

Personal Social Services Survey of Adult Carers in England

England 2021-22

Published 23 June 2022

This report contains findings from the Survey of Adult Carers in England, 2021-22 (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



Excluding carers that had not received support or services, over a third (36.3 per cent) of carers felt they were very or extremely satisfied, this contrasts to 38.7 per cent in 2018-19. 8.5 per cent of carers felt they were very or extremely dissatisfied, this was an increase from 7.2 per cent in 2018-19.



Over half of carers (57.2 per cent) reported their caring role had not caused any financial difficulties over the last 12 months, this was an increase from 53.4 per cent in 2018-19.



Although there has been a steady decline year on year, the proportion of carers who felt they have as much social contact as they want, with people they like decreased more profoundly in 2021-22, from 32.5 per cent in 2018-19 to 28.0 per cent in 2021-22. The proportion that felt they have little social contact and feel socially isolated increased from 17.4 per cent to 20.9 per cent.



The per cent of carers that feel they have encouragement and support has fallen year on year and most recently from 34.6 per cent in 2018-19 to 31.5 per cent in 2021-22. The per cent of carers that feel they have no encouragement or support increased from 20.7 per cent in 2018-19 to 22.8 per cent in 2021-22.

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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 informal, unpaid 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.

149 of the 152 Councils with Adult Social Services Responsibilities (CASSRs) took part in the 2021-22 SACE.

Due to the impact of coronavirus (COVID-19) the 2020-21 survey was postponed by one full year and took place in 2021-22. The survey will continue to take place biennially from 2021-22 onwards. It is important to bear this in mind when considering the time series charts and comparisons.

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: <http://digital.nhs.uk/pubs/psscscarerssurvey2122>

Details of all questions are included as part of the associated data files.

SACE is a biennial survey that first took place in 2012-13. Details of comparability is available in the data quality report. The fieldwork for the survey was conducted between October and November 2021 when there were still restrictions imposed due to the (COVID-19) pandemic. A summary of the impact of COVID-19 on the survey data is included in the [data quality report](#) that accompanies this publication.

Responses collected for the carers survey are also used to populate five of the measures within the [Adult Social Care Outcomes Framework \(ASCOF\)](#).

Data presentation

Percentages are rounded to one decimal place; the percentages given for each question may therefore not add up to 100 per cent. 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 document](#).

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, (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. Charts which contain estimates included a standard error line. Further information on margins of error and how these are presented on the charts is provided in the '[Methodology and Further Information](#)' document.

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. All data differences included in this report are statistically significant. Further information on the statistical tests used is provided in the '[Methodology and Further Information](#)' document.

Supplementary information

Users of this report are encouraged to also consult and utilise the additional information published as part of this statistical release, these accompanying documents are available at <http://digital.nhs.uk/pubs/psscscarerssurvey2122> and include:

- **Methodological and Further Information** which provides information about the survey including understanding the eligible population, sample sizes and the demographic profile of those that responded, together with calculating standard errors, weighting methodology and analysis.
- **Data Quality Report** and the **Data Quality Annex** contain information on the quality of the data, validation methods and analysis on whether subgroups of carers, i.e. those that used translated questionnaires, answer questions differently.
- **Annex Tables** provide question response and demographic data, response rates and margin of errors.
- **CSV Data and Dictionary** contain record level information together with a guidance document.
- **Time Series** contains England and CASSR level question response data and identifies which are statistically different.
- **Tables for report charts** contains the tables for the charts used in the report.
- **Interactive Report** ([ASC Analytical Hub](#)) presents the 'Key Findings' of this report, together with CASSR level charts to allow users to compare data at England or CASSR level.

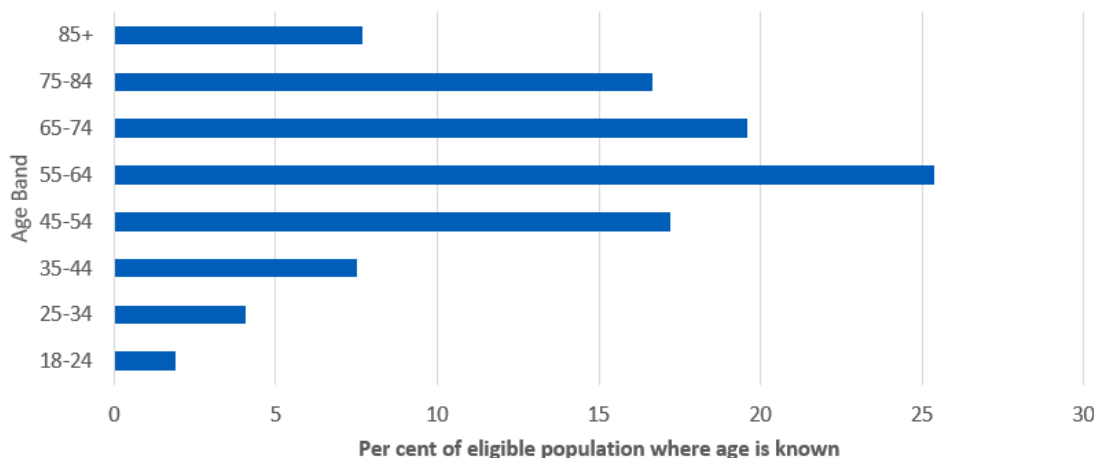
About the Carers

The eligible population includes all informal, unpaid 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 2021-22 survey was 322,105, this was an increase from 292,360 in 2018-19. From the eligible population, 133,980 carers were sampled, a total of 43,525 responses were received. In 2018-19, 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.

Chart 1: Age of carers

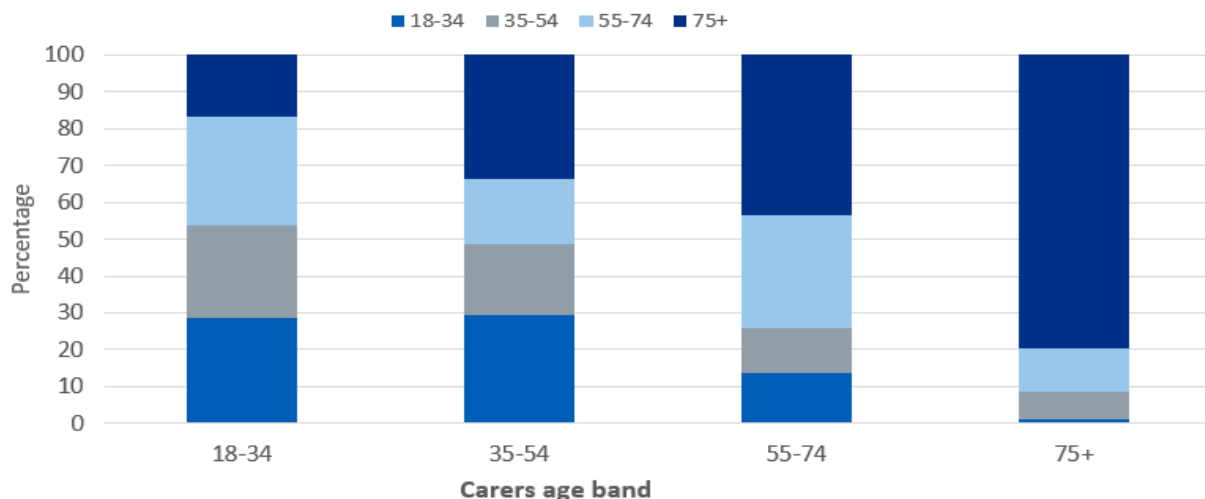


Source: SACE 2021-22

- The largest age band was 55-64 years, which accounted for 25.4 per cent of the eligible population (73,580 carers)
- The smallest group was 18-24 years which accounted for 1.9 per cent of the eligible population (5,550 carers).

Chart 2 shows the age of the carers and the age of the person they care for. The chart shows most carers aged 75 and over (79.6 per cent, 71,090 carers), care for someone also aged over 75.

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



Source: SACE 2021-22

Gender of carers

The majority of carers whose gender was known were female (67.7 per cent, 202,180). 32.3 per cent (96,370) of carers were male.

Employment status of carers

Chart 3 gives a breakdown of the employment status of carers who responded to the survey. Over half of carers (56.7 per cent, 182,770 carers) were retired. 20.5 per cent of carers (66,130) were not in paid work¹.

Chart 3: Employment status of carers



Source: SACE 2021-22

Parental caring responsibilities

The vast majority of carers (89.3 per cent, 287,750) do not have parental responsibility for any children aged 18 years or under. This was an increase from 87.3 per cent (247,930) in the 2018-19 survey.

Completing the survey

Over 90 per cent (91.6 per cent, 293,230) of carers did not have help to complete the survey. This was an increase from 90.8 per cent (265,560) in 2018-19.

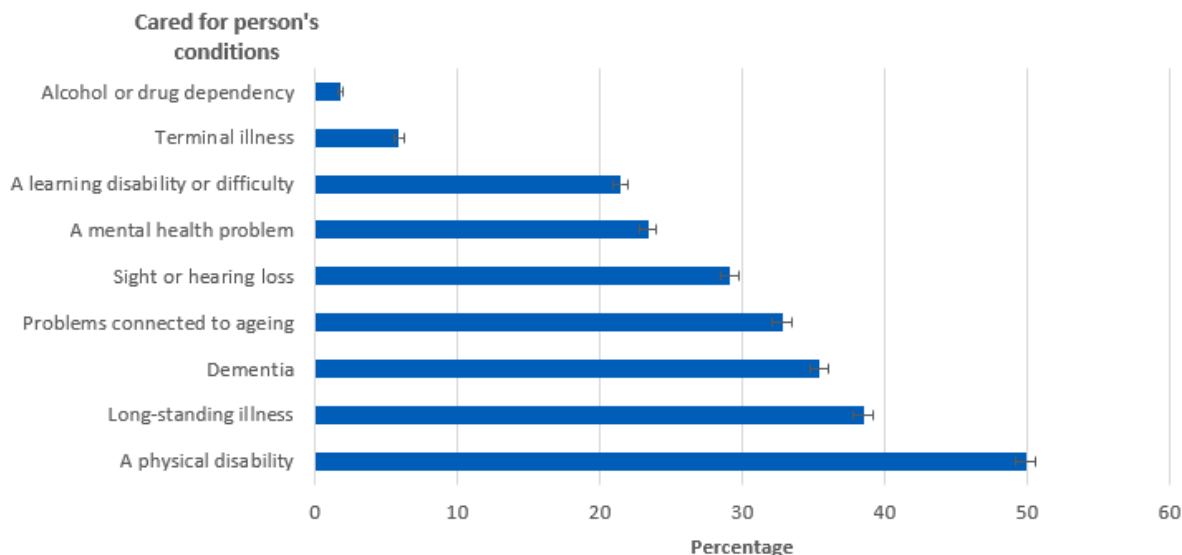
¹ It should be noted that some people may fall into more than one category, so the total may add up to more than 100 per cent.

About the Cared-for person

Support needs of the cared-for person

Almost half of carers (49.9 per cent, 160,580 carers) who responded to the survey, care for someone with a physical disability. 38.5 per cent (124,060) care for someone with a long-standing illness and 35.4 per cent (113,970) care for someone with dementia².

