

**Your Essex
is changing**

let's talk

about it

Have your say...

**Adult Social Care Carer's
Survey**

Developed by Social Care Information Centre (HSCIC)

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Essex County Council

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Introduction

The introduction of the Adult Social Care Survey (ASCS) in 2010-11 was the first time all service users had been surveyed on a national basis using the same methodology and questionnaires. The Adult Social Care Survey consults annually with service users and biennially with carers, the questions in the survey cover a range of social care related issues, including satisfaction with services and choice and control. This survey provides an opportunity for service users and carers to give their views and feedback about social care provision and the services that they receive and or have access to.

Growing demand for social care services, together with limited funding means Essex County Council has a duty to make sure it gets best value from all resources. This will help protect the council's financial sustainability and services for the future for all its citizens, especially the most vulnerable. The ASCS survey provides assured, benchmarked local data, in order to support local services to think about ways of improving outcomes within the current financial climate.

The most recent ASCS survey took place during October and November 2014, a random selection of adult carers in Essex (people over the age of 18 who care for someone also over 18) were sent the survey.

The results of this survey are currently being used by Essex County Council and CCGs to inform future planning, commissioning of services and to make sure there is a well-developed and managed market that is able to deliver the range of options required to support carers and individuals in a cost effective way.

This report will be accessible to members of the public via our online portal and alternative formats are available on request.

Key Conclusions

- Over half of the respondents said that the person they care for is aged 75+, whilst most carers themselves were aged 55-64. Over a third of respondents care for someone more than 100 hrs. a week, for some this is 24/7 care, day and night.
- Several positive comments were made about social services and agency personnel, praising the work of social workers and care staff. For some the care packages and support services that they have in place allows them to have a break from caring and continue with their normal routines.
- A number of respondents praised respite services and commented that without them they would not be able to care full time, however for some there is an anxiety and worry around respite care, with some people reporting bad experiences and others just unable to get the respite care that they feel they need.
- A number of people commented about personal budgets and carer's allowance, for some personal budgets have helped the people they care for have a sense of independence and enabled them to access services and activities that they otherwise would not have been able to. Some respondents criticized carer's allowance, commenting that it was inadequate and that working part-time to earn extra money just wasn't feasible due to caring duties.
- A number of respondents highlighted issues around the quality of care and services received, stating issues such as punctuality of staff, poor quality of care when visiting the home, inconsistencies with carers and not following instructions properly.
- Other respondents criticized the lack of information and advice, highlighting the importance of having correct, relevant and up to date information. For some there were issues around not knowing where to find information or finding it difficult to access it.
- A number of respondents also criticized the efficiency of social services, stating issues with high staff turnover, fragmented services, poor communication and often very long waiting times to speak or meet with a professional in order to set up services or support.
- When asked to provide additional information, several comments were made about the effects of caring for someone else, highlighting a number of issues including; feeling isolated, lonely, stressed, depressed and unable to cope at times.

Executive summary

The majority of respondents said that the person they care for was aged 75 + years (56%) and lived with them (64%), while 36% said that the person they cared for lived somewhere else. Over 60% of respondents said that the person they cared for had a physical disability, 41% had problems connected to ageing and 36% had a long-standing illness. When asked about how long they had been looking after the person they care for the majority (73%) said 5 years or more, while 27% said 5 years or less. A third (33%) of all respondents said that they look after the person they care for more than 100 hours a week.

When asked about the things that they did for the person they care, the highest rated answers were, 'practical help', 'keeping an eye on him/her' and 'helping with paperwork or financial matters.'

Respondents were asked how satisfied they were with the support or services that they have received from social services, over half (51%) said that they were satisfied while 14% said that they were dissatisfied. When asked about the support or services they receive, over half (58%) said that they either usually or always felt involved or consulted, while 6% said that they never felt involved or consulted.

Respondents were given a list of support and services and asked if the person that they care for had used any of them in the last 12 months. For respite services, personal assistance lunch club, meal services and day centre/day activities the majority of people answered no. For home care/home help, lifeline alarm and equipment or adaptation to their home the majority of respondents answered yes.

Respondents were asked about their social life and how they spent their time, over half the responses (61%) said that they did things that they value or enjoy but not enough, while 14% said that they didn't do anything that they value or enjoy with their time. Nearly half (44%) said that they felt they had a good social life, while 41% said that they had some social contact with people but not enough. When asked about their own well-being, over a third said that they sometimes didn't look after themselves or felt they were neglecting their own personal care.

Respondents were asked how easy they have found it to find information and advice about support, services or benefits, 40% said that they find it easy, while in comparison 28% said that they find it difficult. For respondents that found it difficult to find information a number of issues were highlighted, including knowing where to look, issues concerning telephone services and feeling pushed and pulled between different departments.

