



Personal Social Services Survey of Adult Carers in England 2015-16

Consultation Report

January 2017

Method	Number of questionnaires returned	Completion rate
Paper	373	99.7%
Telephone	1	0.3%
Total returned	374	100%
Non returns	405	-

Data was collected between October & November 2016.

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Introduction

The Personal Social Services Survey of Adult Carers in England 2015 -16 is a statutory survey, coordinated by the Health and Social Care Information Centre (www.ic.nhs.uk), which aims to collect information about carers' experiences of social care services and support and will feed into the monitoring of the national carers strategy.

It is important for the Department of Health to understand at the national level how well services are meeting user and carer needs. The information about services is not intended to be used solely to monitor performance through national outcomes measures but should also be used locally to inform service delivery and to monitor and develop standards.

The carers' survey contained sections which asked questions:

- About the carer & the person cared for
- About the needs and experiences of support
- The impact of caring and quality of life
- Information & advice quality
- Arrangement of support and services in the last 12 months
- About yourself

Methodology

Surveys were posted to 779 eligible carers aged 18 or over who have been assessed or reviewed by social services in the last 12 months prior to the sample being extracted. A single reminder was sent to those who did not reply to the first questionnaire.

The summary tables in this report were constructed using the number of carers who had responded to each question, as the denominator, (as per last report).

Where there was a multiple response question i.e. where respondents could select more than one answer, the total percentage will add up to more than 100%.

Data quoted in the summary of results is rounded to nearest whole number, whereas data within the report is quoted to one decimal point.

Summary of results

About the person you care for (Questions 1-5)

- The highest frequency of ages is 75-84 (31%) and 85+ (29%). 83% of carers live with the person they care for.
- Over half of people cared for have a long standing illness (56%), around 37% have learning disability or difficulty, and 36% experiencing problems connected with aging and approximately 36% experiencing dementia.
- 56% of carers were satisfied with the support received from Social Services in the last 12 months, with 9% of those extremely satisfied. 13% were neither satisfied nor dissatisfied and just fewer than 10% were dissatisfied overall. 21% said they hadn't received any support.
- In the last 12 months, 50% of people being cared for used equipment or adaptations to their home, 24% used support or services allowing them to take a break from caring for more than 24 hours.

About the needs and experiences of support (Question 6)

- In the last 12 months 59% of carers have used information and advice services. Fewer carers used support from carers groups (40%), carers training (6%), or employment support (3%).

The impact of caring and quality of life (Questions 7-15)

- 20% of carers stated that they were able to spend their time doing things they value, whereas 65% didn't have enough time and 16% didn't do anything they valued with their time.
- 28% of carers say they have control over their daily life, 59% of carers said they have some control over their daily life but not enough with 13% having no control.
- 55% of carers felt they looked after themselves in terms of getting enough sleep or eating well with 29% not looking after themselves well enough and 16% neglecting themselves.
- 85% of carers had no worries about personal safety and 15% have some worries.
- Around 34% of carers had as much social contact as they wanted, with 18% feeling socially isolated.
- 38% feel they have encouragement and support in their caring role. Just over 44% feel they have some encouragement but not enough, while 17% have no encouragement and support.

- 24% of carers feel they don't have enough time to care for other people with 44% don't have caring responsibilities for anyone else.
- 78% of carers feel tired as an effect of their caring role, with 66% reporting disturbed sleep and 60% commenting on experiencing a general feeling of stress.
- 41% had experienced financial difficulties to some extent through their caring duties.

Information & advice quality (Questions 16, 17)

- In the last 12 months 29% of carers have not sought information and advice. 53% found it easy to find with 19% finding it difficult to find.
- Of the information and advice received by carers 67% found it helpful, while only 8% found it unhelpful.

Arrangement of support and services in the last 12 months (Question 18)

- In the last 12 months 28% of carers always felt involved in discussions about the support provided to the person they care for.

About yourself (Questions 19-29)

- 65% of carers describe themselves as retired, with 18% of carers not in paid employment because of their caring duties.
- 21% of carers have been looking after the person they care for over 5 years (but less than 10 years); however 19% have had caring responsibilities for over 20 years.
- 51% of carers spend over 100 hours per week looking after the person they care for.
- Carers performed a variety of tasks for the person they cared for, from personal care (68%) to helping deal with care services (82%) and giving medicines (81%).
- 27% of carers have themselves got a physical impairment or disability, 21% have sight or hearing loss.