Chart 4: Support needs of cared-for person



Source: SACE 2021-22

Although physical disability is still the most common support need, the percentage of carers who care for someone with a physical disability dropped from 51.4 per cent (150,260) in 2018-19 to 49.9 per cent (160,580) in 2021-22. Chart 5 also shows there has been an increase in the proportion of carers caring for someone with a mental health problem and alcohol or drug dependency.

² Please note that some carers reported caring for someone with multiple health conditions, so the total adds up to more than 100 per cent.

Chart 5: Support needs of cared-for person over time

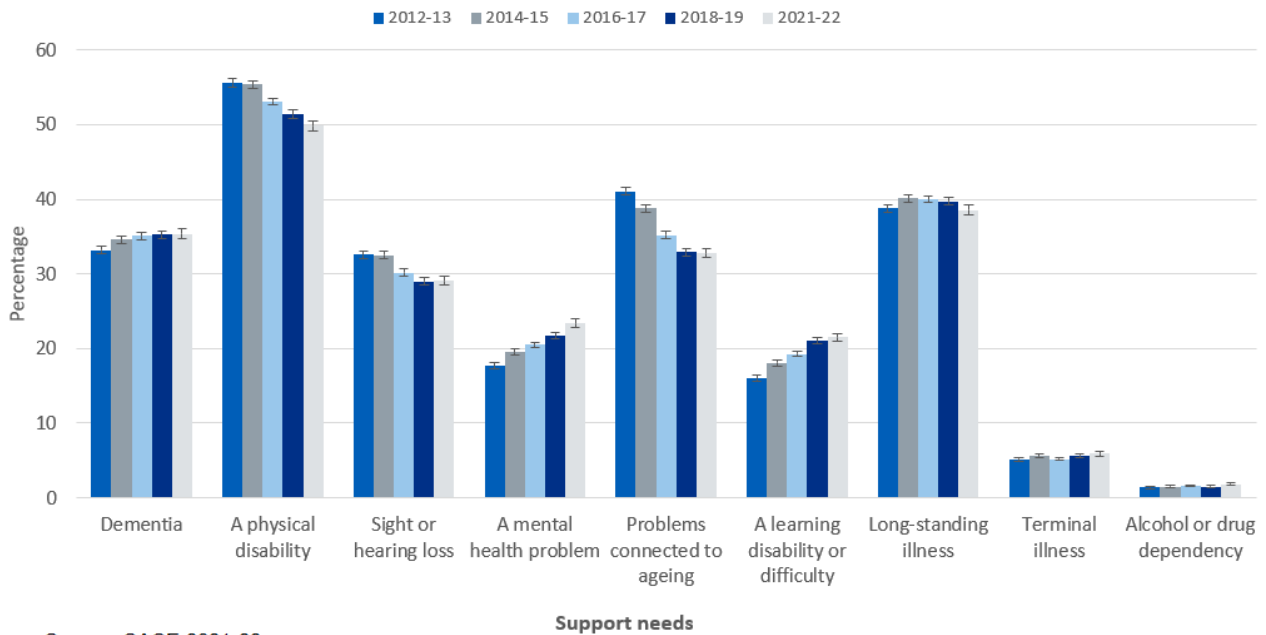
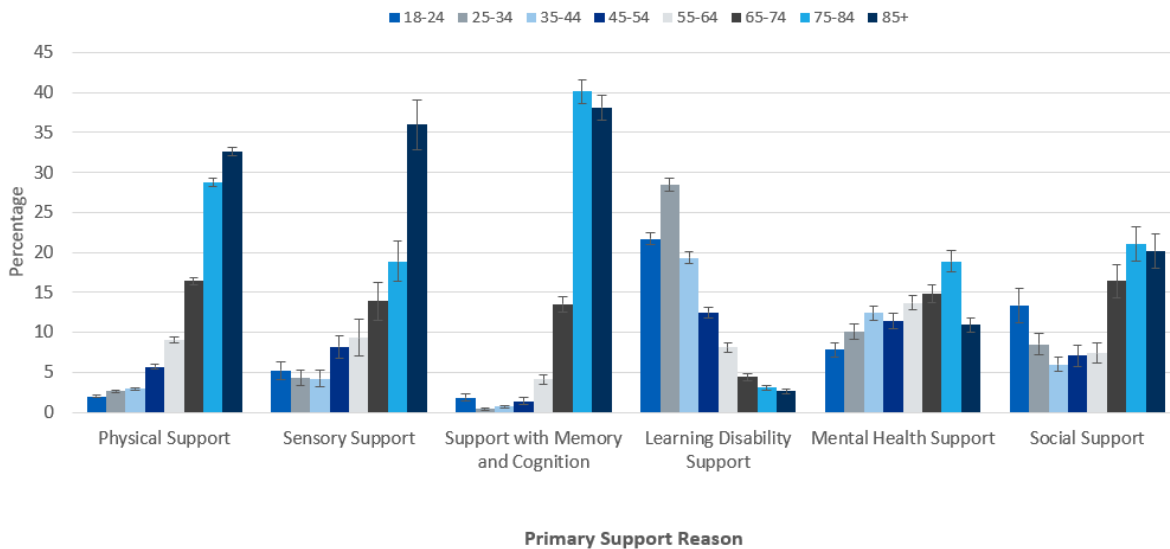


Chart 6 shows the Primary Support Reason of the cared-for person and the age of cared-for person. The chart shows that the majority of cared-for people with a physical support need are aged 65 and over. Also, the majority of cared-for people with a learning disability support need are aged under 44.

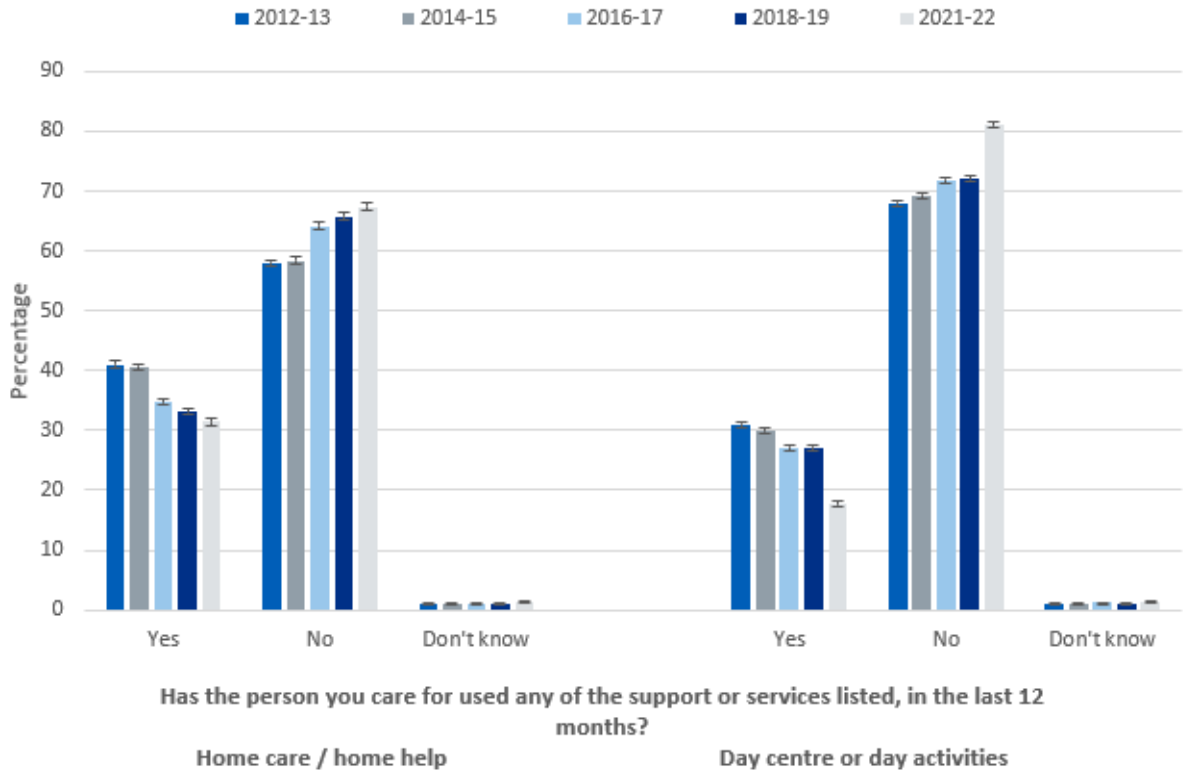
Chart 6: Primary Support Reason by age of cared-for person



Support or services used by the cared-for person

Carers were asked if the person they care for has used home care / home help or day care / day activities in the last 12 months. Chart 7 shows there has been a decrease in the number of cared-for people accessing these services. It is likely the COVID-19 pandemic has impacted on what services are available.

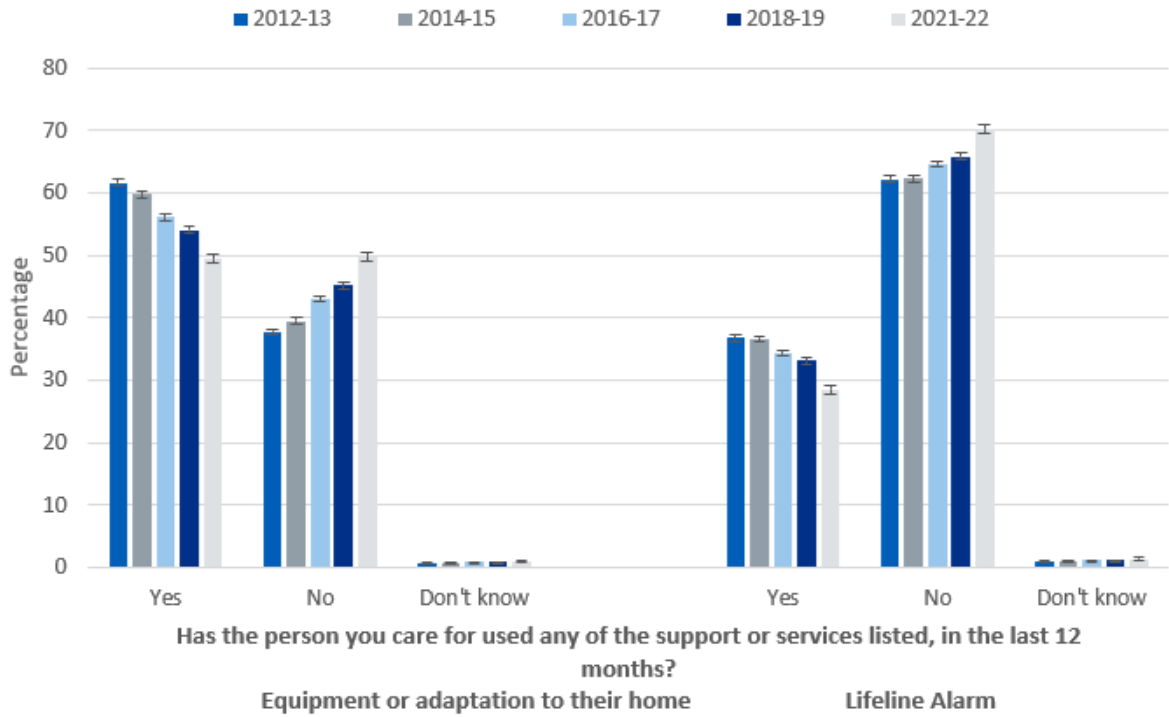
Chart 7: Changes in support provided by home care / home help and day centre or day activities over time



Source: SACE 2021-22

Carers were also asked if the person they care for has used equipment or adaptation to their home (such as a wheelchair or handrails) or lifeline alarms in the last 12 months. Chart 8 shows there has been a decrease in the number of cared-for people accessing these supports and equipment. Like the support services, the impact of COVID-19 pandemic should be considered.