For those that have received information and advice, over half (57%) found it helpful, while 9% found it unhelpful. For respondents that found this information unhelpful a number of issues were highlighted including, the information and advice provided not being relevant or up to date, the time it takes to receive information and little or no feedback or follow up.

Respondents were asked about how they found out about support available for carers from voluntary organisations, over a third (38%) were not aware that there was any support available. For those that had approached the voluntary sector for support, 21% said that the support had helped them, while 10% said that the support had helped them either a little or not a lot.

When asked to describe any other experiences and provide feedback, 233 comments were made. Out of those 16 respondents made positive comments about social services and agency personnel, 3 people made positive comments about personal budgets, saying that it has enabled the person they care for to live a more independent and full life and 12 people highlighted the importance of additional support from family members. For some respondents the care packages and support services that they have in place allows them to have a break from caring and continue with their normal routines.

However just over a third (34%) of all comments made criticised the quality of social care services, with 34 people highlighting that they have received no help or support, 30 people commenting that the time and efficiency of services has been poor and 26 people said that they had issues with the quality of the services and care that was provided (mainly staff). Other respondents (20) criticised the lack of information and advice, saying that it is difficult to find correct up to date information and to know what support services are available and where to look.

There were 12 negative comments made regarding social services assessment processes, saying that assessments took a very long time and were difficult to complete. There were nine people that made negative comments relating to respite care, some around the quality of care when received while in respite and others that they have found it difficult to request respite services. Several respondents highlighted issues around their carers allowance and in most cases saying that this was inadequate and had a huge impact on their own personal well-being and quality of life.

Respondents also spoke about the effects of caring for someone else and the support that they receive as a carer, with over 20 comments highlighting that they felt isolated, stressed or depressed.

Who gave their views?

A total of 520 people responded to the survey. Of the total, 67% of respondents were female and 33% male. For ethnicity, 496 respondents identified as White British, while 6 were Black/Black British, 2 were mixed race, 1 respondent Chinese and one identified as other ethnic group. Nearly half of respondents (49%) said that they do not have a disability, while 21% stated that they have a long-standing illness, 17% a physical impairment or disability, 12% sight or hearing loss, 5% a mental health problem or illness and 2% stated that they had a learning disability or difficulty.

Most respondents were aged between 55-64

		Response Total	Response Percent
16-24		2	0.3%
25-34		2	0.3%
35-44		20	4%
45-54		82	16%
55-64		156	30%
65-74		137	26%
75+		107	20%
Unknown		14	3%
Total Respondents			520

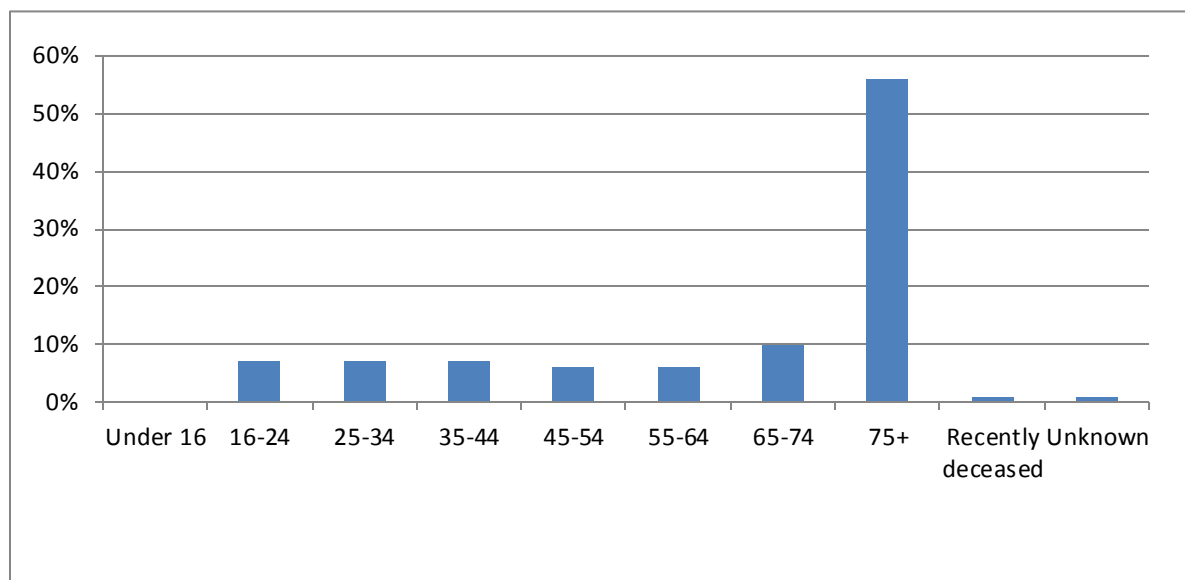
The breakdown of respondents by the home district is shown below

