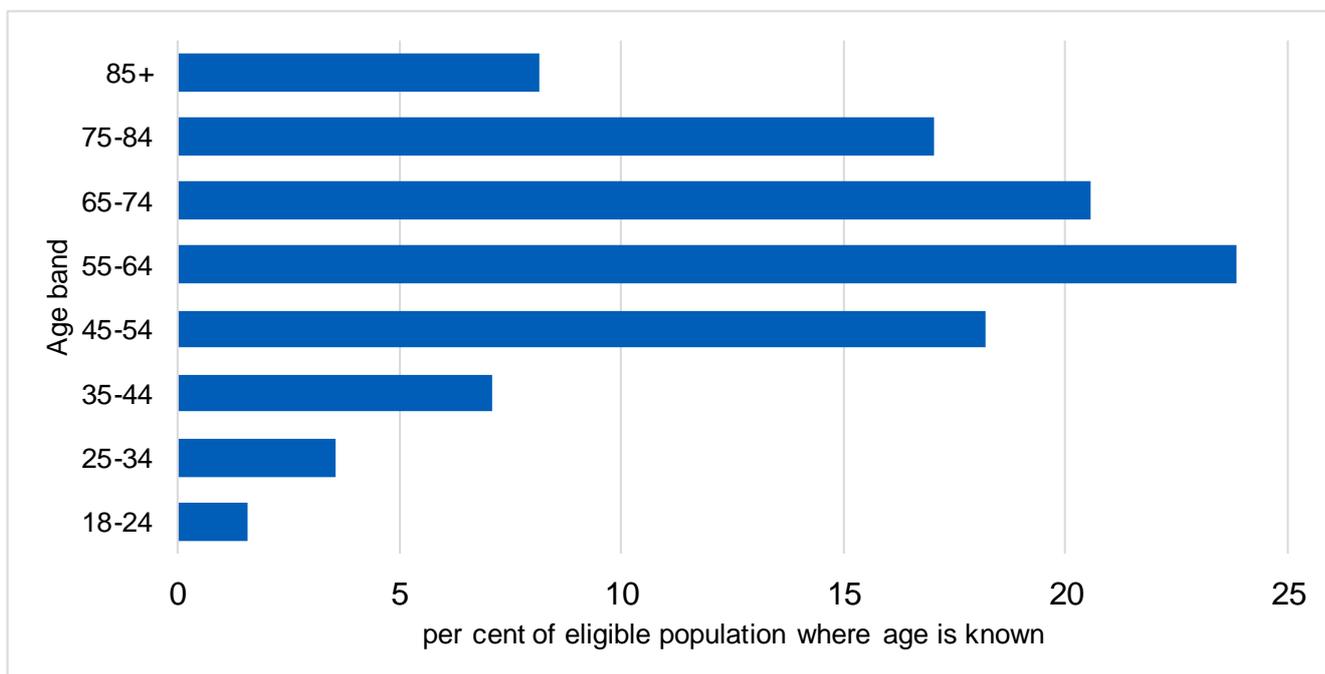
The eligible population includes all carers aged 18 or over who are known to the council and who are also caring for somebody over the age of 18. The total eligible population for the 2018-19 survey was 292,360, from which a sample of 136,095 people was drawn. A total of 50,800 responses were received.

Age of carers

Chart 1 shows the age breakdown of the eligible population, where the age of the carer is known (approximately 261,005 people).

- The largest age band was 55-64 years, which accounted for 23.8% of the eligible population (approximately 62,210 people).
- The smallest group, 18-24 years, accounted for only 1.6% of the eligible population (approximately 4,080 people).

Chart 1: The largest group of carers is aged 55-64

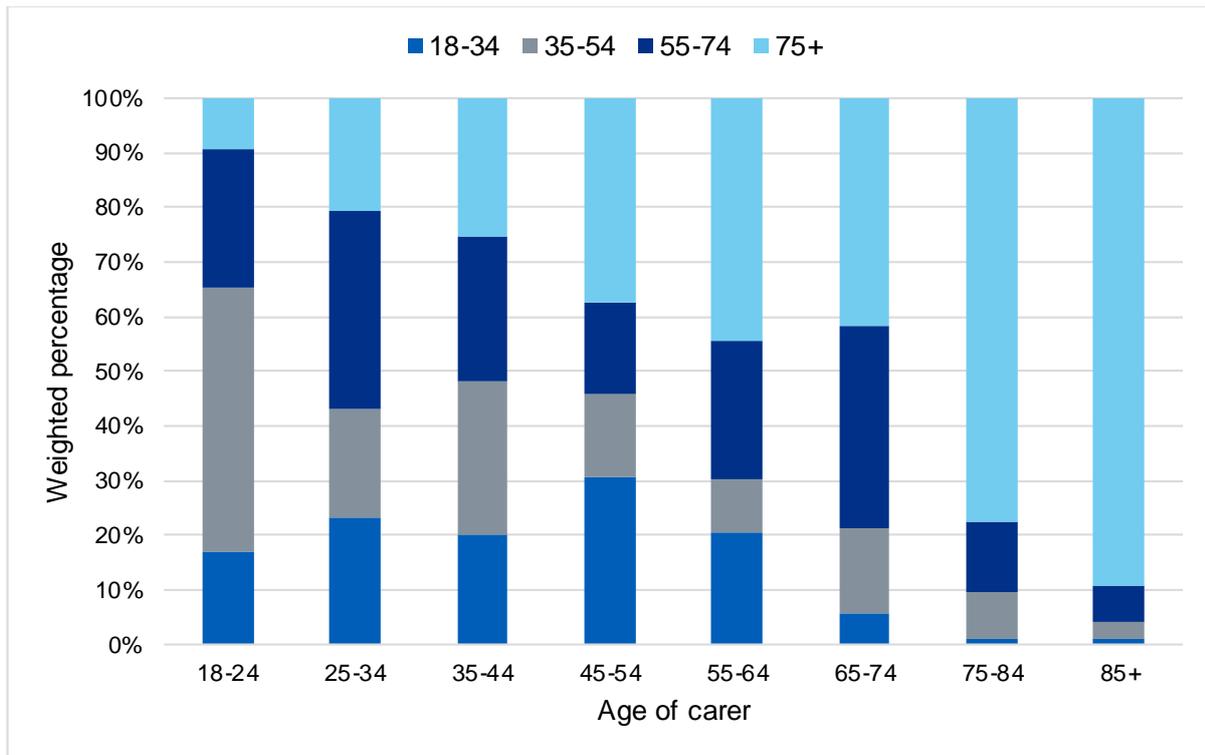


Source: SACE 2018-19, NHS Digital

The age of the carer is generally indicative of the age of the person they are caring for. Chart 2 shows the breakdown of the age of the cared-for person by the age of the carer.

89.3% of carers aged 85 or over were caring for somebody aged 75 or over. For all carers aged 45 or over, the largest group of people they care for is aged 75 or over.