Chart 8: Changes in support provided such as equipment or adaptations to the home and lifeline alarms over time



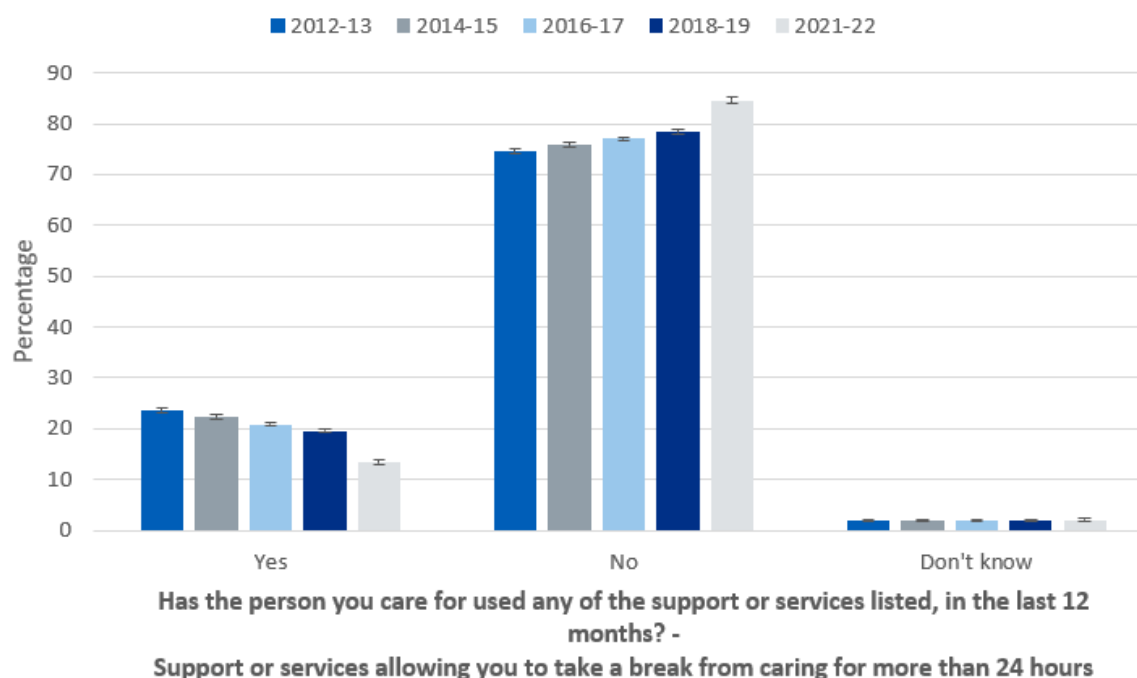
Source: SACE 2021-22

The impact of caring and quality of life

Support or services used by the cared-for person to allow carers to have a break or rest

In 2021-22, 13.3 per cent (42,800) of carers reported the person they care for used services that allowed them to take a break from caring for more than 24 hours, this compares to 19.6 of carers (57,280) in 2018-19.

Chart 9: Changes in support to allow carers to take a break from caring for more than 24 hours over time



Source: SACE 2021-22

The percentage of carers where the person they care for received services that allowed them to take a break from caring at short notice or in an emergency, decreased from 13.6 per cent (39,670) in 2018-19 to 10.5 per cent (33,780) in 2021-22.

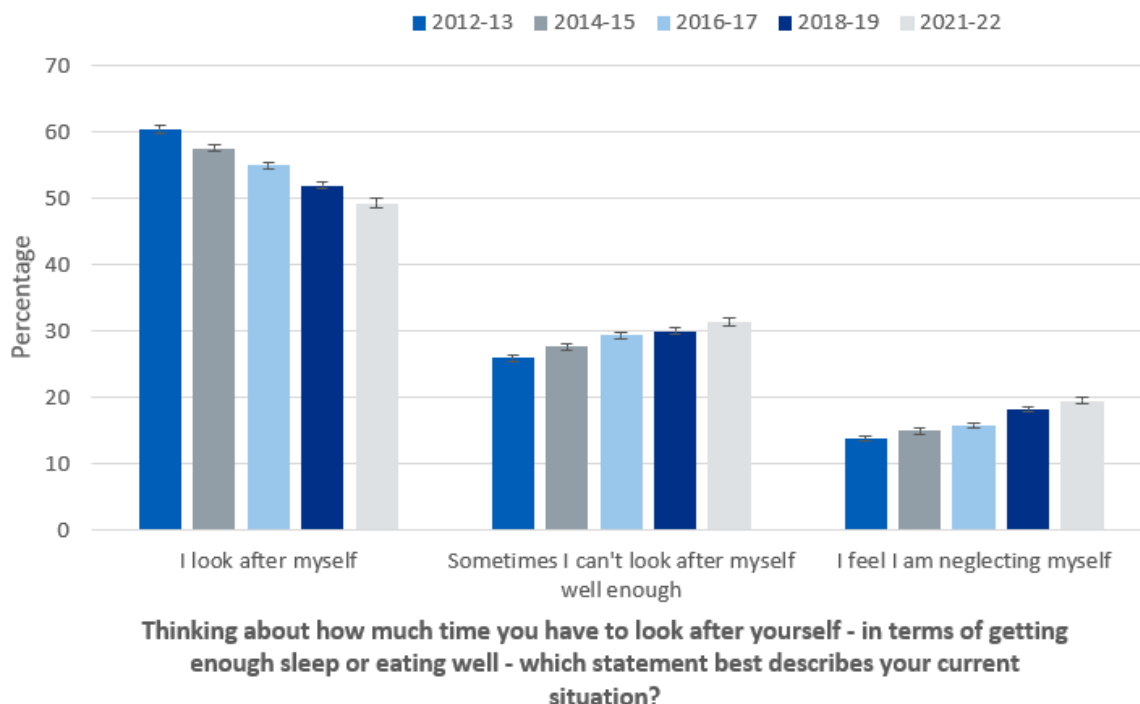
How carers spend their time

There was a decrease in the proportion of carers who felt they are able to spend their time as they want, doing things they value or enjoy from 17.3 per cent (50,570) in 2018-19 to 16.2 per cent (52,310) in 2021-22. There was also a higher proportion (18.3 per cent) not doing anything they value or enjoy with their time. The impact of COVID-19 should be considered with this question.

Looking after yourself

The proportion of carers who felt they can look after themselves, decreased from 51.9 per cent (151,760) in 2018-19 to 49.2 per cent (158,350) in 2021-22. 19.5 per cent (62,750) of carers reported they are neglecting themselves, this was an increase from 18.1 per cent (52,930) in 2018-19.

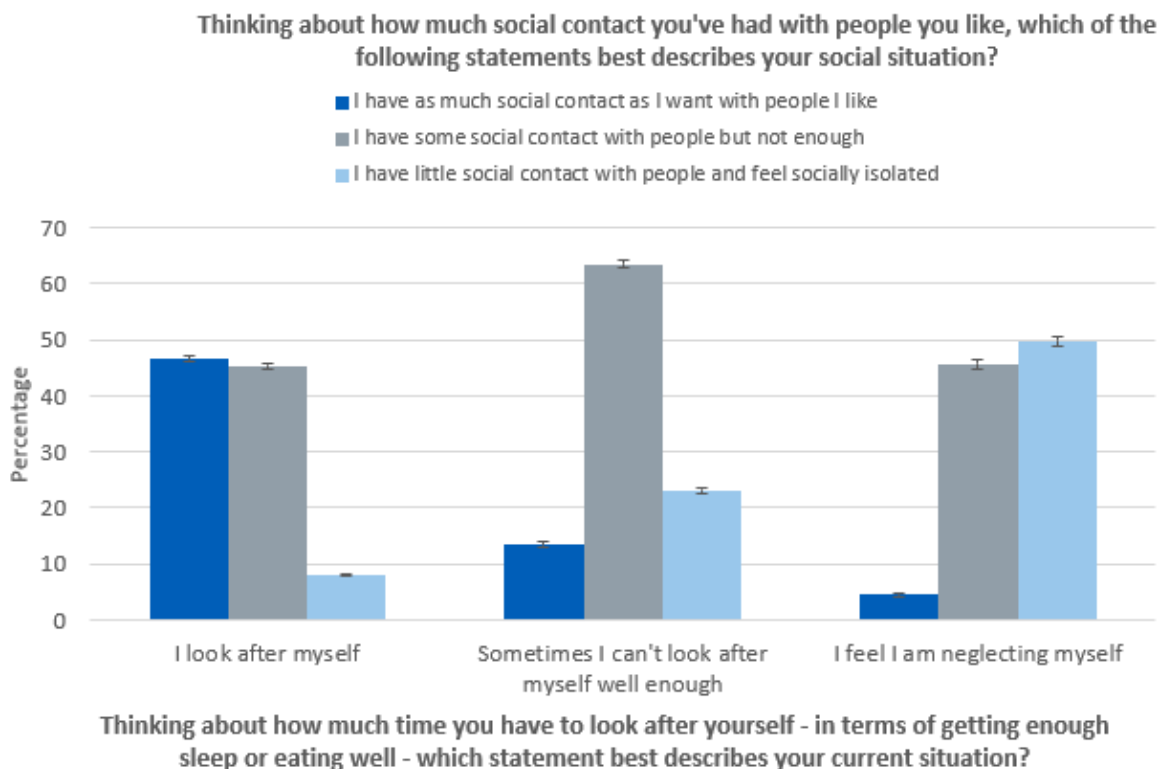
Chart 10: How carers look after themselves over time



Source: SACE 2021-22

Almost half of carers (46.6 per cent, 72,400) who look after themselves also feel they have as much social contact as they want. In contrast for carers who are neglecting themselves, 4.6 per cent (2,830) felt they have as much social contact as they want.