		Response Total	Response Percent
Basildon		56	12%
Braintree		38	8%
Brentwood		32	7%
Castle Point		40	8%
Chelmsford		52	11%
Colchester		69	14%
Epping Forest		39	8%
Harlow		24	5%
Maldon		17	4%
Rochford, including Rayleigh		36	8%
Southend-on-Sea		4	1%
Tendring		52	11%
Uttlesford		21	4%
Total Respondents			480

Detailed findings

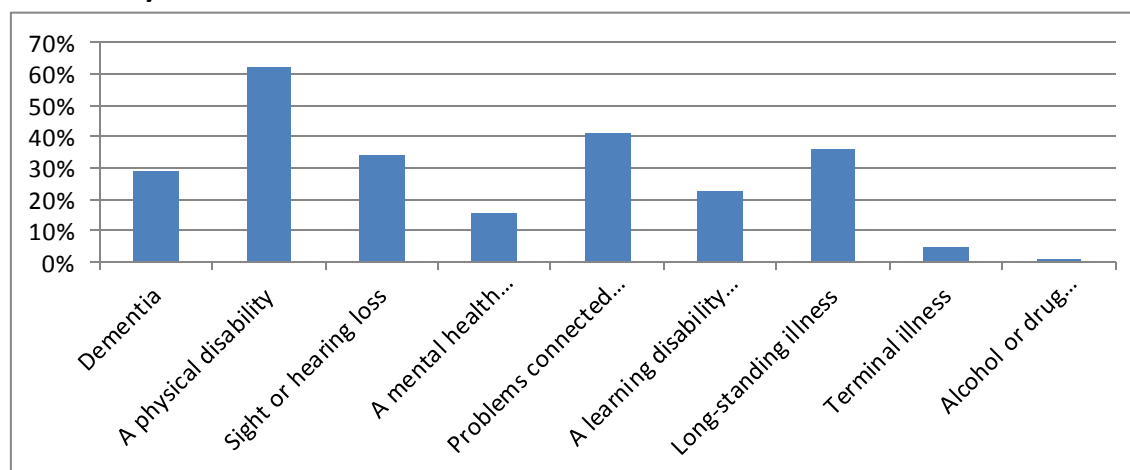
Section 1: About the person you care for

Q1. This question asked respondents the age of the person being cared for.



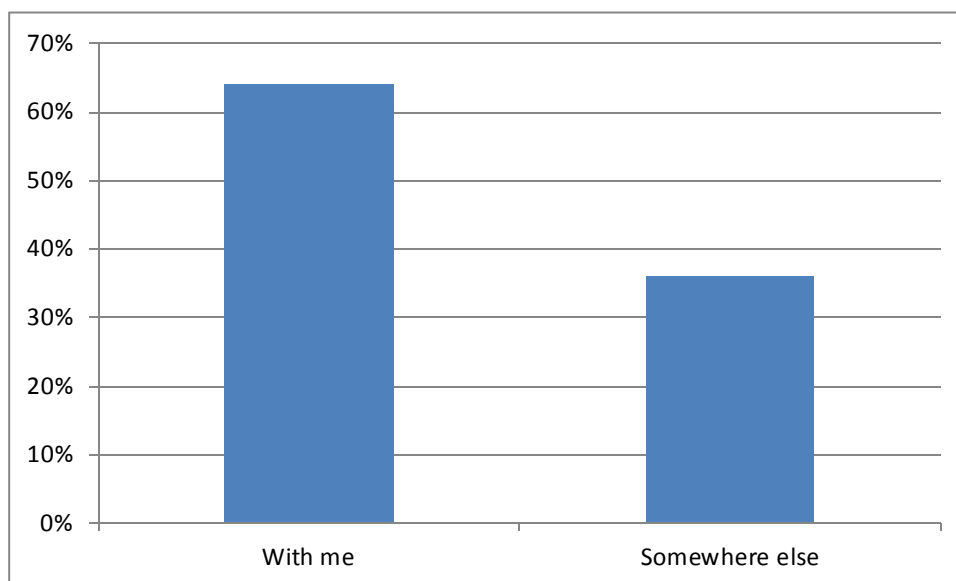
Respondents were asked the age of the person that they care for, with the majority of those aged 75 + years (56%) and 65-74 years (10%). Out of the 520 respondents only one stated that the person they care for was under 16 years.

Q2 This question asked respondents if the person that they care for had any of the below health or disability issues.