Chart 2: Age breakdown of cared-for person by age of carer



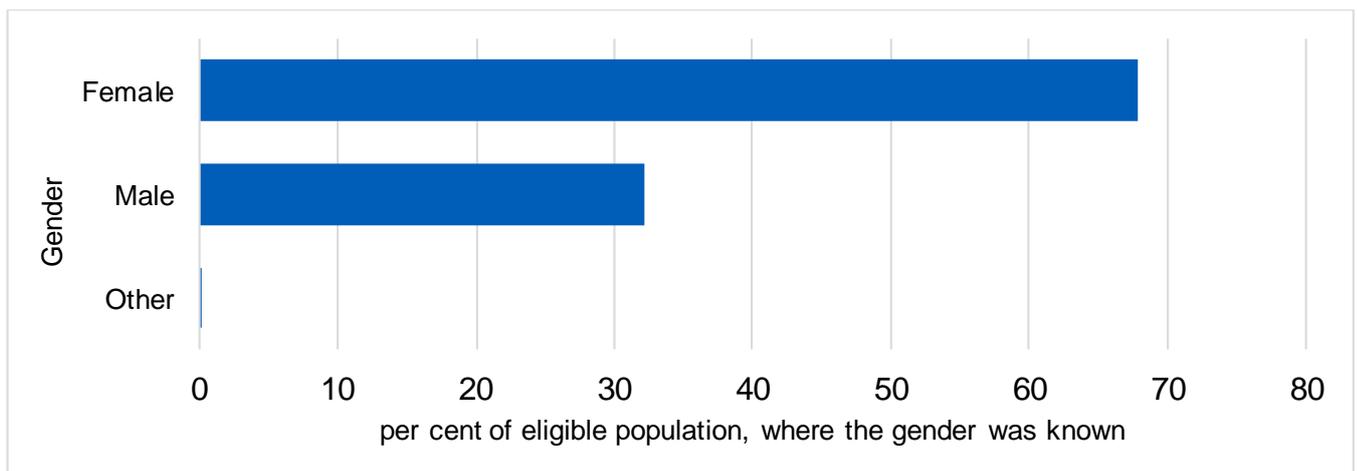
Source: SACE 2018-19 Question 1, NHS Digital

Gender of carers

For the first time, the 2018-19 survey allowed councils to report on carers with a gender of 'Other'. Previously, only 'Female' and 'Male' options were available.

In total 20 people were recorded as having a gender of 'other', which is less than 0.1% of the eligible population. The majority of carers whose gender was known (67.8%) were female (see Chart 3).

Chart 3: The majority of carers were female

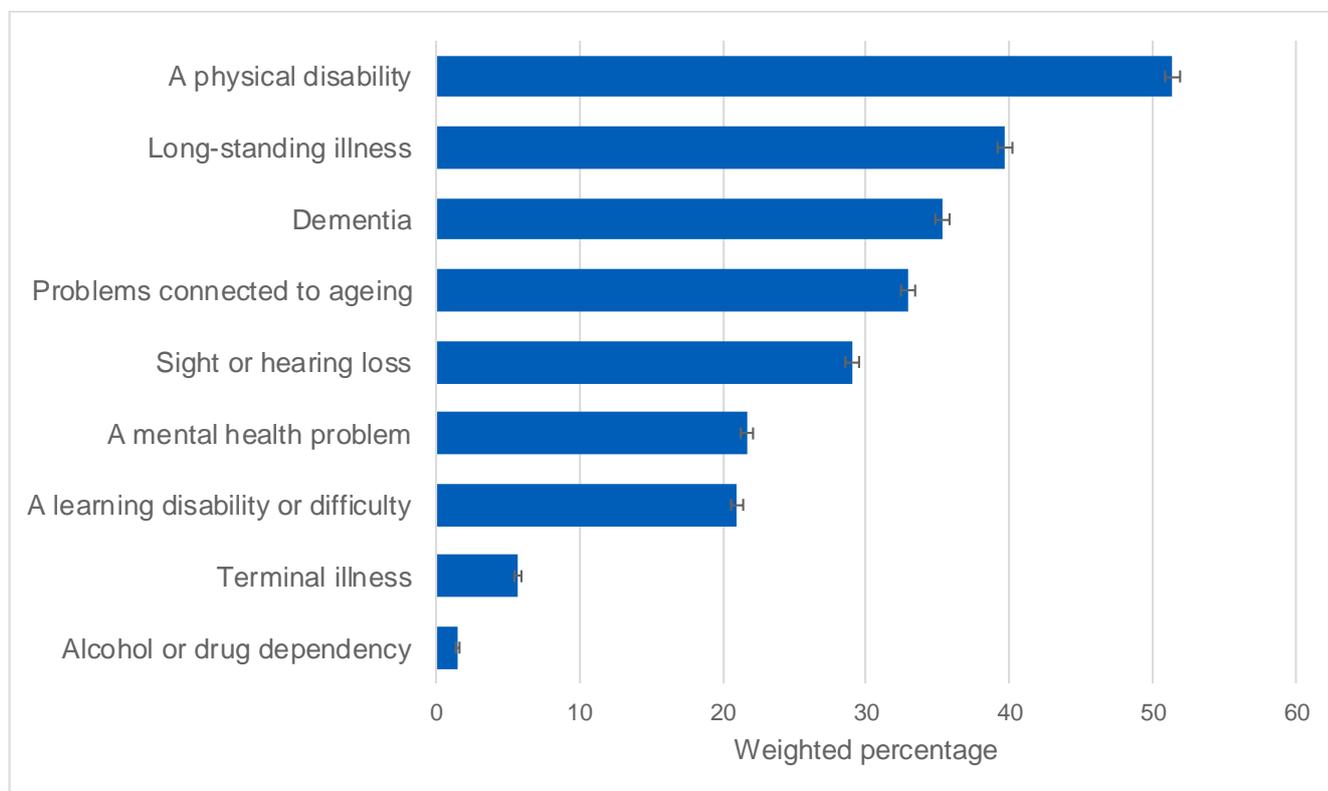


Source: SACE 2018-19, NHS Digital

Support needs of the cared-for person

Most carers who responded to the survey were caring for a person with a physical disability (51.4%), with the next-largest group (39.7%) caring for someone with a long-standing illness (chart 4). Please note that some carers reported caring for someone with multiple health conditions, so the total adds up to more than 100%.

Chart 4: Most carers were caring for someone with a physical disability



Source: SACE 2018-19 Question 2, NHS Digital. Totals may add up to more than 100%.

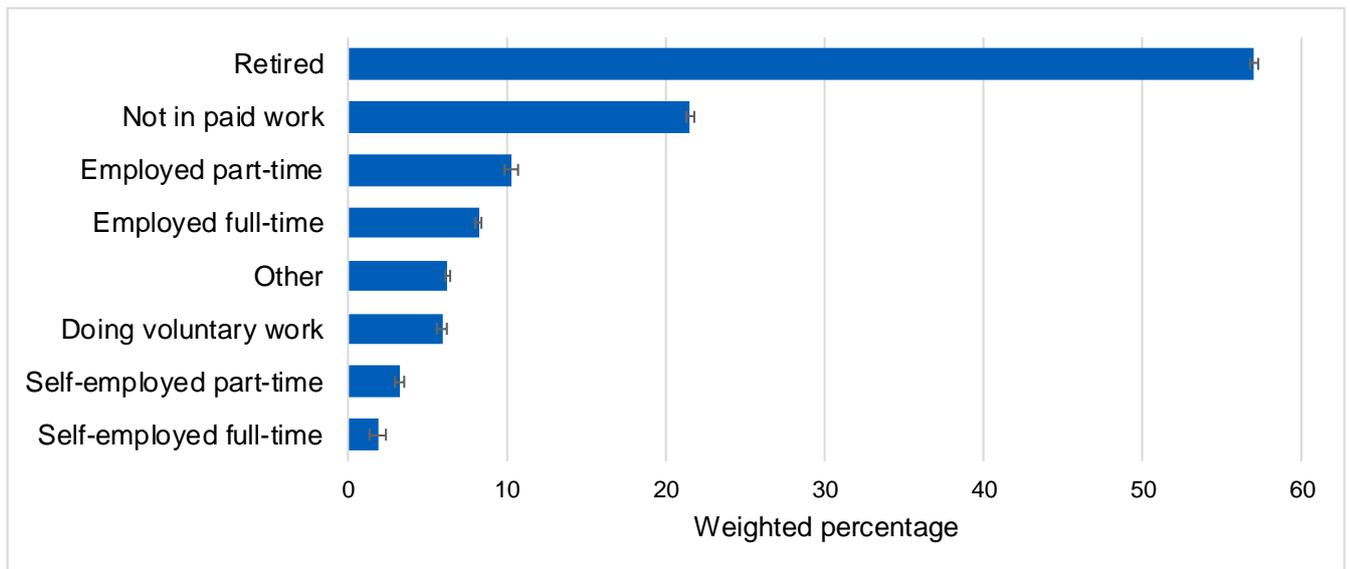
Employment

Chart 5 gives a breakdown of the employment status of carers who responded to the survey. Most carers were either retired (57.0%) or not in paid work (21.5%). Carers who worked either full- or part-time made up 23.6% of all respondents.