Chart 11: How carers look after themselves by social contact



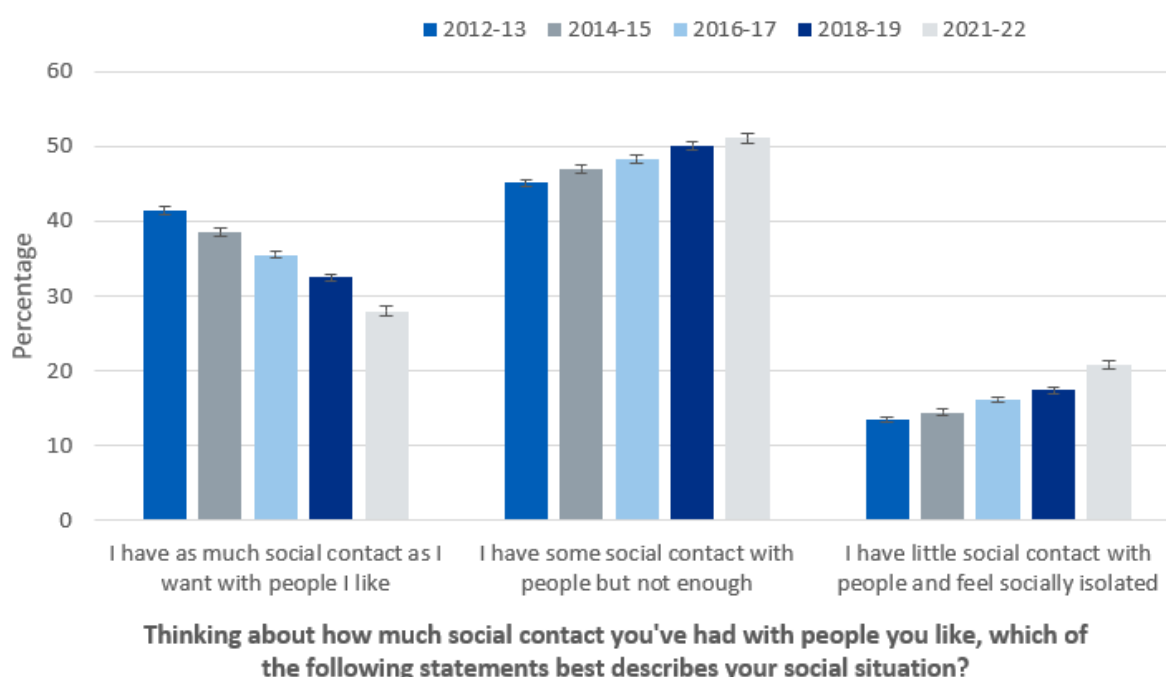
Source: SACE 2021-22

For carers that spend their time as they want, doing things they enjoy, 2.0 per cent (1,030) felt they neglect themselves. In contrast, for carers that don't do anything they value or enjoy with their time, almost half (47.0 per cent, 27,120) also felt they neglect themselves.

Social contact

Although there has been a steady decline year on year, the proportion of carers who felt they have as much social contact as they want, with people they like decreased more profoundly in 2021-22, from 32.5 per cent (95060) in 2018-19 to 28.0 per cent (90,260) in 2021-22. The proportion that felt they have little social contact and feel socially isolated increased from 17.4 per cent (50,910) to 20.9 per cent (67,380). The impact of COVID-19 should be considered with this question.

Chart 12: Carers feelings on social contact over time



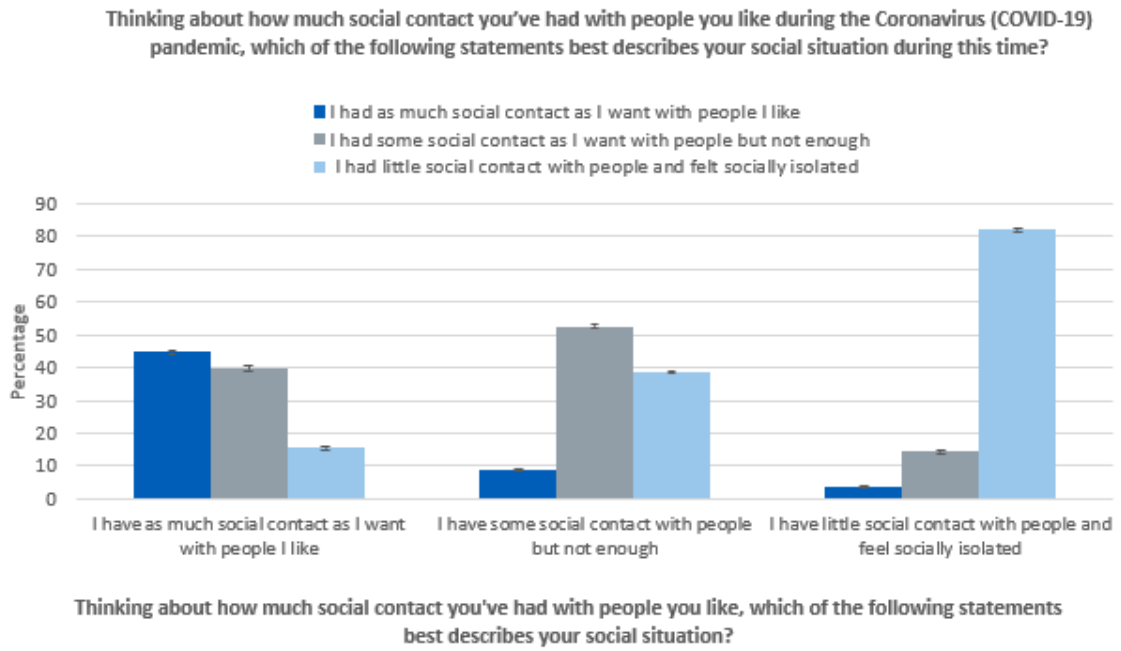
Source: SACE 2021-22

The Office of National Statistics (ONS) carried out an Opinions and Lifestyle Survey to map loneliness during the COVID-19 pandemic. The survey showed levels of loneliness in Great Britain have increased since spring 2020. Further findings are published on the ONS website

<https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/mappinglonelinessduringthecoronaviruspandemic/2021-04-07>.

In the 2021-22 four questionnaires additional questions were included to look at the impact COVID-19 had on the carers quality of life. Chart 13 shows for carers who feel they have as much social contact as they want now, 15.4 per cent (13,460) feel they had little social contact and felt social isolated during the pandemic.

Chart 13: Carers feelings on social contact now by feelings on social contact during the pandemic

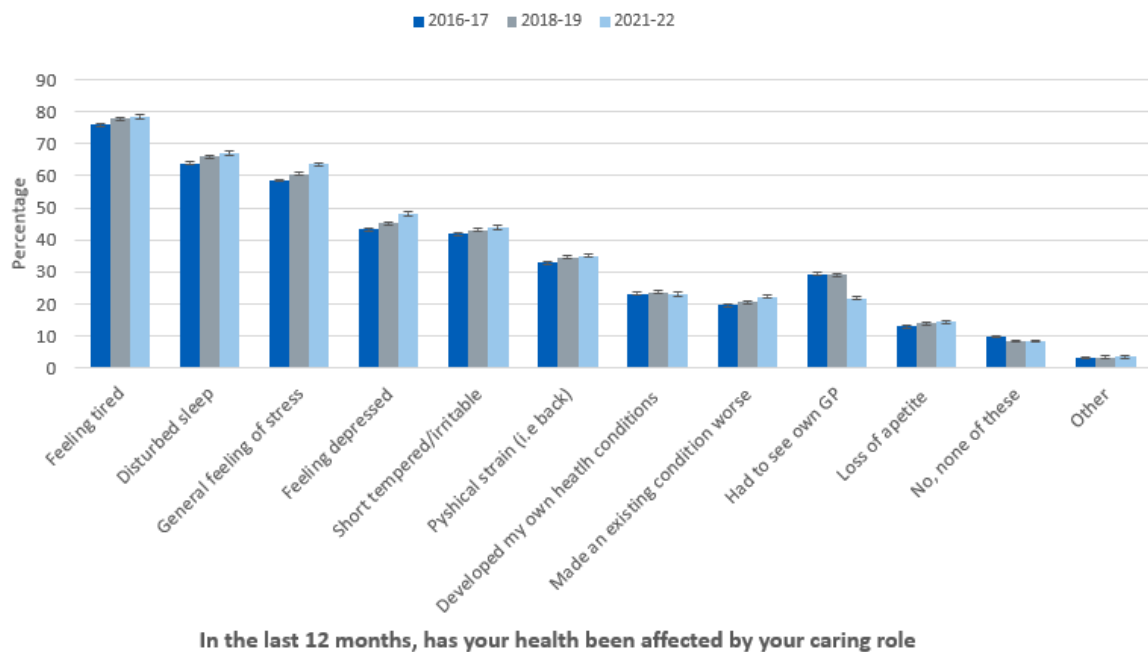


Source: SACE 2021-22

Carers health

Carers were asked if their health has been impacted by their caring role. In 2021-22, there was an increase in the proportion of carers reporting general feelings of stress and feeling depressed. The proportion of carers that had to see their own GP decreased from 29.0 per cent (84,900) in 2018-19 to 21.8 per cent (70,190) in 2021-22. The impact of COVID-19 should be considered with this question.

Chart 14: How carers health has been impacted by their caring role over time

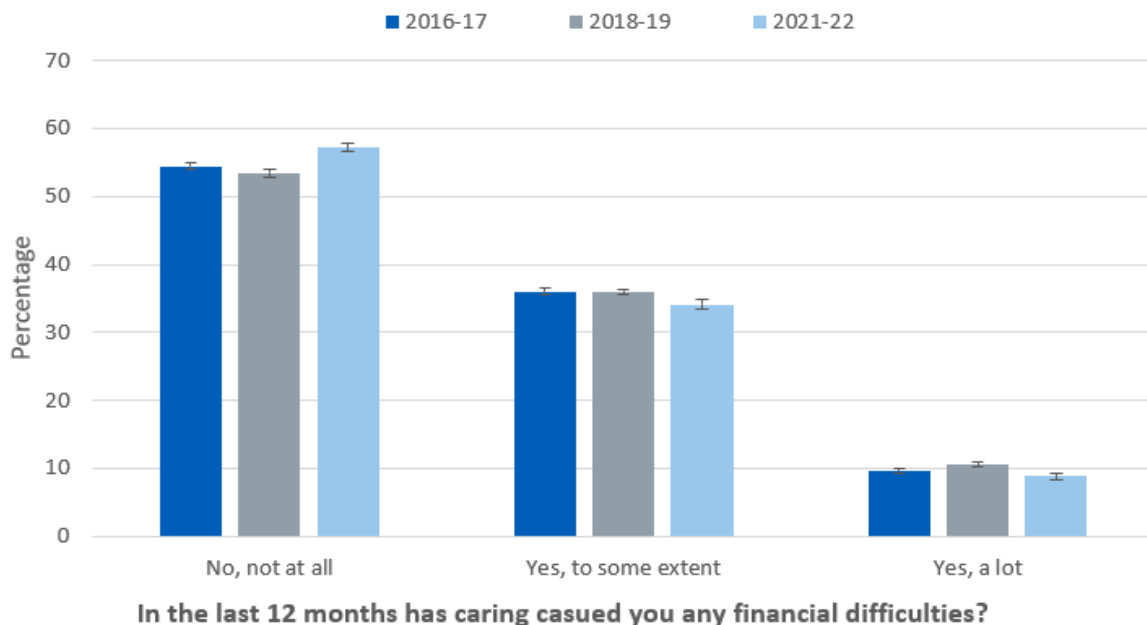


Source: SACE 2021-22

Financial difficulties

Over half of carers (57.2 per cent, 184,200 carers) reported their caring role had not caused any financial difficulties over the last 12 months, this was an increase from 53.4 per cent (156,130) in 2018-19.