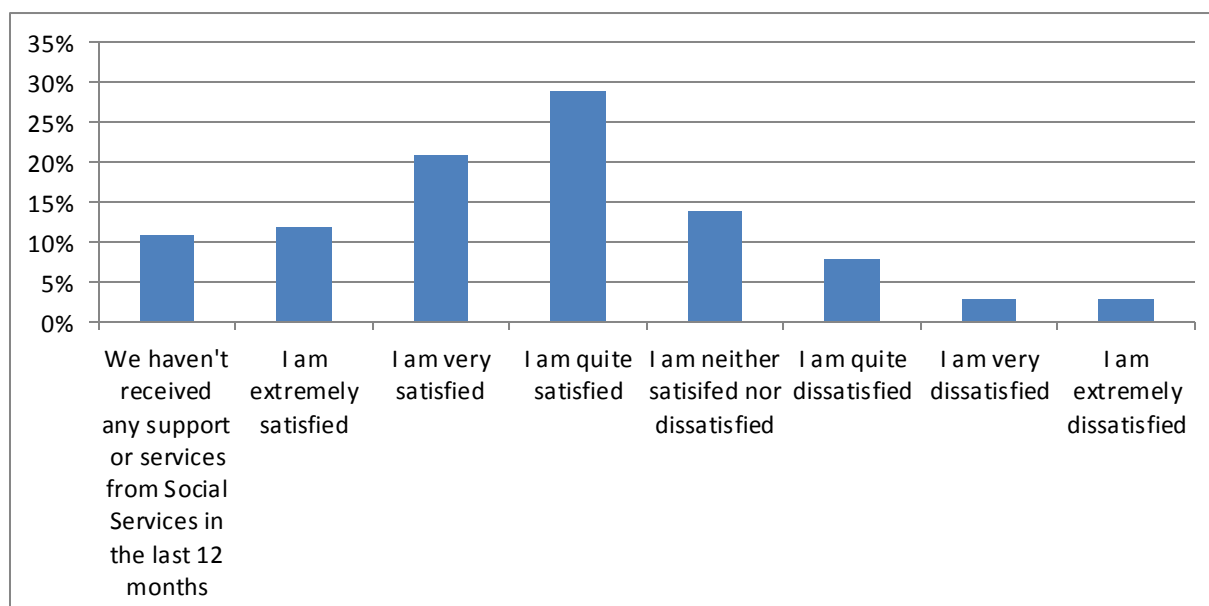
Over 60% of respondents said that the person they cared for had a physical disability, while 41% had problems connected to ageing and 36% had a long-standing illness. Nearly a third of responses (29%) stated dementia, 23% a learning disability or difficulty and 16% a mental health problem. The lowest responses given were 5% have a terminal illness and 1% alcohol or drug dependency.

Q3. This question asked respondents where the person that they care for usually lives.



The majority (64%) of respondents said that the person that they cared for lived with them, while 36% said that they lived somewhere else.

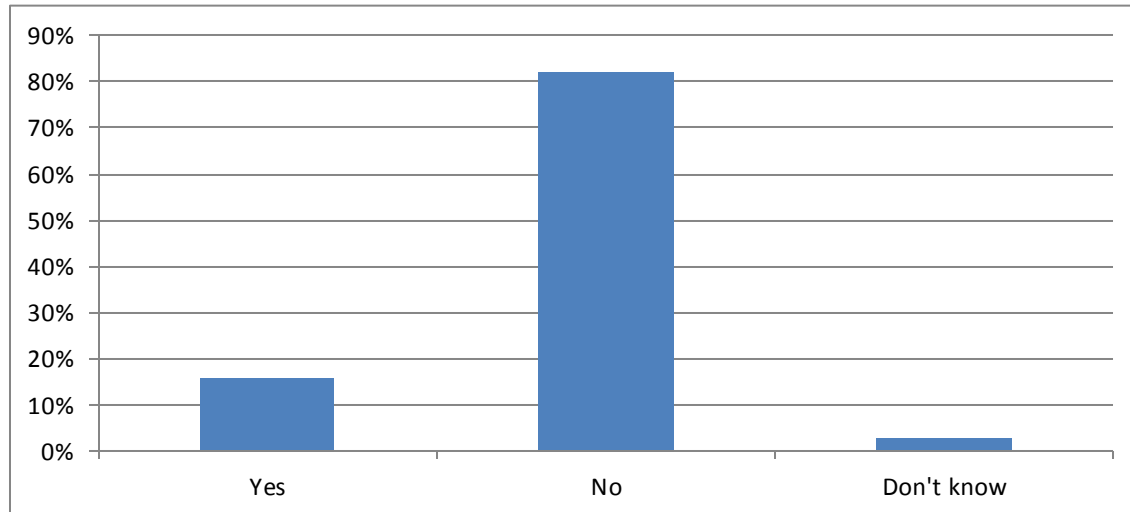
Q4. This question asked respondents how satisfied or dissatisfied they were with the support or services that they and the person they care, for have received from social services in the last 12 months



Nearly a third (29%) of respondents said that they were 'quite satisfied', while 21% said that they were 'very satisfied' and 11% said that they were 'extremely satisfied'. However 8% of respondents said that they were 'quite dissatisfied', 3% said that they were 'very dissatisfied' and 3% 'extremely dissatisfied'. Out of the 506 respondents 11% said that they 'haven't received any support or services from social services' and 14% said that they were 'neither satisfied nor dissatisfied'.