The number of carers who were not in paid work because of their caring responsibilities increased significantly from 21.0% in 2016-17 to 22.6% in 2018-19.

It should be noted that some people may fall into more than one category, so the total may add up to more than 100%.

Chart 5: The majority of carers were retired

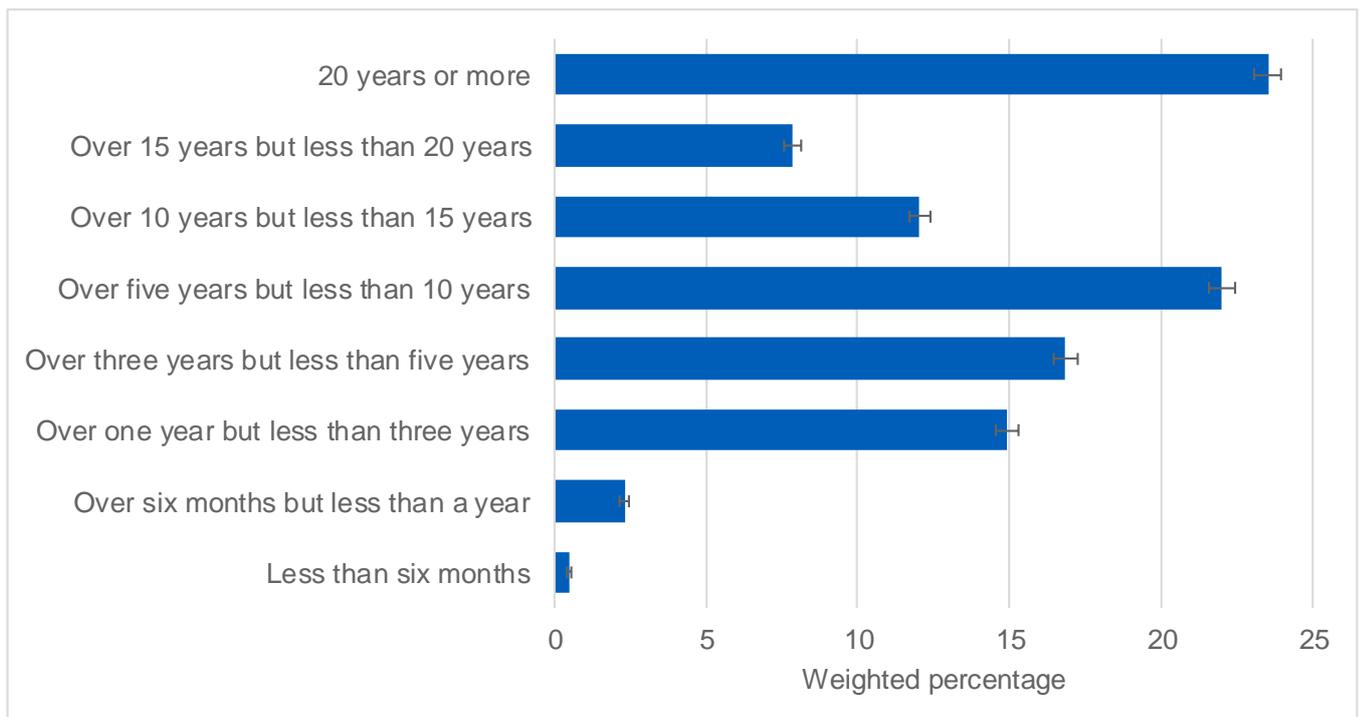


Source: SACE 2018-19 Question 19, NHS Digital. Totals may add up to more than 100%.

Time spent caring

Carers were asked how long they have been looking after the person they care for. The majority (65.4%) have been carers for over five years. Almost a quarter (23.5%) have been caring for 20 years or more (see Chart 6).

Chart 6: Almost a quarter of respondents had been caring for 20 years or more



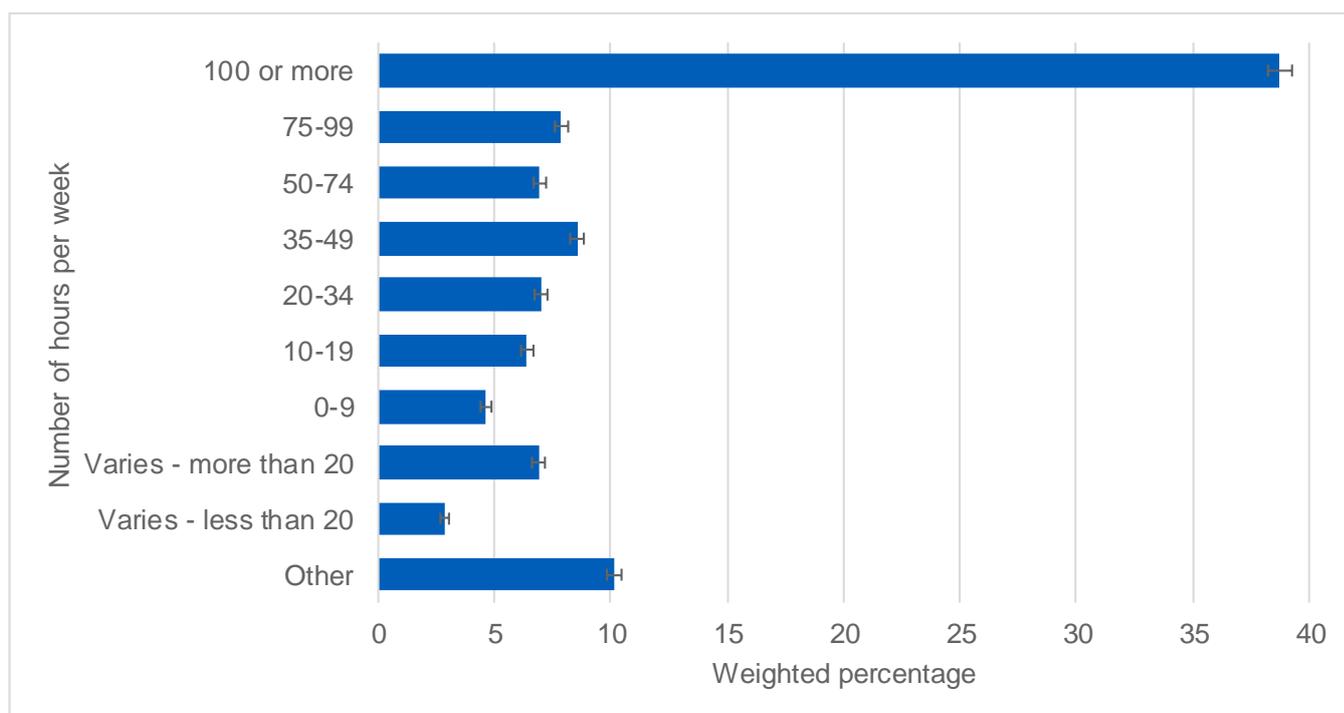
Source: SACE 2018-19 Question 21, NHS Digital

The number of respondents who had been caring for between 5 and 10 years – the largest group in the 2016-17 survey³ – decreased significantly from 23.6% in 2016-17 to 22.0% in 2018-19.

The largest group of carers, those who had been caring for more than 20 years, showed a significant increase from 21.4% of respondents in 2018-19.

Carers were also asked roughly how long they spend on their caring duties each week (Chart 7). More than three quarters (76.0%) reported spending over 20 hours per week looking after the cared-for person, with 38.7% spending over 100 hours per week on their caring duties.