Chart 15: Financial difficulties due to caring role over time

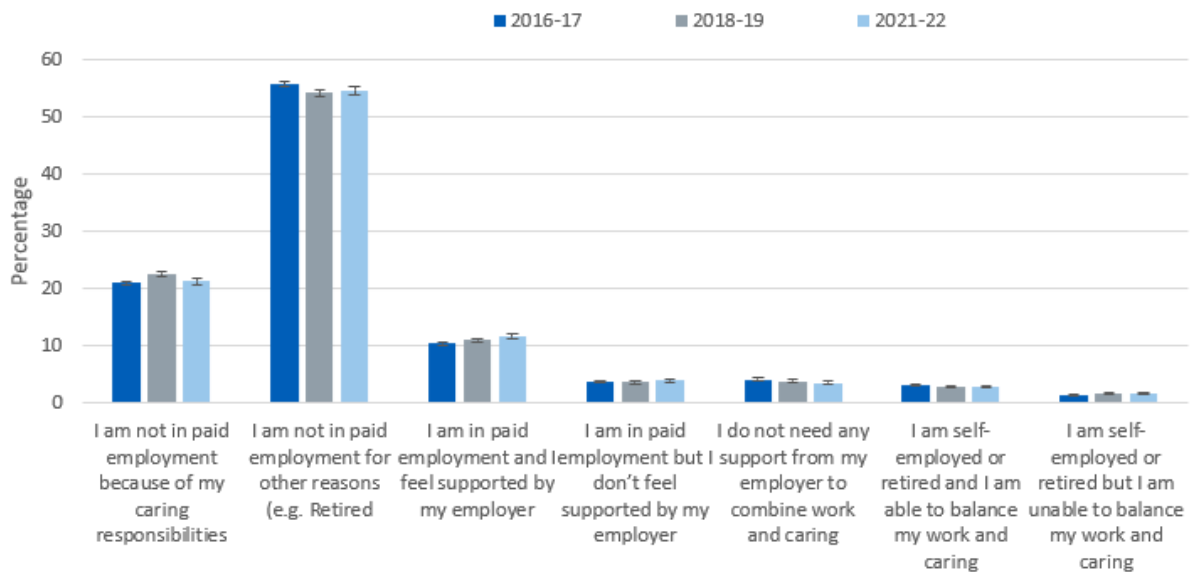


Source: SACE 2021-22

Employment status

The proportion of carers that are not in paid employment due to their caring responsibilities decreased from 22.6 per cent (65,950) in 2018-19 to 21.4 per cent (69,030) in 2021-22.

Chart 16: Employment status over time



Thinking about combining paid work and caring, which of the following statements best describes your current situation?

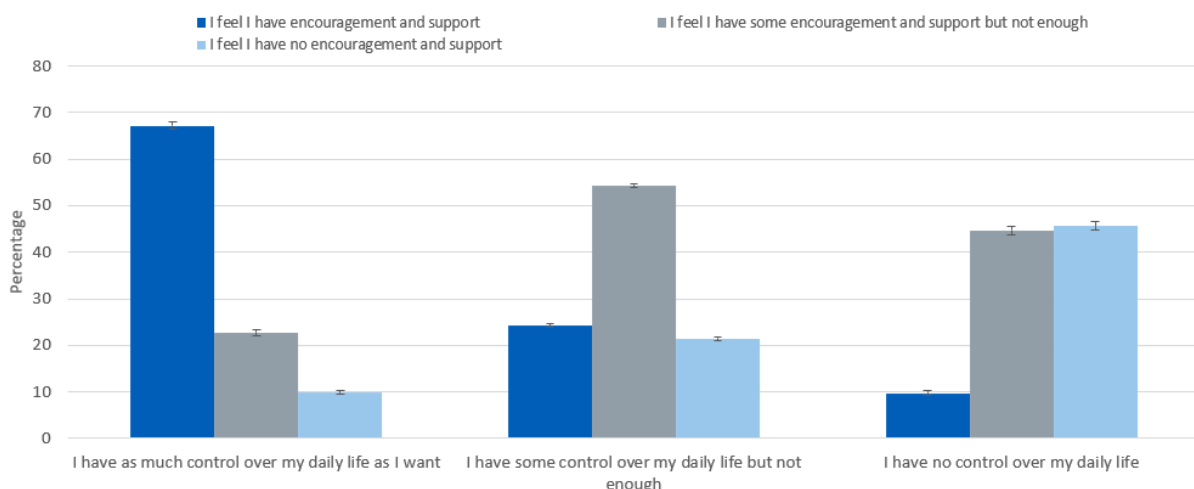
Source: SACE 2021-22

Control

Over two thirds of carers (67.2 per cent, 46,380 carers) that feel they have as much control as they want over their daily life, also feel encouraged and supported in their caring role. For carers that feel they have as much control as they want over their daily life, almost 10 per cent (9.9 per cent, 6,840 carers) also felt they have no encouragement or support.

Chart 17: Feelings on control by encouragement and support

Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?



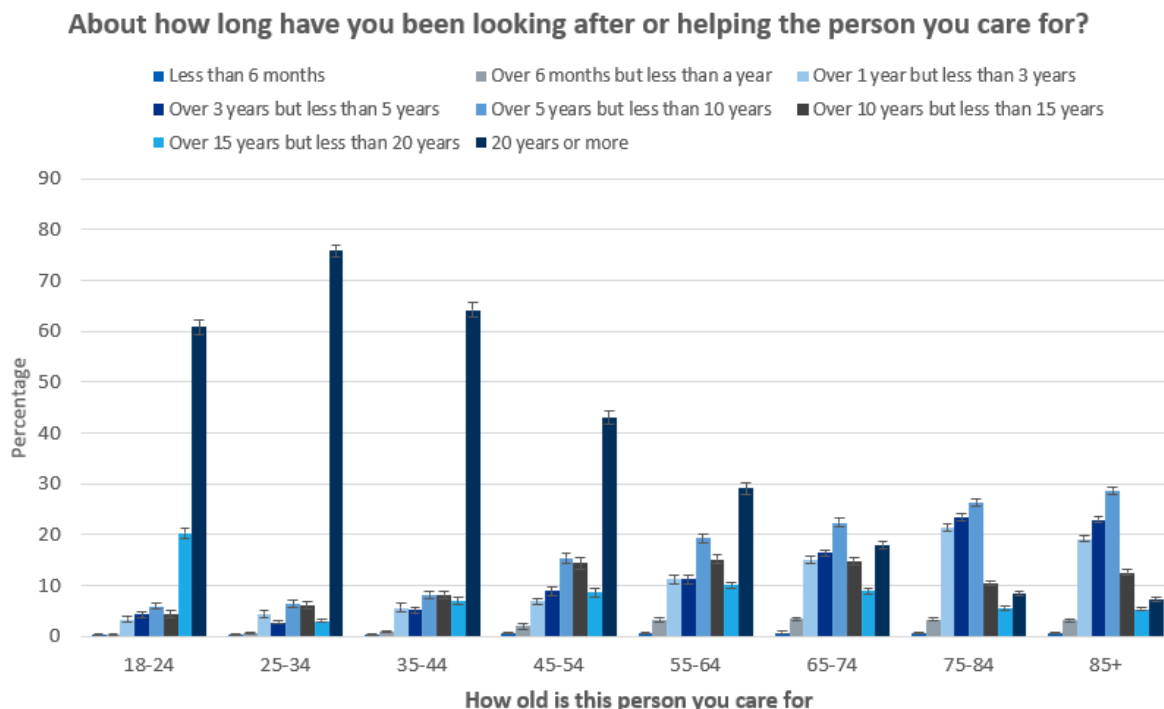
Which of the following statements best describes how much control you have over your daily life?

Source: SACE 2021-22

Time spent caring

Over 80 per cent (81.1 per cent, 15,070 carers) of carers who care for someone aged 18 to 24, have been caring for them for over 15 years. This indicates these carers maybe a parent caring for a child.

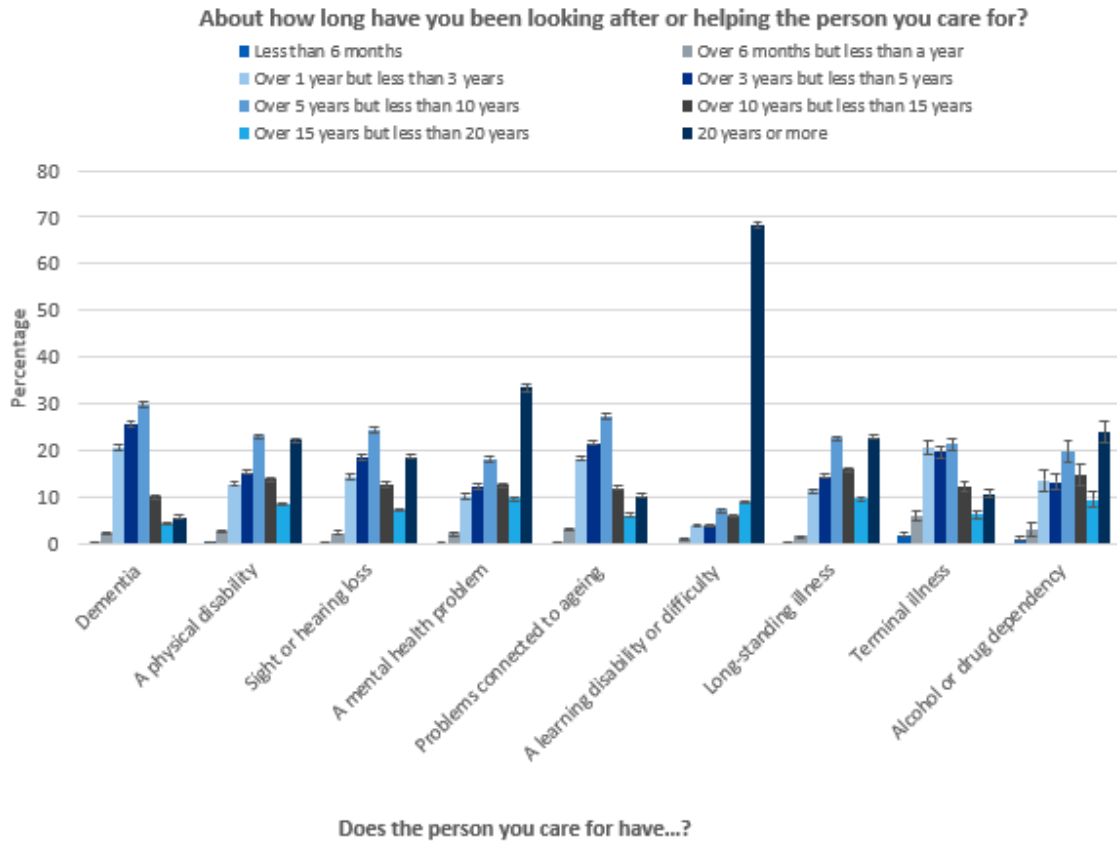
Chart 18: Age of cared-for person by time spent caring



Source: SACE 2021-22

Chart 19 shows for carers who care for someone with learning disabilities, 68.3 per cent (46,500) have been providing care for over 20 years. As published in the [Adult Social Care Activity and Finance report, 2020-21](#), at England level learning disability support has the highest unit cost for both service users aged 18-64 and 65 and over. The total gross current expenditure on long term support for service users with leaning disability support was £6,224,871 in 2020-21. Learning disability support accounted for 69.7% of expenditure for service users aged 18-64.