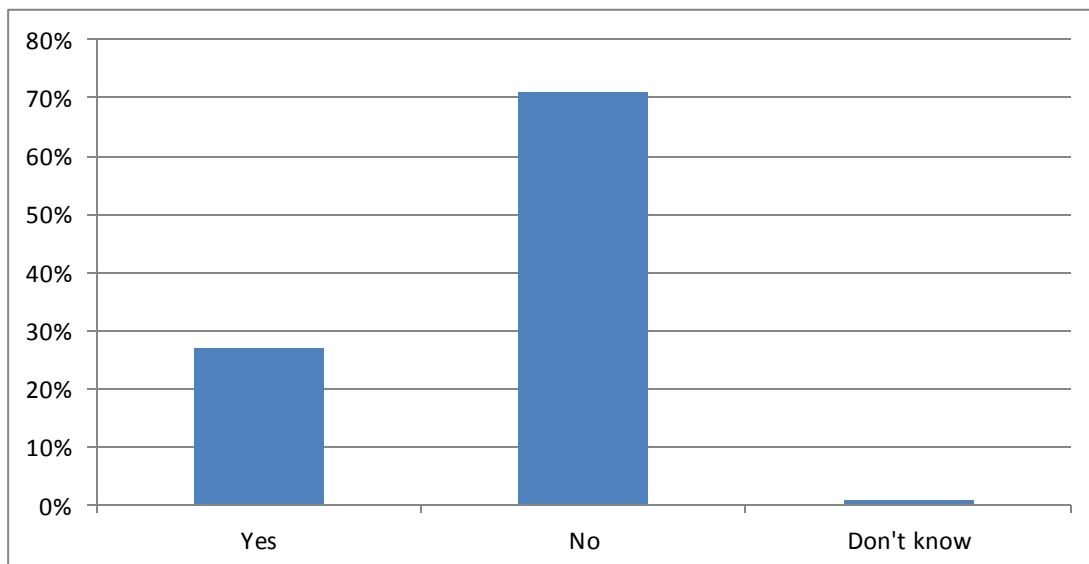
For question 5, respondents were given a list of support and services and asked if the person that they care for had used any of them in the last 12 months.

Q5.a Support services allowing the carer to take a break from caring at short notice or in an emergency



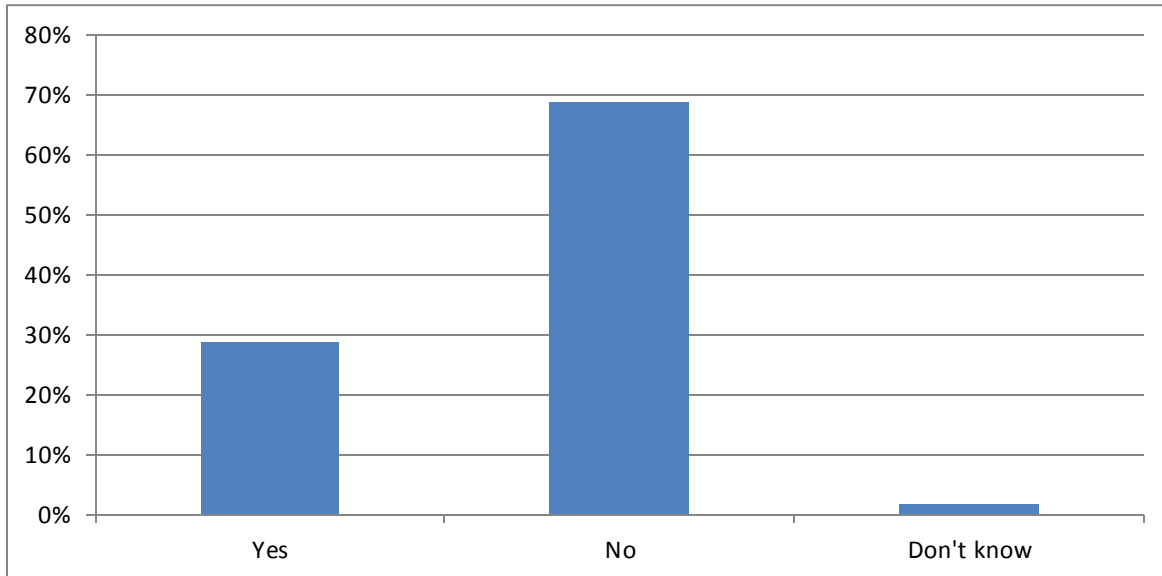
The majority of respondents answered no (82%), while 16% said yes and 3% didn't know.

b. Support or services allowing the carer to take a break from caring for more than 24 hours.