Chart 7: Over one third of carers spend over 100 hours a week on their caring duties



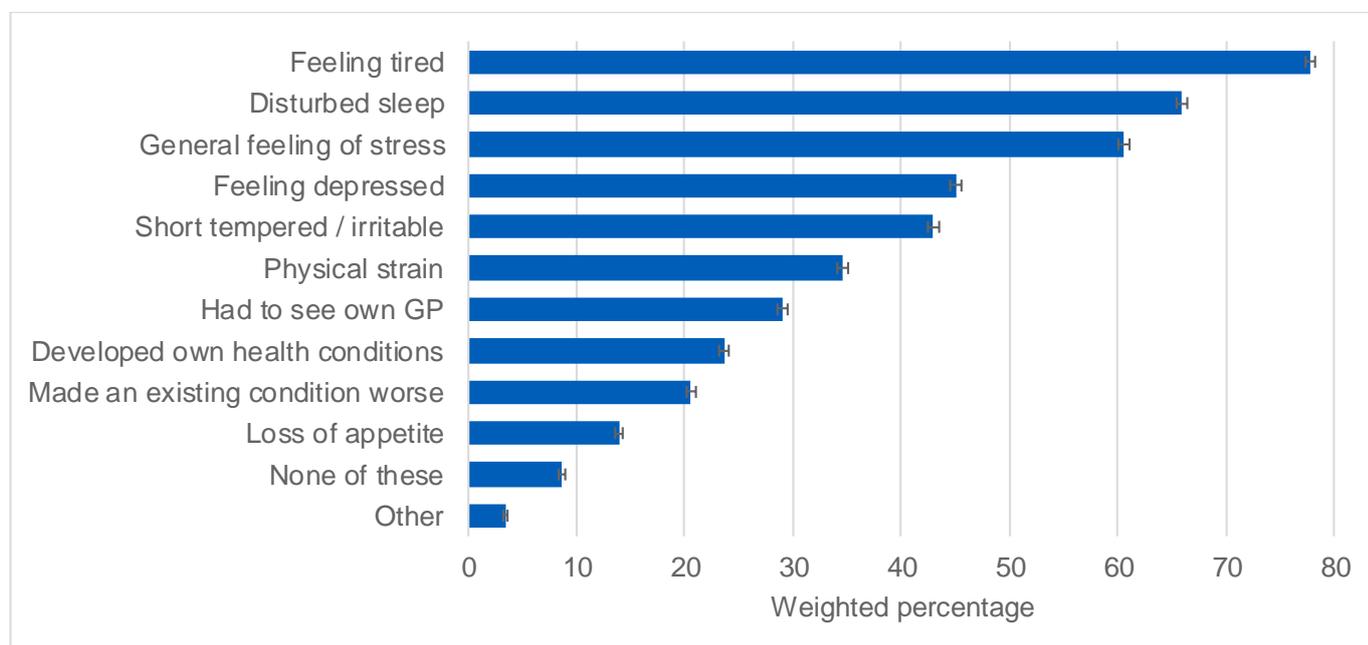
Source: SACE 2018-19 Question 22, NHS Digital

³ <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/personal-social-services-survey-of-adult-carers-in-england-2016-17>

Effects on carers' health

Caring responsibilities can also impact on the physical and mental health of carers. The majority of carers reported that they had been affected by “feeling tired” (77.8%), “disturbed sleep” (66.0%) and a “general feeling of stress” (60.6%). Please note that some carers reported multiple effects on their health, so the total adds up to more than 100% (chart 8).

Chart 8: "Feeling tired" was the most commonly reported effect of caring on carers' health



Source: SACE 2018-19 Question 14, NHS Digital. Totals may add up to more than 100%

There was an increase in the proportion of carers reporting a number of effects on their health from 2016-17 to 2018-19. Effects including feeling tired, feeling depressed and physical strain all showed a significant increase (table 1).

Table 1: Carers reported significant increases in a number of effects on their health

	Weighted percentage		
	2016-17	2018-19	Change
Feeling tired	76.0	77.8	1.8
Disturbed sleep	64.0	66.0	2.0
General feeling of stress	58.7	60.6	1.9
Feeling depressed	43.4	45.1	1.6
Short tempered/irritable	41.8	43.0	1.2
Physical strain (e.g. back)	32.8	34.6	1.8
Made an existing condition worse	19.7	20.6	0.9
Loss of appetite	13.0	13.9	0.9

Source: SACE 2018-19 Question 14, NHS Digital. Percentages may not add up due to rounding

Individual question analysis

The questions that feed into the ASCOF indicators were analysed individually, to see what factors influenced people’s responses to those questions. Following consultation with front-line social services staff, we also included questions that we were advised would be of particular interest to councils.

Analysis was done using a logistic regression model, which is a way of identifying which factors have a significant impact on the question being analysed. It also indicates which factors have the greatest impact. For more details on logistic regression and significance testing, please see the ‘Methodology and further information’ document⁴.

Unless stated otherwise, all relationships discussed in the following section were statistically significant.

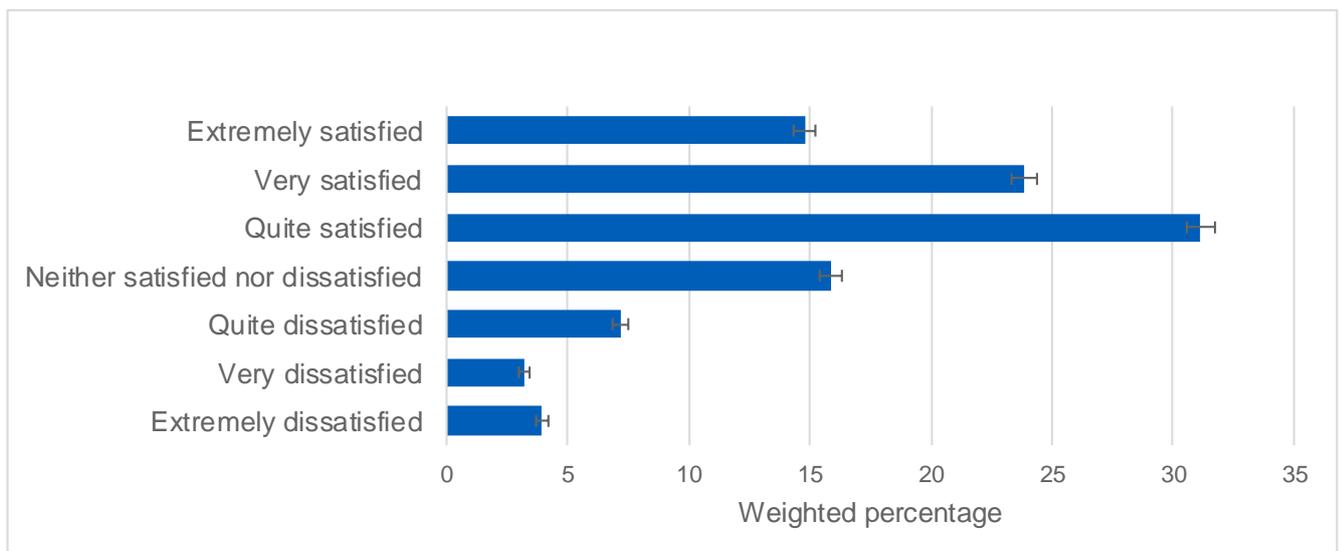
Please note that to make the charts easier to interpret, some central response options may have been removed. Data for all response options are included in the ‘Tables for report charts’ document⁴

Overall satisfaction with services

38.6% of carers who had received services over the last year reported that they were extremely or very satisfied with the services and support received, compared with 39.0% in 2016-17.

7.2% of respondents said that they were extremely or very dissatisfied with the services they received, compared with 6.3% in 2016-17 (see table 2). Neither of these changes was statistically significant.

Chart 9: The largest group of carers were “quite satisfied” with the support and services they received



Source: SACE 2018-19 Question 4, NHS Digital

⁴ <https://digital.nhs.uk/pubs/psscscarersurvey1819>

Overall there was little change between the levels of satisfaction reported in 2016-17 and 2018-19. Table 2 shows the changes for each response. None of the changes were statistically significant.