Chart 19: Health needs of cared-for person by time spent caring

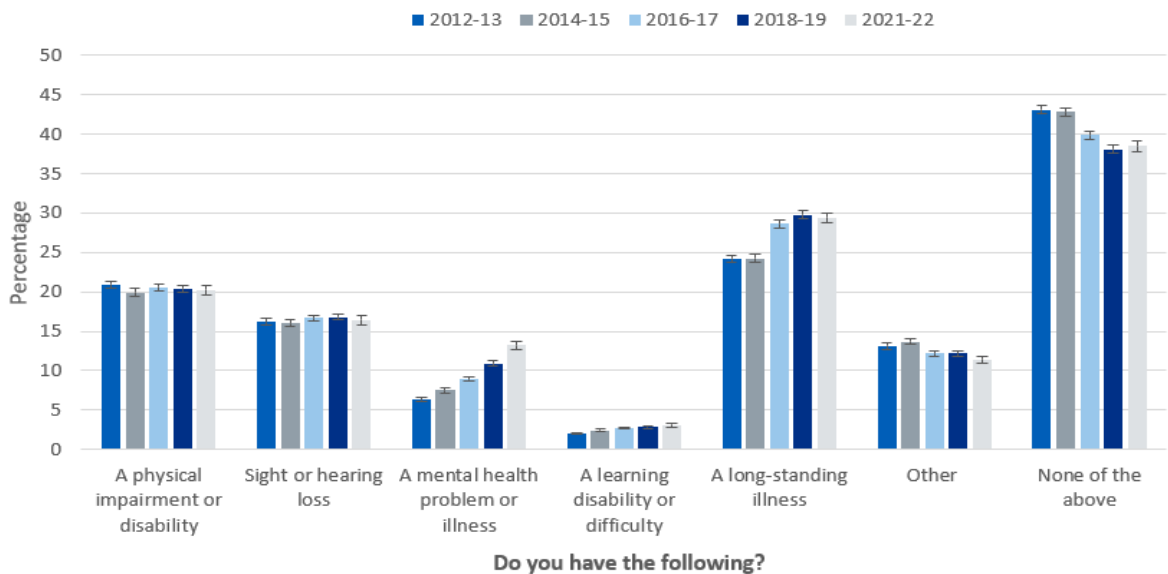


Source: SACE 2021-22

Carers health

Chart 20 shows the percentage of carers with a mental health problem or illness rose from 10.9 per cent (63,410) in 2018-19 to 13.2 per cent (75,390) in 2021-22.

Chart 20: Support needs of carer over time



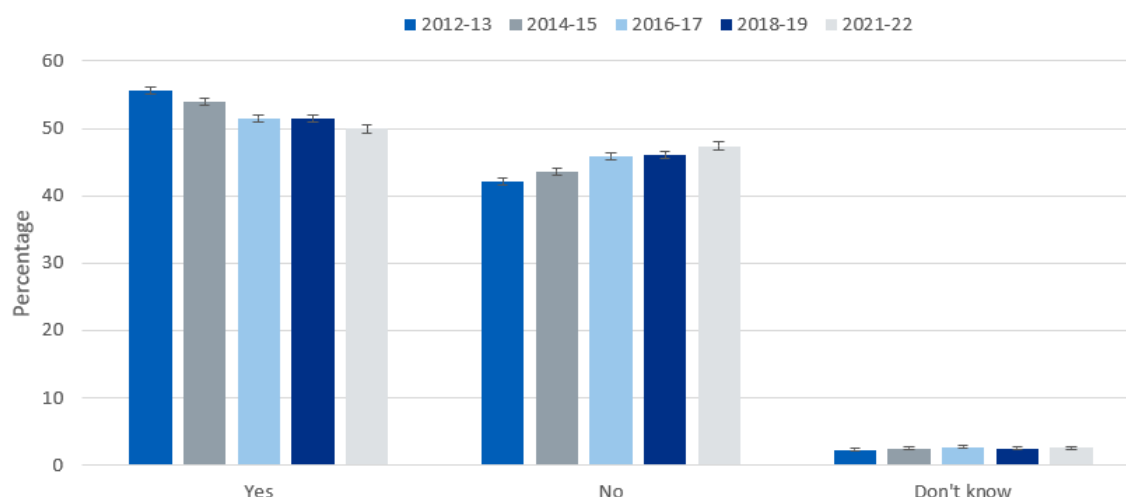
Source: SACE 2021-22

The quality of any information and advice received

Using information and advice to help as a carer

The percentage of carers that used information and advice to help them as a carer dropped from 51.4 per cent (150,220) in 2018-19 to 49.9 per cent (160,760) in 2021-22. 47.4 per cent (294,750) of carers in 2021-22 did not use information and advice.

Chart 21: Use of information over time



Have you used any Information and advice to help you as a carer over the last 12 months?

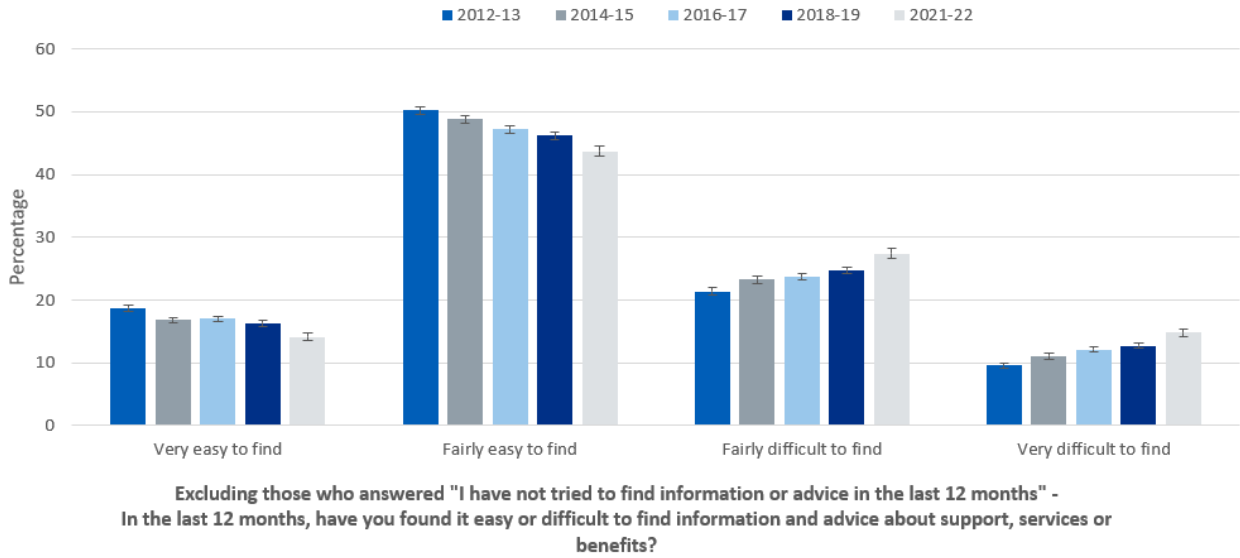
Source: SACE 2021-22

89.0 per cent (136,000) of carers that have not used information or advice in the last 12 months to help them as a carer, also have not used support from carers groups or someone to talk to in confidence.

Ease of finding information

Excluding carers that had not tried to find information or advice, the percentage of carers who found it very easy to find information and advice about support, services or benefits decreased from 16.3 per cent in (47,690) 2018-19 to 14.1 per cent (45,280) in 2021-22. 14.8 per cent (47,780) of carers in 2021-22 found it very difficult to find information.

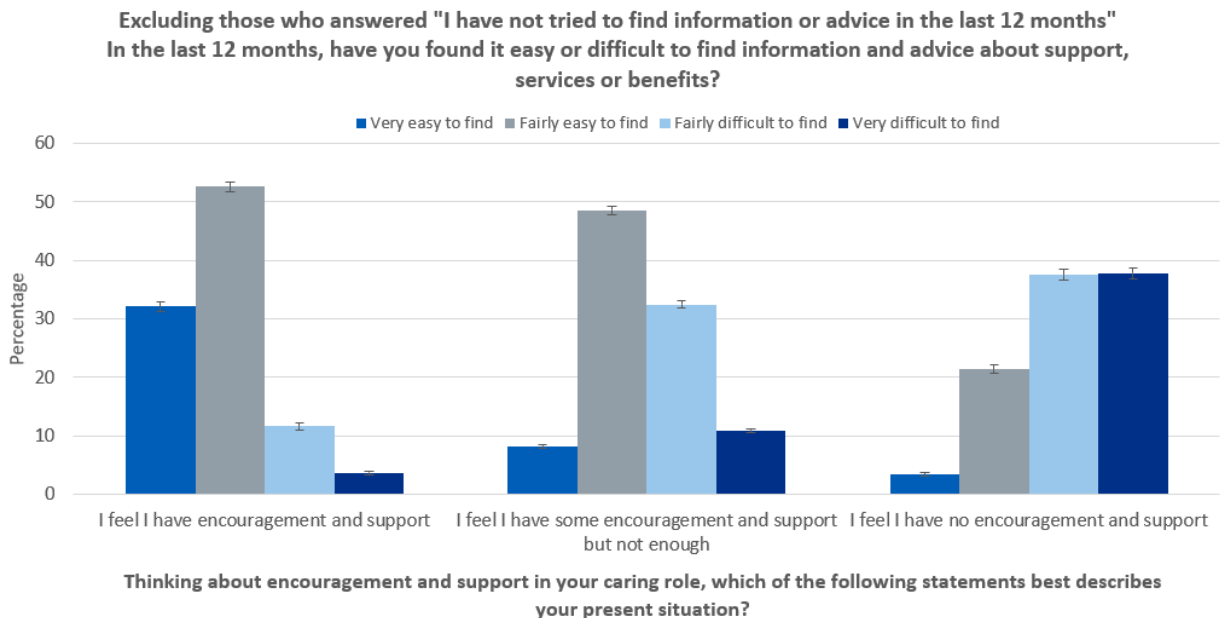
Chart 22: Ease of finding information over time



Source: SACE 2021-22

Over three quarters (75.3 per cent, 52,830) of carers who feel they have no encouragement or support in their caring role also find information fairly or very difficult to find. For carers that do feel they have encouragement and support, 84.7 per cent (77,430) of them find information fairly or very easy to find.

Chart 23: Feeling encouraged by ease of finding information



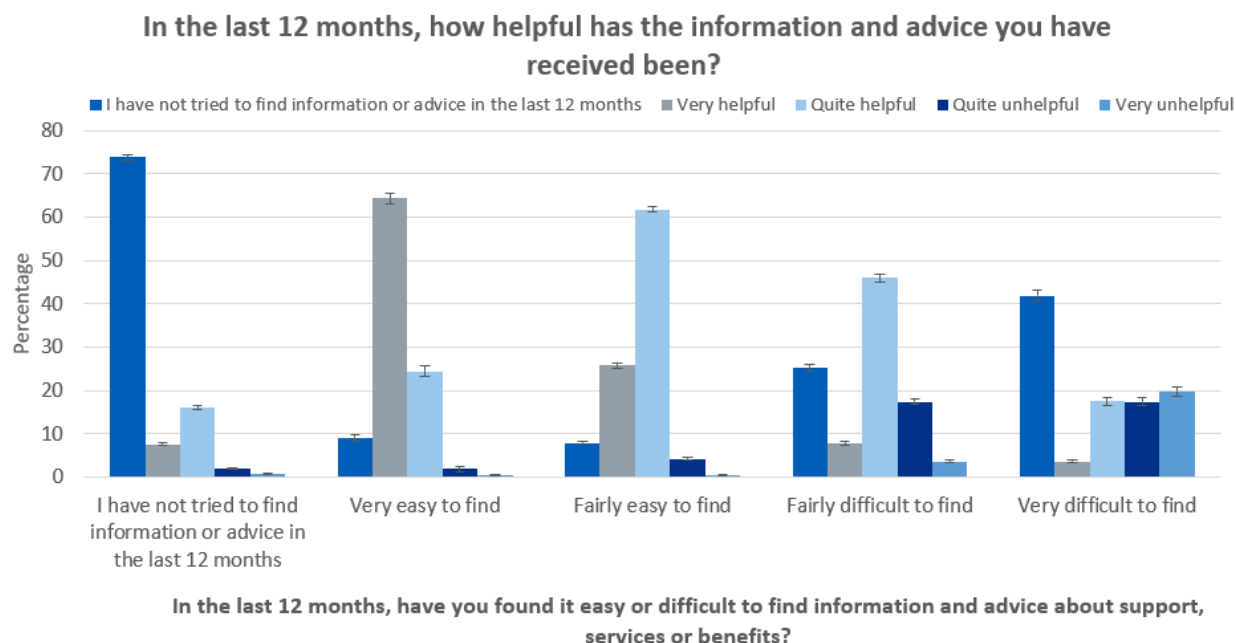
Similarly, for carers that found information very difficult to find, 37.7 per cent (10,970) felt they have never felt involved or consulted in discussions about the support or services provided to the person they care for. For carers that found information easy to find, 71.4 per cent (26,570) always felt involved or consulted in discussions about support.