Optional Questions for Torbay (Questions 30, 31)

- 86% of carers have told their GP that they are a carer (14% have not), 37% of carers felt telling their GP made any difference.

Section 1: About the person you care for

The questions in this section ask about the person being cared for and the carers experiences of support and services.

1 How old is the person you care for:-

Age group	Number	Percent
18-24	9	2.5%
25-34	26	7.2%
35-44	22	6.1%
45-54	25	6.9%
55-64	17	4.6%
65-74	50	13.9%
75-84	110	30.3%
85+	103	28.5%
Total	362	100%
No response	12	

The highest proportion of people being cared for are over retirement age with over 30% falling in the 75-84 age bracket. A further 29% are in the 85+ bracket.

2 Does the person you care for have any of the following illness?

Note: This is multiple response question where respondents were able to select more than one answer so totals will add up to more than 100%.

	Number	Percent
A physical disability	128	34.2%
Long standing illness	208	55.6%
Problems connected to ageing	136	36.4%
Sight or hearing loss	63	16.8%
Dementia	133	35.6%
A mental health problem	55	14.7%
A learning disability or difficulty	140	37.4%
Terminal illness	15	4.0%
Alcohol or drug dependency	5	1.3%

Most people being cared for experience a long standing illness (56%) with 37% experience a learning disability or difficulty.

3 Where does the person you care for usually live?

	Number	Percent
With me	302	82.5%
Somewhere else	64	17.5%
Total	366	100%
No response	8	

83% of people being cared for live with their carer.

4 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 months?

	Number	Percent
I am extremely satisfied	34	9.2%
I am very satisfied	76	20.6%
I am quite satisfied	95	25.7%
I am neither satisfied or dissatisfied	49	13.3%
I am quite dissatisfied	16	4.3%
I am very dissatisfied	8	2.2%
I am extremely dissatisfied	12	3.3%
We haven't received any support in last 12mths	79	21.4%
Total	369	100%
No response	5	

26% of carers are 'quite satisfied' with the services provided to them in the past 12 months. Overall nearly 56% were satisfied.

5 Has the person you care for used any of the support or services listed in the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Note: Numbers listed are where carers have selected 'Yes' they have used the service.

	Number	Percent
Support or services allowing you to take a break from caring at short notice or in an emergency	57	15.2%
Support or services allowing you to take a break from caring for more than 24 hours	89	23.8%
Support or services to allow you to have a rest from caring for between 1 and 24 hours (e.g. a sitting service)	74	19.8%
Personal assistant	25	6.7%
Home care/home help	86	23.0%
Day centre or day activities	85	22.7%
Lunch club	11	2.9%
Meals services	13	3.5%
Equipment or adaption to their home (such as a wheelchair or handrails)	188	50.3%
Lifeline Alarm	87	23.3%
Permanently in residential care home	31	8.3%

50% of people being cared for have used equipment or adaptations in their home, 23% have used home care services and 23% have used a lifeline alarm. Less people used lunch clubs (3%) and meal services (4%).

Section 2: About your needs and experiences of support

This section asked about the support and services used as a carer. They may be arranged by the carer or by Social Services. They may be provided by a voluntary organisation, a private agency or Social Services.

6 Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. Please do not include any unpaid help from family and friends.

	Number	Percent
Information & advice	221	59.1%
Support from carers groups or someone to talk to in confidence	149	39.8%
Training for carers	23	6.1%
Support to keep you in employment	12	3.2%

Nearly 60% of carers have accessed information and advice services in the last 12 months. Just under 40% sought support from carers groups or individuals. Fewer carers (6%) attended training or received support for employment (3%).

Section 3: The impact of caring and your quality of life

Some of the questions in this section look at the impact of caring on particular aspects of the carers life, while others ask about the quality of different parts of the carers life more generally.

- 7 Which of the following statements best describes how you spend your time? When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities.**

	Number	Percent
I am able to spend my time as I want, doing things I value or enjoy	72	19.9%
I do some of the things I value or enjoy with my time but not enough	234	64.6%
I don't do anything I value or enjoy with my time	56	15.5%
Total	362	100%
No response	12	

65% of carers feel they do not have enough time to do things they enjoy with 19% able to spend as much time as they want doing things they value.