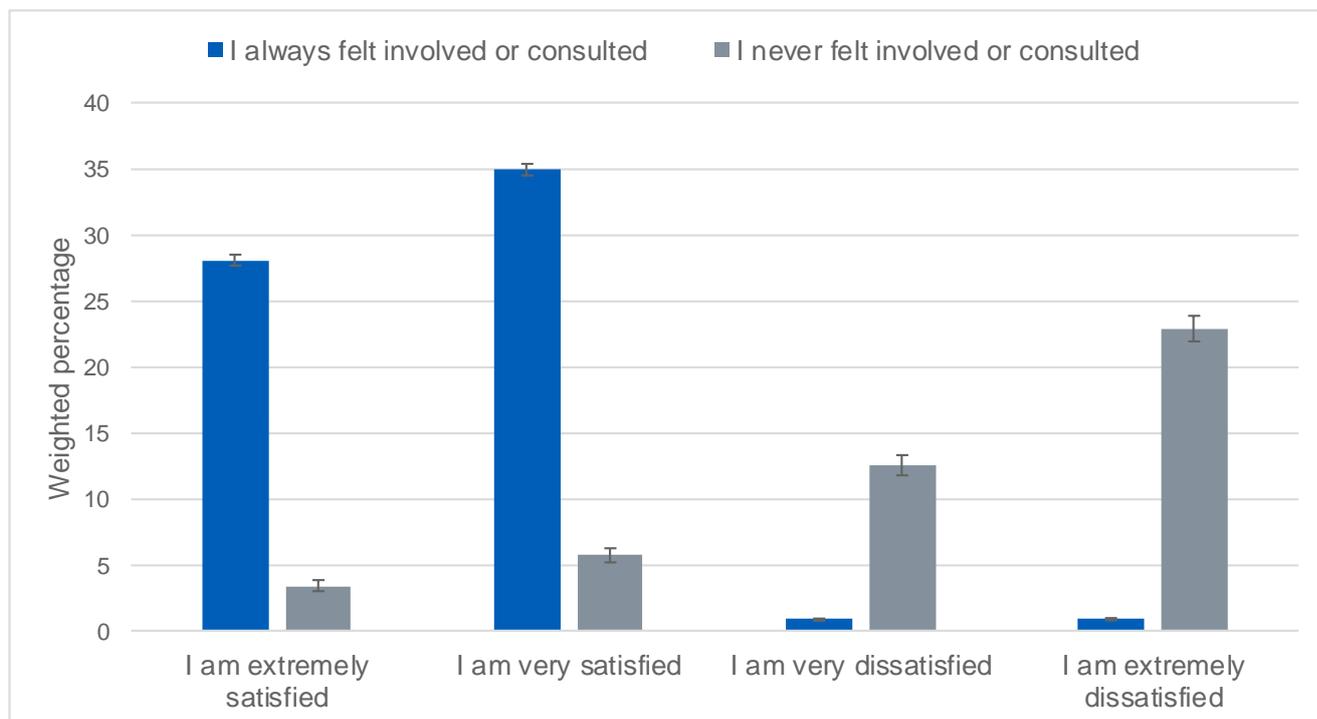
Table 2: Levels of satisfaction reported by carers who had received services or support

	Weighted percentage		
	2016-17	2018-19	Change
Extremely satisfied	14.8	14.8	0.0
Very satisfied	24.2	23.9	-0.4
Quite satisfied	32.0	31.2	-0.9
Neither satisfied nor dissatisfied	15.6	15.9	0.2
Quite dissatisfied	7.0	7.2	0.2
Very dissatisfied	2.8	3.2	0.4
Extremely dissatisfied	3.5	4.0	0.4

Source: SACE 2018-19 Question 4, NHS Digital. Percentages may not add up due to rounding

The factors contributing to carers’ satisfaction ratings were analysed. Among people who were aware of discussions that had taken place relating to support for the cared-for person, feeling involved in these discussions was the greatest factor influencing their overall satisfaction. People who felt more involved in discussions reported a greater level of general satisfaction than those who did not feel involved (see chart 10).

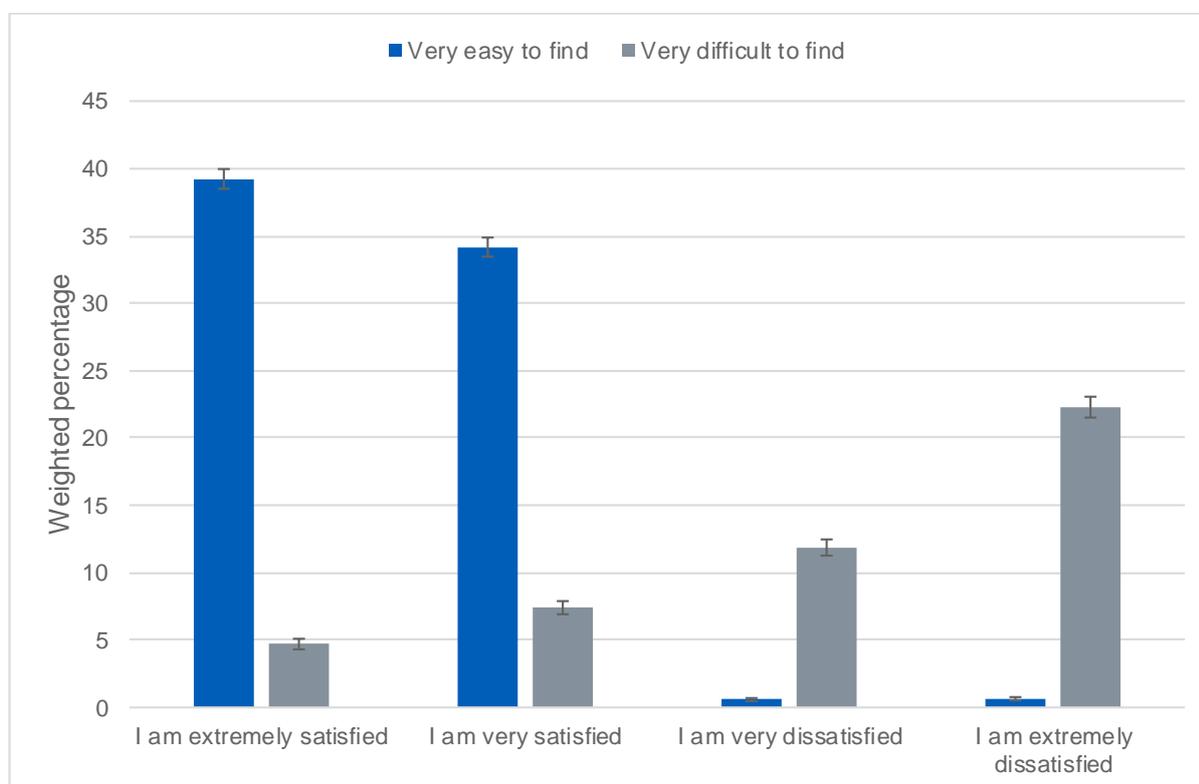
Chart 10: Carers who felt involved in discussions about the cared-for person were more satisfied with the services they received



Source: SACE 2018-19 Questions 4 and 18, NHS Digital

Access to information about available support and services was also a major factor influencing carers' satisfaction. For people who had tried to find information and advice, there was a strong link between satisfaction and ease of finding information. Carers who found it easy to access information reported a greater level of satisfaction than those who found it difficult (chart 11).