Helpfulness of information

Excluding carers that had not received any information or advice in the last 12 months, the proportion of carers who found the information and advice received very helpful decreased from 31.6 per cent (92,280) in 2018-19 to 28.2 per cent (90,780) in 2021-22. The proportion that found the information very unhelpful increased from 4.0 per cent (11,770) to 4.8 per cent (15,580).

For carers that find it very easy to find information about support, services or benefits, 88.7 per cent (25,900) found the information they received very or quite helpful. For carers that found information very difficult to find in the last 12 months, 21.1 per cent (6,360) found the information they received very or quite helpful.

Chart 24: Ease of finding information by helpfulness of information



Source: SACE 2021-22

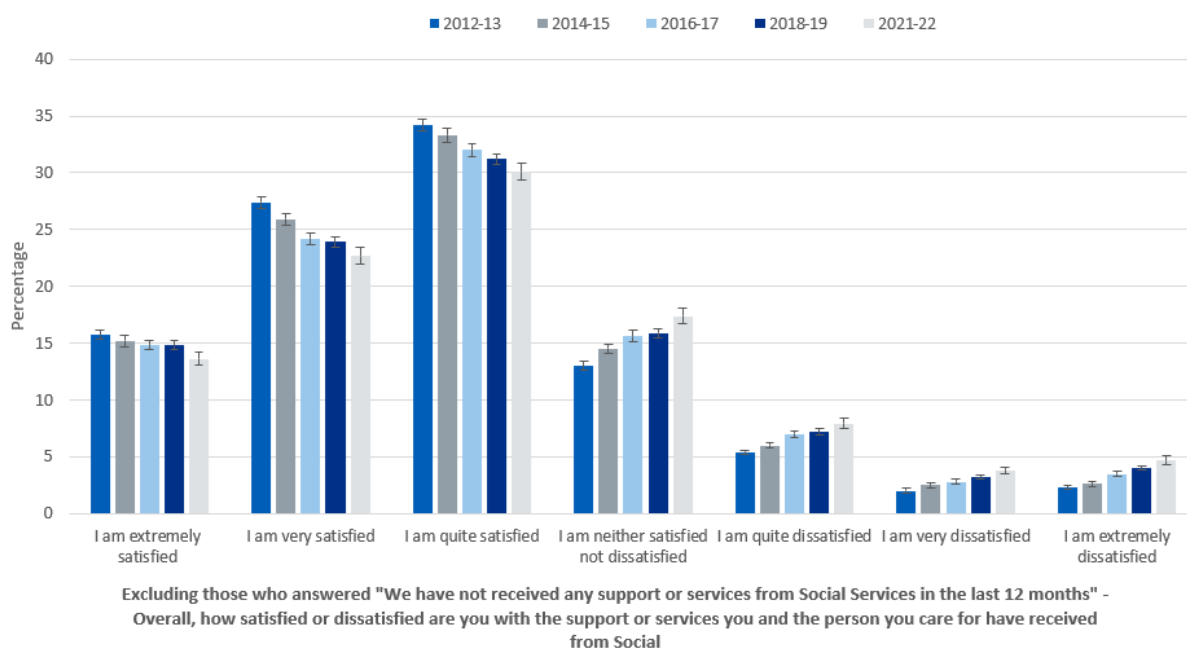
The carer’s needs and experiences of support

Overall satisfaction with the support or services

28.6 per cent (92,080) of carers answered they had not received support or services from Social Services in the last 12 months. This was an increase from 23.1 per cent (67,420) in 2018-19.

Excluding carers that had not received support or services from Social Services in the last 12 months, Chart 25 shows how the levels of satisfaction have changed over time. In 2021-22, 36.3 per cent (116,830) of carers felt they were very or extremely satisfied with the support or services they received, this was a decrease from 38.7 per cent (112,960) in 2018-19. 8.5 per cent (27,150) of carers felt they were very or extremely dissatisfied, an increase from 7.2 per cent (20,930) in 2018-19.

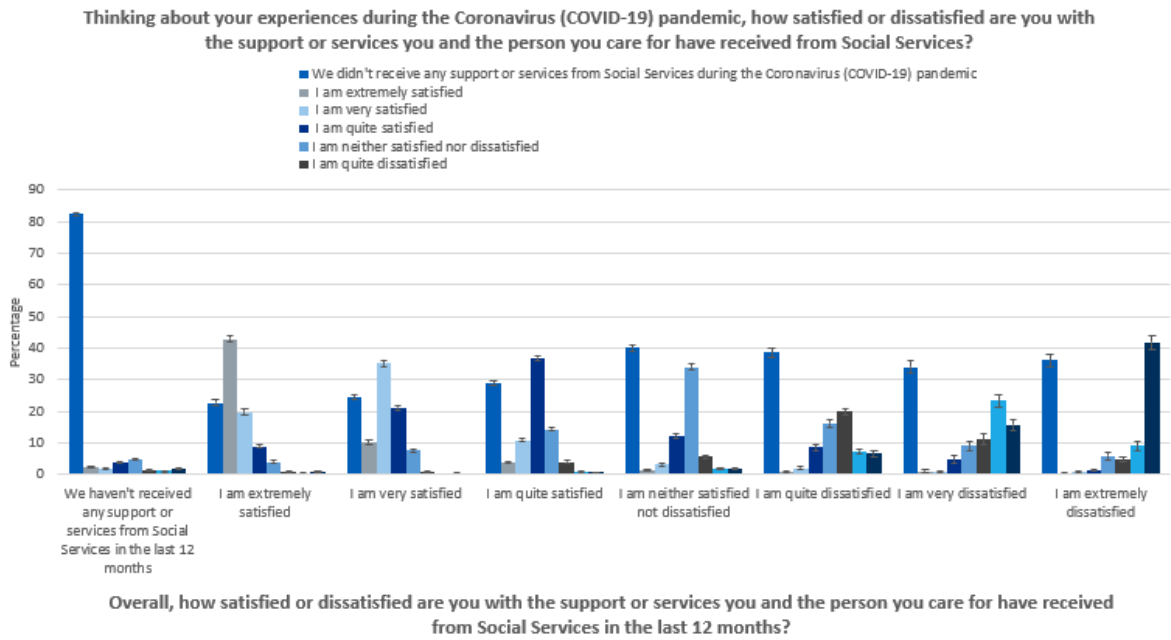
Chart 25: Satisfaction over time



Source: SACE 2021-22

36.1 per cent (3,560) of carers that are extremely dissatisfied with the support or services did not receive any support or services during the COVID-19 pandemic. For carers that are extremely satisfied with the support or services, 22.7 per cent (6,690) didn't receive any support or services during the pandemic.

Chart 26: Satisfaction by satisfaction during the pandemic

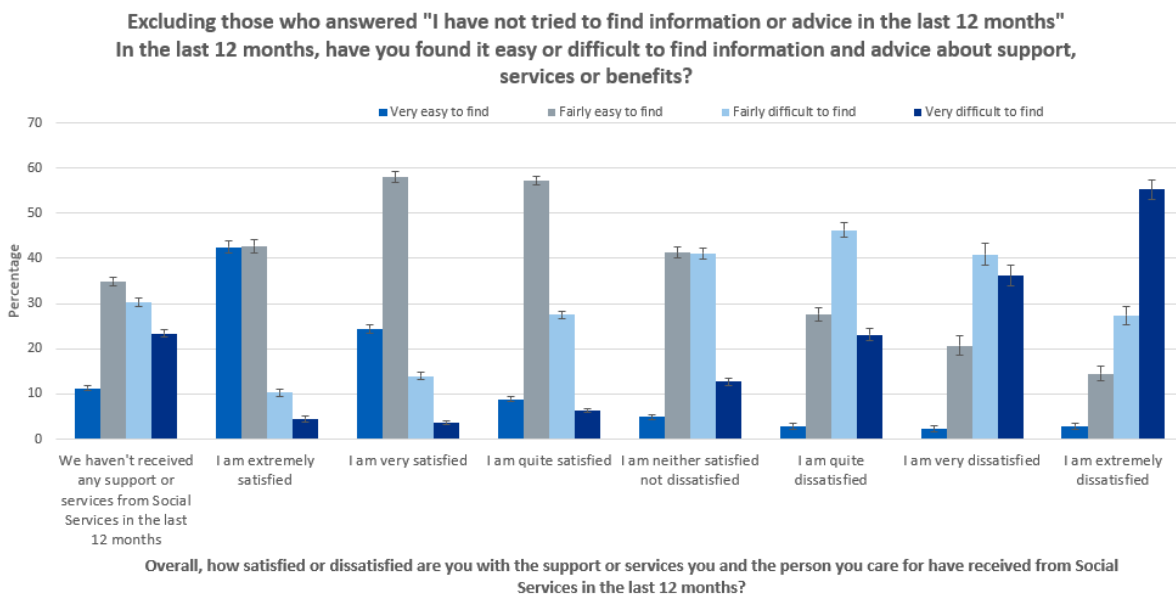


Source: SACE 2021-22

Chart 27 shows levels of satisfaction by ease of finding information, excluding those that have not tried to find information or advice in the last 12 months. 42.5 per cent (13,370) of carers that were extremely satisfied with the support or services received from Social Services in the last 12 months, found information very easy to find. For carers that were extremely dissatisfied, 2.9 per cent (370) found information very easy to find.

In contrast, for carers that were extremely satisfied, 4.5 per cent (1,420) found information very difficult to find. For carers that were extremely dissatisfied with the support or services, over half (55.2 per cent, 7,120 carers) found the information very difficult to find.