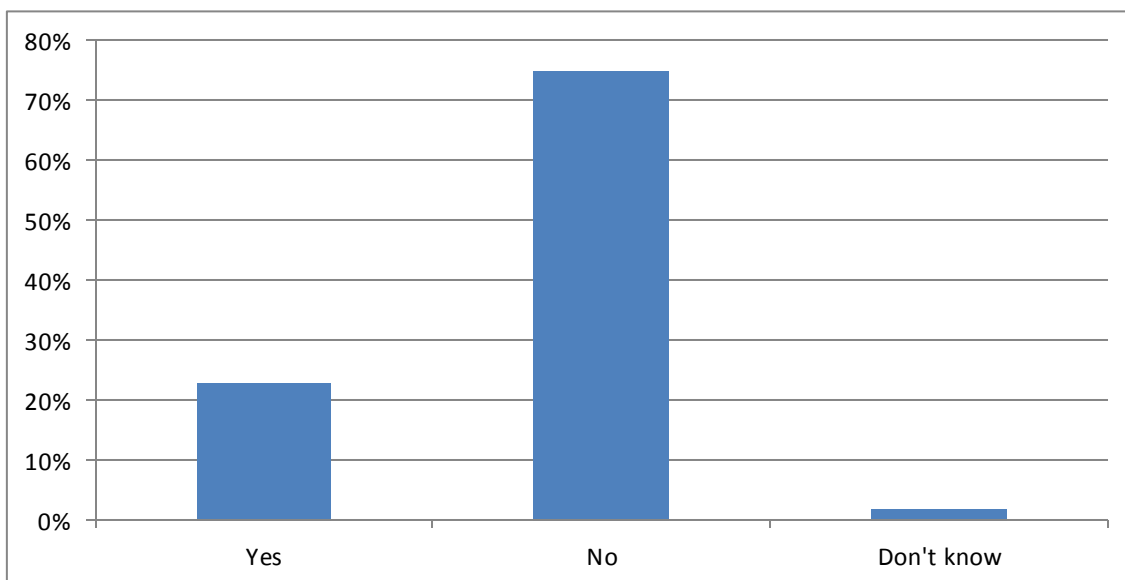
The majority of respondents answered no (71%), while 27% answered yes and 1% said that they did not know.

C. Support or services allowing the carer to have a rest from caring for between 1 and 24 hours (eg. a sitting service)



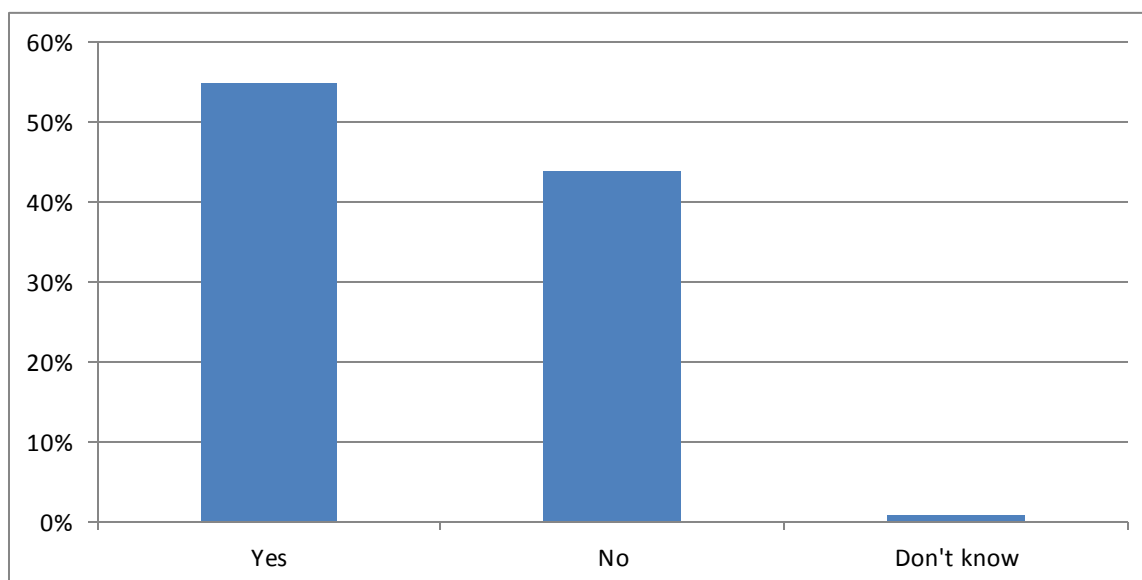
The majority of respondents answered no (69%), while 29% answered yes and 2% said that they did not know.