Chart 11: Carers who found it easy to access information were more satisfied with the services they received



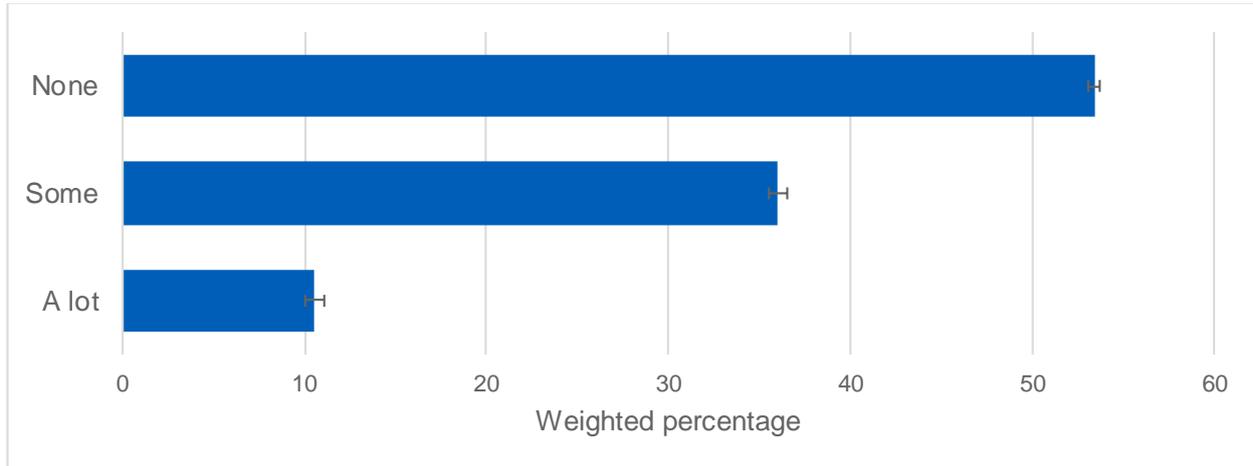
Source: SACE 2018-19 Questions 4 and 16, NHS Digital

Financial difficulties

In response to the question “In the last 12 months, has caring caused you any financial difficulties?”, 53.4% of carers responded “No, none at all” (chart 12).

10.6% of respondents reported that caring had caused them a lot of financial difficulties in the past 12 months. This is a significant increase from the 2016-17 figure of 9.6%

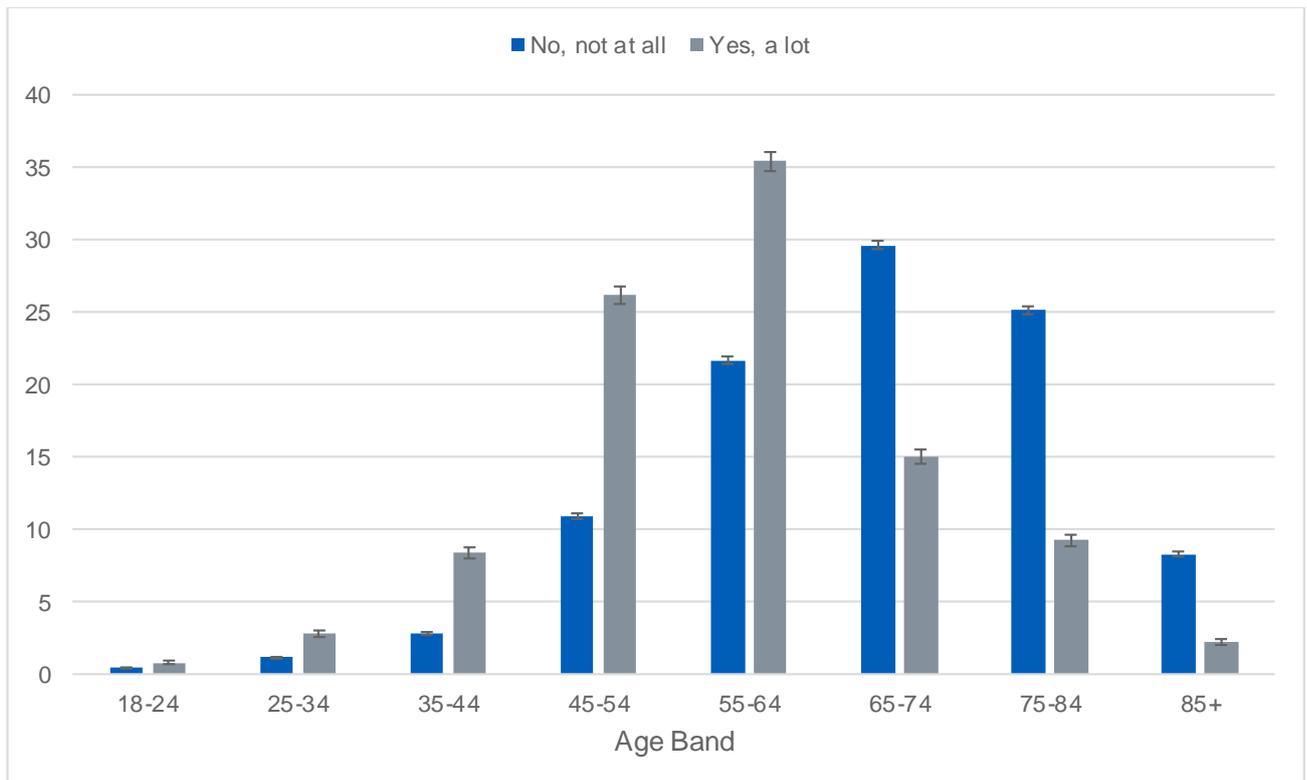
Chart 12: The majority of carers reported that caring had not caused them any financial difficulties



Source: SACE 2018-19 Question 15, NHS Digital

Age band of the carer was the biggest factor influencing whether they had experienced financial difficulties. In all age bands under 65 years old, carers were more likely to report that they had faced a lot of financial difficulties than none. However, in all age bands aged 65 and over, carers were more likely to report that they had experienced no financial difficulties (chart 13).

Chart 13: The age of the carer had a significant impact on whether their caring had caused them any financial difficulties



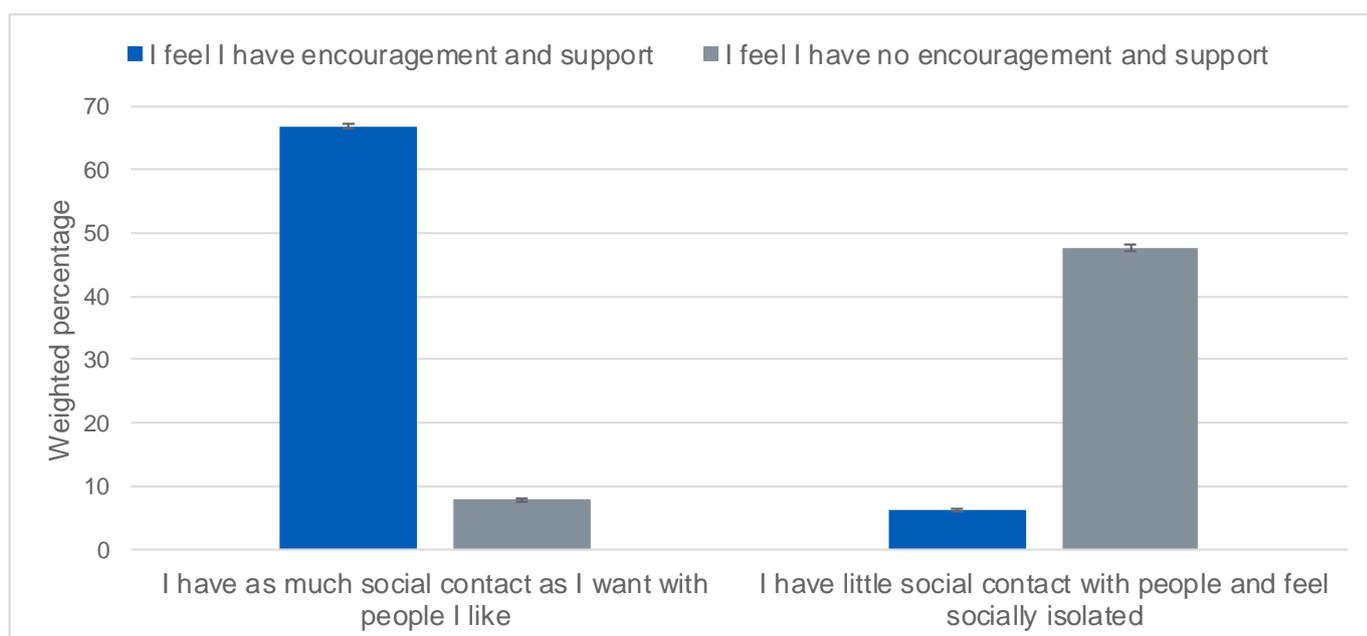
Source: SACE 2018-19 Question 15, NHS Digital

Social contact, social isolation, support and control

A number of questions in the survey relate to social contact, how carers spend their time, whether they feel supported and how much control they feel they have over their lives.