Chart 27: Satisfaction by ease of finding information



Source: SACE 2021-22

Excluding carers that have not received support or services from Social Services in the last 12 months, for carers that always feel involved or consulted 27.6 per cent

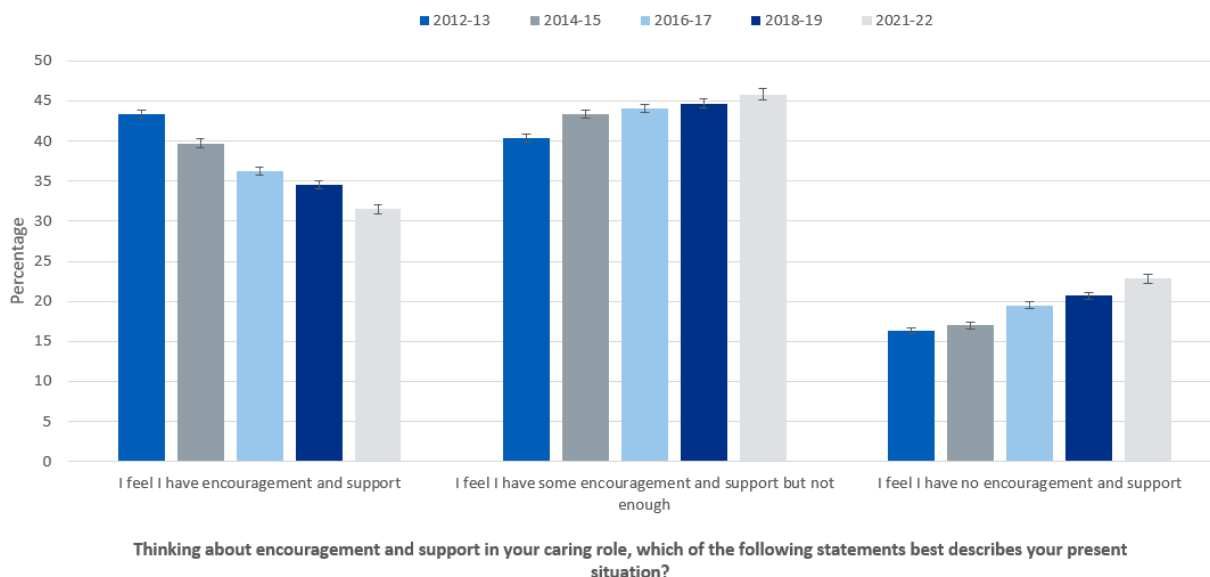
(23,950) feel extremely satisfied with the support received. For carers that never feel involved or consulted, 4.0 per cent (740) feel extremely satisfied with the support received.

Similarly, for carers that always felt involved or consulted in discussions during the COVID-19 pandemic, 30.4 per cent (16,990) were extremely satisfied in the support or services received. For carers who never felt consulted during the pandemic, 3.9 per cent (930) were extremely satisfied with the support received.

Feeling encouraged and supported

Chart 28 shows how carers feelings on encouragement and support in their caring role have changed over time. The per cent of carers that feel they have encouragement and support has fallen year on year and most recently from 34.6 per cent (101,040) in 2018-19 to 31.5 per cent (101,360) in 2021-22. The per cent of carers that feel they have no encouragement or support increased from 20.7 per cent (60,520) in 2018-19 to 22.8 per cent (73,370) in 2021-22.

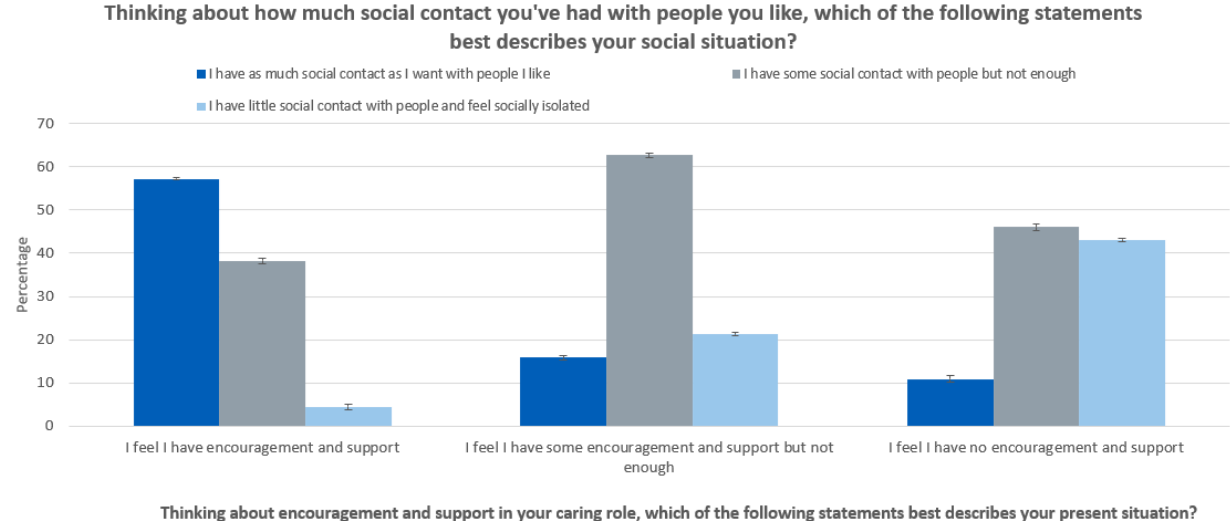
Chart 28: Feelings on encouragement and support over time



Source: SACE 2021-22

57.2 per cent (56,780) of carers who feel supported and encouraged in their caring role also feel they have as much social contact as they want. For carers that feel they have no encouragement or support, 10.9 per cent (7,820) felt they have as much social contact as they want.

Chart 29: Feelings on encouragement by social contact



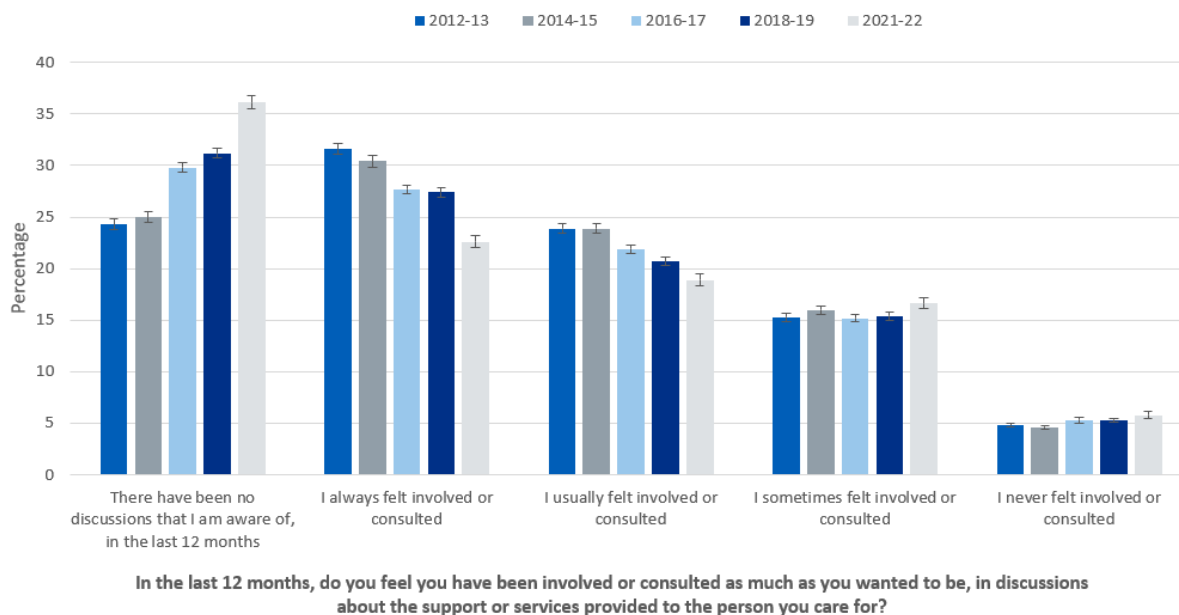
Source: SACE 2021-22

Carers’ involvement in arranging services for the cared-for person

Feeling involved or consulted

Chart 30 shows the percentage of carers that said there had been no discussions about support or services provided to the person they care for in the last 12 months increased from 31.2 per cent (91,250) to 36.1 per cent (116,360) in 2021-22. The percentage of carers that always felt involved or consulted in discussions dropped from 27.4 per cent (80,090) in 2018-19 to 22.6 per cent (72,780) in 2021-22.

Chart 30: Feelings on involvement in discussions over time



Source: SACE 2021-22

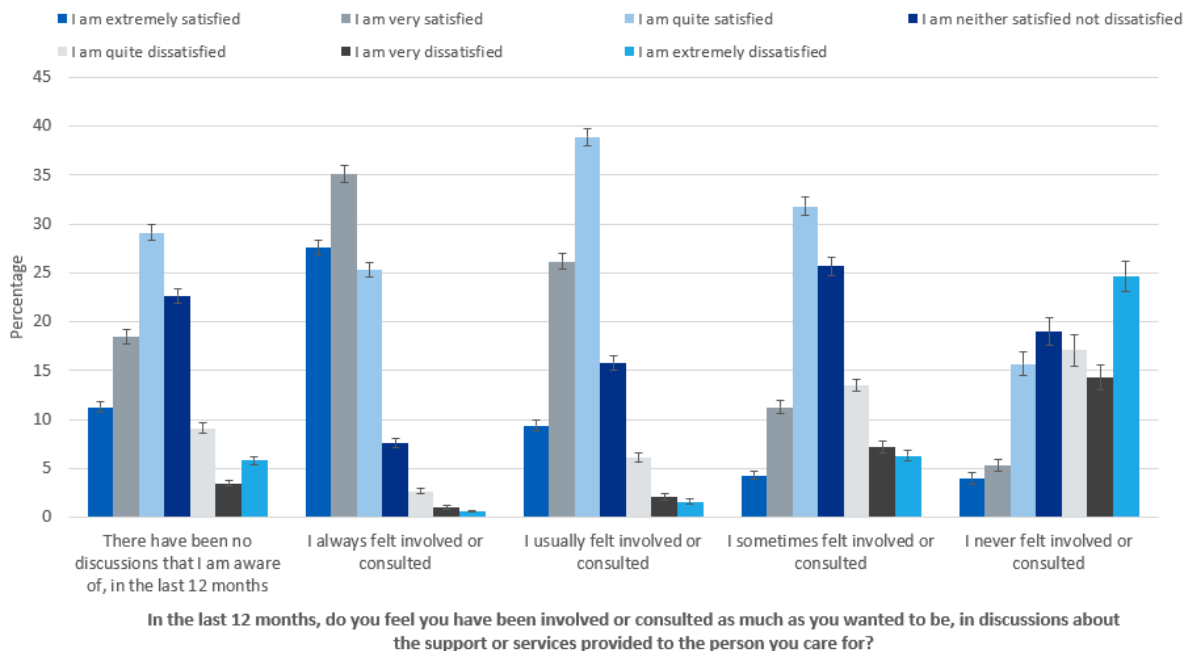
Chart 31 shows carers view on if they have been involved or consulted in discussion about the support or services provided to the person they care for in the last 12 months by their satisfaction in the support or services received. Carers who did not receive any support or services in the last 12 months have been excluded.

Chart 31 shows for carers that always feel involved or consulted, 62.7 per cent (54,410) are very or extremely satisfied with the support or services received. For carers that never feel involved or consulted, 9.3 per cent (1,720) are very or extremely satisfied with the support or services received.

Chart 31: Feelings on involvement in discussions by satisfaction

Excluding those who answered "We haven't received any support or services from Social Services in the last 12 months"

Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 month?



Source: SACE 2021-22

Excluding carers that answered there had been no discussions about the support or services provided to the person they care for in the last 12 months, for carers that feel encouragement and support in their caring role, 57.8 per cent (80,090) always felt involved or consulted in discussions about the person they care for. For carers that do not feel they have any encouragement or support, 13.9 per cent (7,450) always felt involved or consulted in discussions.

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