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

	Number	Percent
I have as much control over my daily life as I want	101	27.6%
I have some control over my daily life but not enough	216	59.0%
I have no control over my daily life	49	13.4%
Total	366	100%
No response	8	

28% of carers have as much control over their daily life as they want whereas 59% of carers feel they have some control but not enough. Just over 13% feel they have no control over their daily life.

- 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?**

	Number	Percent
I look after myself	199	54.7%
Sometimes I can't look after myself well enough	107	29.4%
I feel I am neglecting myself	58	15.9%
Total	364	100%
No response	10	

55% of carers feel they look after themselves, in terms of adequate sleep and eating well whereas 29% of carers feel they can't look after themselves well enough. 16% feel they are neglecting themselves.

- 10 **Thinking about your personal safety, which of the statements best describes your present situation?**

	Number	Percent
I have no worries about my personal safety	315	85.4%
I have some worries about my personal safety	51	13.8%
I am extremely worried about my personal safety	3	0.8%
Total	369	100%
No response	5	

85% of carers have no worries about their personal safety, whereas 15% of carers have some worries.

- 11 **Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?**

	Number	Percent
I have as much social contact as I want with the people I like	127	34.4%
I have some social contact with people but not enough	174	47.2%
I have little social contact with people and feel socially isolated	68	18.4%
Total	369	100%
No response	5	

34% of carers have as much social contact as they want, whereas 47% of carers don't have enough social contact. 18% of carers feel socially isolated.

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

	Number	Percent
I feel I have encouragement and support	138	38.4%
I feel I have some encouragement & support but not enough	159	44.3%
I feel I have no encouragement & support	62	17.3%
Total	359	100%
No response	15	

38% of carers feel they have encouragement and support, whereas 44% of carers feel that they don't have enough. 17% of carers feel that they have no encouragement & support.

- 13 **Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? Please exclude the person you spend most time helping.**

	Number	Percent
I always have enough time to care for them	85	23.9%
I sometimes have enough time to care for them	98	27.5%
I never have enough time to care for them	17	4.8%
I don't have caring responsibilities for anyone else	156	43.8%
Total	356	100%
	18	

24% of carers felt they have enough time to care for other people. 44% don't have caring responsibilities for anyone else.

- 14 **In the last 12 months, has your health been affected by your caring role in any of the ways listed below?**

	Number	Percent
Feeling tired	293	78.3%
Feeling depressed	155	41.4%
Loss of appetite	52	13.9%
Disturbed sleep	246	65.8%
General feeling of stress	226	60.4%
Physical strain (e.g. back)	118	31.6%
Short tempered/irritable	169	45.2%
Had to see own GP	113	30.2%
Developed my own health conditions	94	25.1%
Made an existing condition worse	78	20.9%
Other	16	4.3%
No, none of these	20	5.3%

78% of carers feel tired as an effect of their caring role, with 66% reporting disturbed sleep and 60% commenting on experiencing a general feeling of stress.

15 In the last 12 months, has caring caused you any financial difficulties?

	Number	Percent
No, not at all	213	59.3%
Yes, to some extent	111	30.9%
Yes, a lot	35	9.7%
Total	359	100%
No response	15	

41% had experienced financial difficulties to some extent through their caring duties.

Section 4: Information and advice quality

The next questions ask for the carers views about the quality of information and advice.

16 In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.

	Number	Percent
Very easy to find	64	17.5%
Fairly easy to find	128	35.1%
Fairly difficult to find	47	12.9%
Very difficult to find	22	6.0%
I have not tried to find information or advice in the last 12 months	104	28.5%
Total	365	100%
No response	9	

53% of carers found it easy to access information about support, services or benefits, 19% finding it difficult although 29% of carers haven't tried to find information or advice in the last 12 months.

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:

	Comments made by respondents
<p>Difficulty understanding information</p>	<p><i>“Because there are so many different areas that can help - different phone numbers - different names - it would be so much better if they were all under one roof - one phone number so they can direct to the area or areas that could help.”</i></p> <p><i>“Non computer literate”</i></p>
<p>Difficult to find information</p>	<p><i>“Because there are so many different areas that can help - different phone numbers - different names - it would be so much better if they were all under one roof - one phone number so they can direct to the area or areas that could help.”</i></p> <p><i>“It took a long time before I spoke to the right people who could offer help, support and advice. Lots of phone calls to wrong services or given out of date advice. Torbay Carers put me on the right track. More information in GP surgeries/ health centres.”</i></p> <p><i>“Most information is on the internet which I can't use. Need info more local for people to find and read.”</i></p>
<p>Difficulty making contact with services</p>	<p><i>“Carers group at GP Surgery not helpful at all. I only started reviewing support and information when my dad was diagnosed with dementia. Chadwell have been really helpful.”</i></p> <p><i>“With working full time I found that the places I needed to go were closed and I try to keep Saturday free for my family and to not have to use this day for anything but me and my family.”</i></p> <p><i>“Need a one stop shop, advice on computer, place etc. carers centre. Treat carer as a whole. A lot of support helps unemployed cares because of courses being all held in the day time they are all held in the day time, they are not accessible to workers. Support cover support workers need more. Maybe the hospitals on discharge into the community give out more contact info asap.”</i></p>