d. Personal assistant



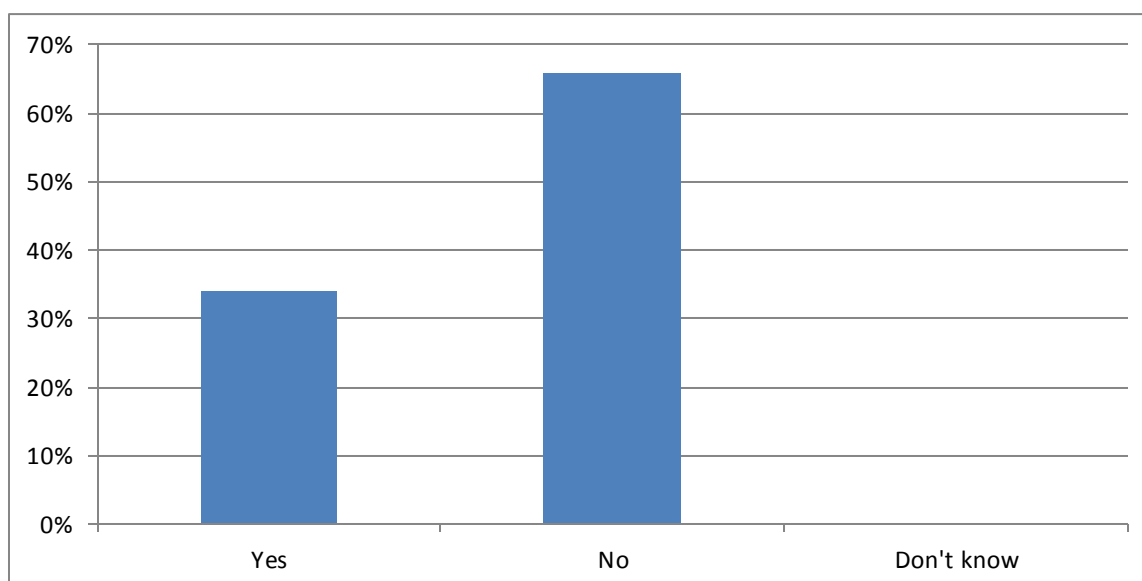
The majority of respondents (75%) answered no, while 23% answered yes and 2% said that they did not know.

e. Home care/home help



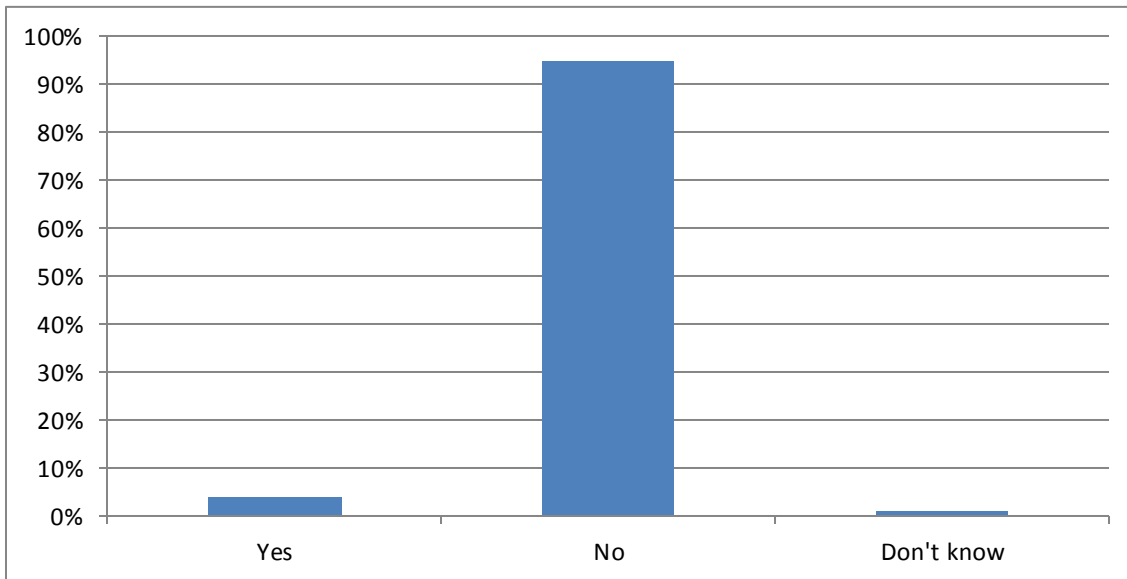
The majority of respondents (55%) answered yes, while 44% answered no and 1% said that they did not know.