Analysis of these questions found a significant link between the responses. For example, of the factors analysed, the biggest influence on whether or not a carer felt encouraged and supported was the level of social contact they felt they had. Carers who felt socially isolated were more likely to report that they felt they had no support or encouragement (chart 14).

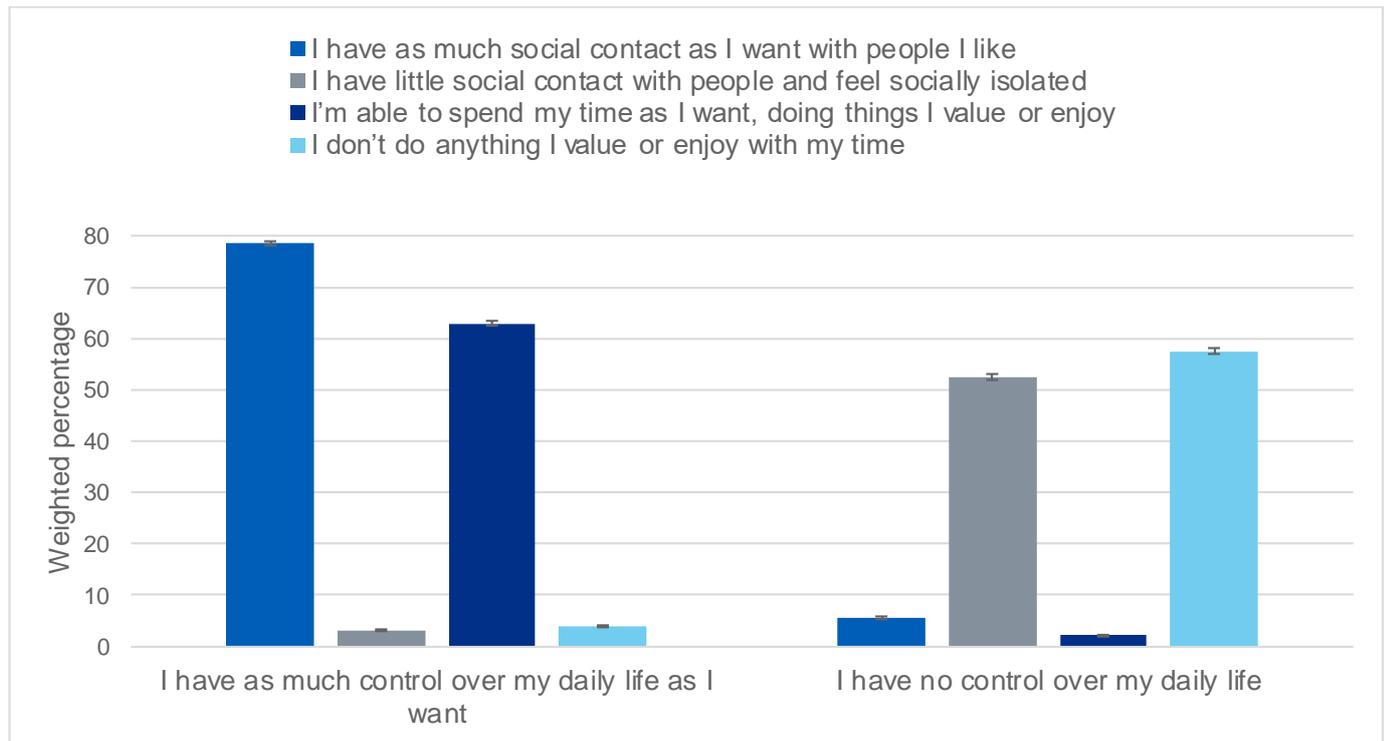
Chart 14: Carers who have as much social contact as they want are more likely to feel encouraged and supported



Source: SACE 2018-19 Questions 11 and 12, NHS Digital

Significant links were found between the level of control carers had over their lives and a number of other factors. Of the factors analysed, the biggest influences on whether or not carers felt they had control over their lives were being able to spend time doing what they wanted and the level of social contact they had (chart 15).

Chart 15: Carers who have as much social contact as they want and can do things they enjoy feel they have more control over their lives



Source: SACE 2018-19 Questions 7, 8 and 11, NHS Digital

Carers were also asked how well they feel they are looking after themselves. There was a significant link between this question and those relating to social contact and control. Carers who feel they have enough control over their lives and who have as much social contact as they want were more likely to report that they look after themselves (chart 16).

Chart 16: Carers who have as much social contact as they want and have control over their lives are more likely to look after themselves



Source: SACE 2018-19 Questions 8, 9 and 11, NHS Digital

When compared with the 2016-17 survey, there were significant decreases in the number of carers reporting that they have as much control as they want, that they feel encouraged and supported, that they look after themselves and other related factors (table 3)

Table 3: Carers reported significant decreases in a range of factors relating to social contact and support

	Weighted percentage		
	2016-17	2018-18	Change
I have as much social contact as I want with people I like	35.5	32.5	-3.0
I look after myself	54.9	51.9	-3.0
I'm able to spend my time as I want, doing things I value or enjoy	19.5	17.3	-2.2
I feel I have enough encouragement and support	36.3	34.6	-1.8
I have as much control over my daily life as I want	25	23.3	-1.7

Source: SACE 2018-19 Questions 7, 8, 9, 11 and 12, NHS Digital. Percentages may not add up due to rounding