- 17 In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.

	Number	Percent
Very helpful	103	28.7%
Quite helpful	136	37.9%
Quite unhelpful	20	5.6%
Very unhelpful	7	1.9%
I have not received any information or advice in the last 12 months	93	25.9%
Total	359	100%
No response	15	

Of the information and advice received by carers 67% found it helpful, while only 8% found it unhelpful.

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

	Comments made by respondents
Need for clear information	<p><i>"1. Lack of information of cost of respite care under new arrangements 2. No communication regarding increase of respite care from 21 to 28 days."</i></p> <p><i>"Very difficult to understand. Does not cover all the aspects of caring. Very condescending."</i></p>
Hard to make contact with the right person/service	<p><i>"Information can be quite vague unless you get through the proper department and that takes times and patience. I also find that different departments play different roles within the complex "holistic" support given, yet there is little or no feedback to the main carer and little or no connection between departments. So each role stands alone when in fact they should be connected."</i></p> <p><i>"Information mainly concentrates on physical care not emotional support which a lot of elderly people needing help require ie feeling of loneliness, being cut off from the outside world. Also people caring all day do not want to attend carers meetings because they just want to be at home relaxing."</i></p>
Problems receiving information	<p><i>"The only help or advice we have received was when Bay Tree was closing until then nothing."</i></p> <p><i>"I have accessed the newsletter that has been emailed to me. Not sure what else I can do."</i></p>

Section 5: Arrangement of support and services in the last 12 months

The next question is about organising the support and services for you and the person you care for.

- 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?**

	Number	Percent
There have been no discussions that I am aware of, in the last 12 months	110	30.2%
I have always felt involved or consulted	103	28.3%
I usually felt involved or consulted	79	21.7%
I sometimes felt involved or consulted	51	14.0%
I never felt involved or consulted	21	5.8%
Total	364	100%
No response	10	

In the last 12 months 28% of carers always felt involved in discussions about the support provided to the person they care for.

Section 6: About yourself

The next group of questions helps us to get a better picture of the types of carers who took part in this survey.

- 19 In addition to your caring role, please tell us which of the following also applies to you?**

Note: This is multiple response question where respondents can select more than one answer so totals will add up to more than 100%.

	Number	Percent
Retired	243	65.0%
Employed full-time	18	4.8%
Employed part time (working 30 hrs or less)	30	8.0%
Self employed full time	4	1.1%
Self employed part time	9	2.4%
Not in paid work	78	20.9%
Doing voluntary work	12	3.2%
Other	30	8.0%

65% of carers are retired, with 16% are working.

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

	Number	Percent
I am not in paid employment because of my caring responsibilities	62	18.2%
I am not in paid employment for other reasons (e.g. retired)	220	64.7%
I am in paid employment and I feel supported by my employer	27	7.9%
I am in paid employment but I don't feel supported by my employer	9	2.6%
I do not need any support from my employer to combine my work and my caring responsibilities	10	2.9%
I am self-employed and I am able to balance my work and caring responsibilities	7	2.1%
I am self-employed but I am unable to balance my work and caring responsibilities	5	1.5%
Total	340	100%
No response	34	

18% of carers are currently not in work because of their caring responsibilities.

21 About how long have you been looking after or helping the person you care for?

	Number	Percent
Less than 6 months	1	0.3%
Over 6 months but less than a year	12	3.3%
Over 1 year but less than 3 years	71	19.2%
Over 3 years but less than 5 years	65	17.6%
Over 5 years but less than 10 years	79	21.4%
Over 10 years but less than 15 years	36	9.8%
Over 15 years but less than 20 years	34	9.2%
20 years or more	71	19.2%
Total	369	100%
No response	5	

21% of carers have been looking after the person they care for over 5 years (but less than 10 years), however 19% have had caring responsibilities for over 20 years.

22 About how long do you spend each week looking after or helping the person you care for?

	Number	Percent
0-9 hours per week	8	2.2%
10-19 hours per week	16	4.4%
20-34 hours per week	19	5.2%
35-49 hours per week	26	7.1%
50-74 hours per week	27	7.4%
75-99 hours per week	32	8.8%
100 or more hours per week	187	51.4%
Varies - under 20 hours per week	18	4.9%
Varies - 20 hours or more per week	27	7.4%
Other	4	1.1%
Total	364	100%
No response	10	

51% of carers spend over 100 hours per week looking after the person they care for.

23 Over the last 12 months, what kinds of things did you usually do for the person you care for?

Note: This is multiple response question where respondents can select more than one answer so totals will add up to more than 100%.

	Number	Percent
Personal care?	256	68.4%
Physical help?	232	62.0%
Helping with dealing with care services and benefits?	306	81.8%
Helping with paperwork or financial matters?	309	82.6%
Other practical help?	347	92.8%
Keeping him/her company?	280	74.9%
Taking him/her out?	282	75.4%
Giving Medicines?	302	80.7%
Keeping an eye on him/her to see he/she is all right?	354	94.7%
Giving emotional support?	311	83.2%
Other help?	48	12.8%

Carers performed a variety of tasks for the person they cared for, from personal care (68%) to helping deal with care services (82%) and giving medicines (81%).

24 Do you have any of the following?

Note: This is multiple response question where respondents can select more than one answer so totals will add up to more than 100%.

	Number	Percent
A physical impairment or disability	100	26.7%
Sight or hearing loss	76	20.6%
A mental health problem or illness	38	10.2%
A learning disability or difficulty	9	2.4%
A long-standing illness	109	29.1%
Other	44	11.8%
None of the above	108	28.9%

29% of carers reported to having a long standing illness.

25 How many children aged 18 or under do you have parental responsibility for?

	Number	Percent
0	170	91.4%
1	8	4.3%
2	6	3.2%
3	1	0.5%
4	1	0.5%
Total	186	100%
No response	188	

16 carers in total who responded to the question have children aged 18 or under.

26 How old are you?

	Number	Percent
Below 18	1	0.3%
18-24	5	1.4%
25-34	4	1.1%
35-44	10	2.8%
45-54	35	9.9%
55-64	76	21.4%
65-74	108	30.4%
75-84	89	25.1%
85+	27	7.6%
Total	355	100%
No response	19	

85% of carers are aged between 55 years and 85 years+.

27 Are you male or female?

	Number	Percent
Male	113	30.4%
Female	259	69.6%
Total	372	100%
No response	2	

70% of carers are female.

28 To which of these groups do you consider you belong?

	Number	Percent
English / Welsh / Scottish / Northern Irish / British	359	97.3%
Irish	3	0.8%
Gypsy or Irish Traveller	0	0.0%
Any other White background	4	1.1%
White and Black Caribbean	0	0.0%
White and Black African	0	0.0%
White and Asian	0	0.0%
Any other Mixed / Multiple background	0	0.0%
Indian	1	0.3%
Pakistani	0	0.0%
Bangladeshi	0	0.0%
Chinese	0	0.0%
Any other Asian background	1	0.3%
African	0	0.0%
Caribbean	0	0.0%
Any other Black / African / Caribbean background	0	0.0%
Arab	0	0.0%
Any other background	1	0.3%
Total	369	100%
No response	5	

97% of carers are of English / Welsh / Scottish / Northern Irish / British origin.

29 Did someone help you to complete the questionnaire?

	Number	Percent
Yes	26	7.0%
No	343	93.0%
Total	369	100%
No response	5	

7% of carers had someone to help them complete the questionnaire.

30 Have you told your GP that are a carer? (*Optional question for Torbay*)

	Number	Percent
Yes	320	85.6%
No	50	13.5%
Total	370	100%
No response	4	

86% of carers have told their GP's that they are a carer.

31 Did telling your GP you were a carer make any difference (*Optional question for Torbay*)

	Number	Percent
Yes	116	36.6%
No	201	63.4%
Total	317	100%
No response	57	

37% of carers felt that telling their GP they were a carer made any difference.

32 If further research were to take place, would you be happy for us to contact you?

	Number	Percent
Yes	184	54.1%
No	156	45.9%
Total	340	100%
No response	34	