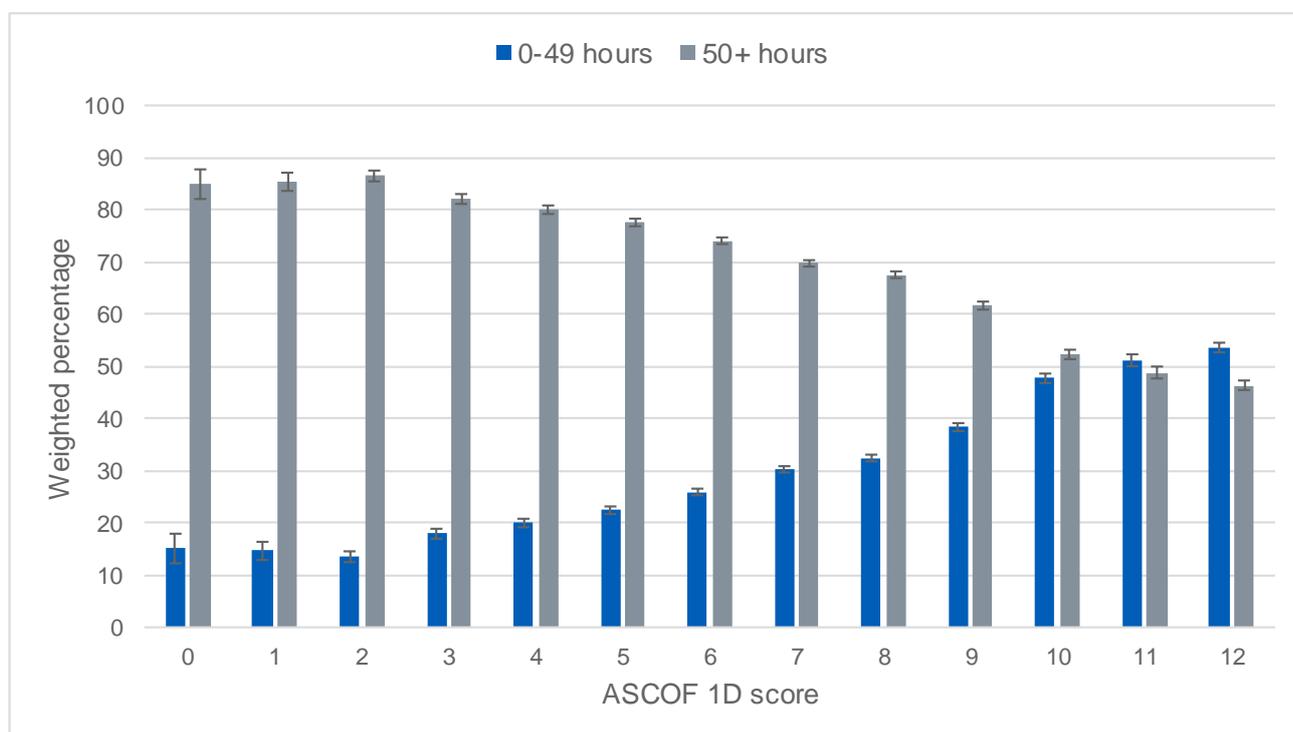
Quality of life

ASCOF measure 1D uses the responses to six questions within the SACE to calculate a quality of life score for each carer⁵. The score ranges from 0-12, with 0 as the lowest and 12 the highest. The England level quality of life score in 2018-19 was 7.5.

Analysis was carried out on the factors that influence the quality of life scores. A range of questions, excluding those used to calculate the score, were analysed to see which had the greatest influence on quality of life score. This analysis found that the amount of time spent caring and whether or not caring caused financial difficulties had the greatest impact.

Chart 17 shows the quality of life score by amount of time spent caring⁶. Of those with the lowest quality of life score (0), 84.9% of respondents spent 50 hours or more on their caring responsibilities. For those with the highest score (12), the figure is 46.4%.

Chart 17: Carers who spend 50 hours or more per week on their caring duties tend to have a lower quality of life score



Source: SACE 2018-19 Question 22, NHS Digital

Looking at financial difficulties, it is clear that people whose caring responsibilities cause them financial difficulties tend to have a lower quality of life score (chart 18).

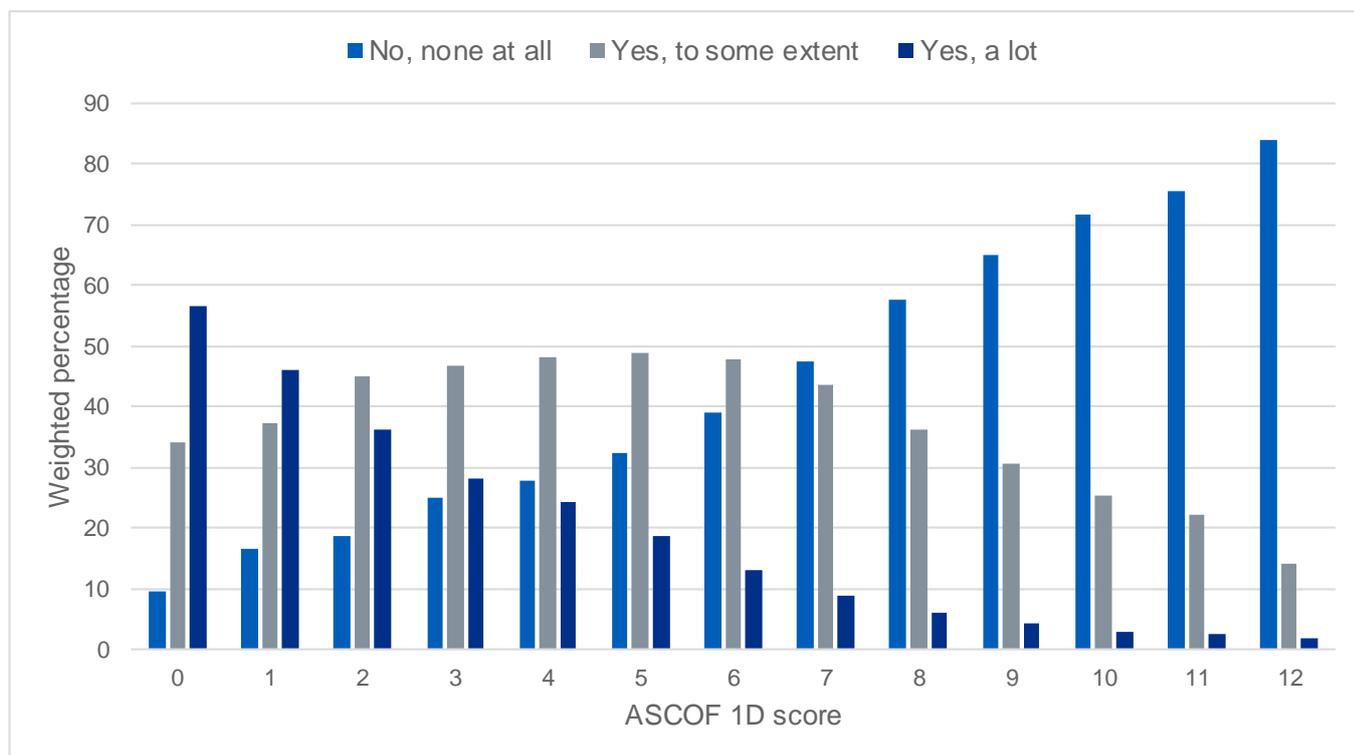
Of the carers with a quality of life score of 0, 56.5% said that their caring had caused a lot of financial difficulties and 34.0% said that it had caused some. For those with a score of 12, 84.0% of respondents said that their caring caused them no financial

⁵ For full details of the methodology for the measure, see the ASCOF Handbook of Definitions at <https://www.gov.uk/government/publications/adult-social-care-outcomes-framework-handbook-of-definitions>

⁶ The analysis excluded those who gave responses of 'Variable: under 20 hours', 'Variable: over 20 hours' and 'Other' to remain consistent with the 2016-17 analysis

difficulties. Only 1.8% of respondents whose caring caused them a lot of financial difficulties had a quality of life score of 12.

Chart 18: Carers whose caring duties cause them financial difficulties tend to have a lower quality of life score



Source: SACE 2018-19 Question 15, NHS Digital

Both time spent caring and the level of financial difficulties caused by caring were also found to have a significant impact on quality of life in the 2016-17 survey⁷, with the overall pattern being very similar in each year. However as noted above, the 2018-19 survey found a significant increase in the number of carers reporting that their caring caused them a lot of financial difficulties.

Further information

The Department for Work and Pensions (DWP) publish information on the number of people in receipt of the carer’s allowance. Although differing definitions mean that direct comparisons with the SACE should not be made, the DWP figures may provide some further background information and context.

All DWP benefits statistics are available from their website:

<https://www.gov.uk/government/collections/dwp-statistical-summaries>

⁷ <https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/personal-social-services-survey-of-adult-carers-in-england-2016-17>

Information and technology for better health and care

www.digital.nhs.uk

0300 303 5678

enquiries@nhsdigital.nhs.uk

 [@nhsdigital](https://twitter.com/nhsdigital)

This publication may be requested
in large print or other formats.

**Published by NHS Digital,
part of the Government Statistical Service**

Copyright © 2019 NHS Digital.

NHS Digital is the trading name of The Health and Social Care
Information Centre a non-departmental body created by statute.

OGL

You may re-use this document/publication (not including logos)
free of charge in any format or medium, under the terms of the Open
Government Licence v3.0.

To view this licence visit

www.nationalarchives.gov.uk/doc/open-government-licence

or write to the Information Policy Team, The National Archives,
Kew, Richmond, Surrey, TW9 4DU;

or email: psi@nationalarchives.gsi.gov.uk