f. Day Centre or day activities



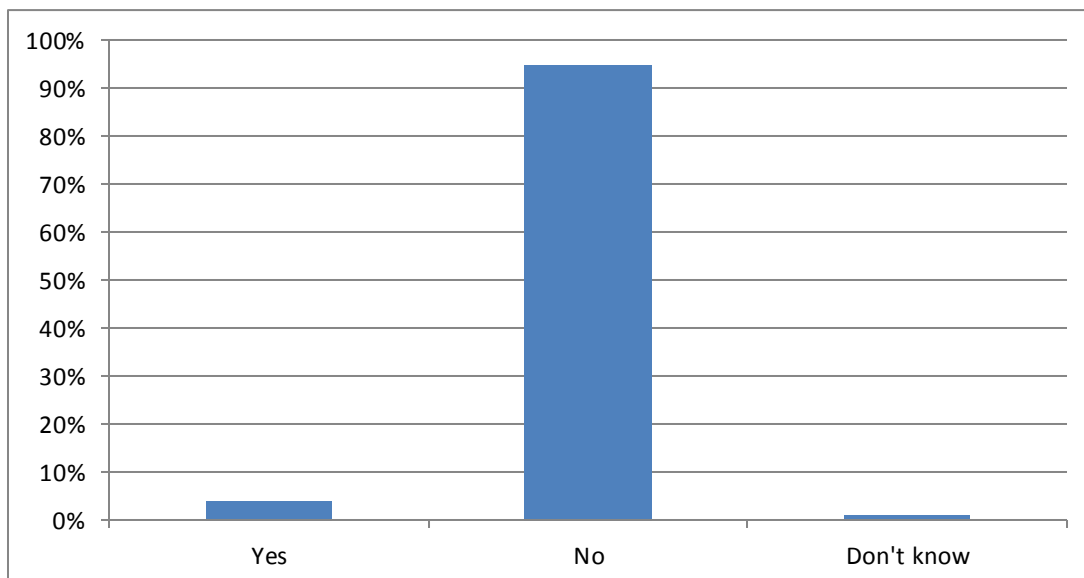
The majority of respondents (66%) answered no, while 34% answered yes and two people said that they did not know.

g. Lunch club



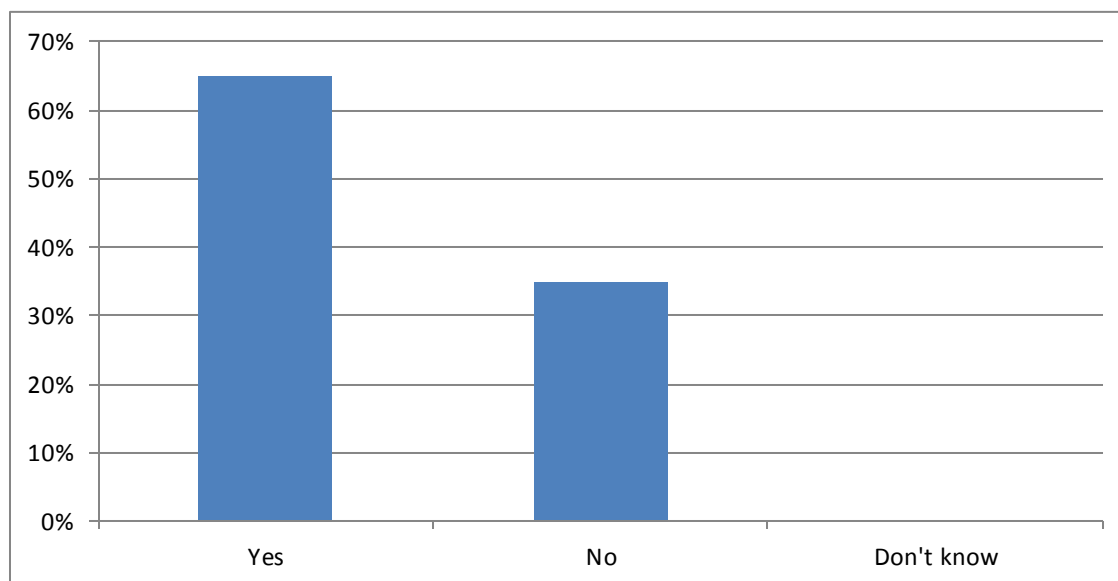
The majority of respondents (95%) answered no, while 4% answered yes and 1% said that they did not know.

h. Meal services



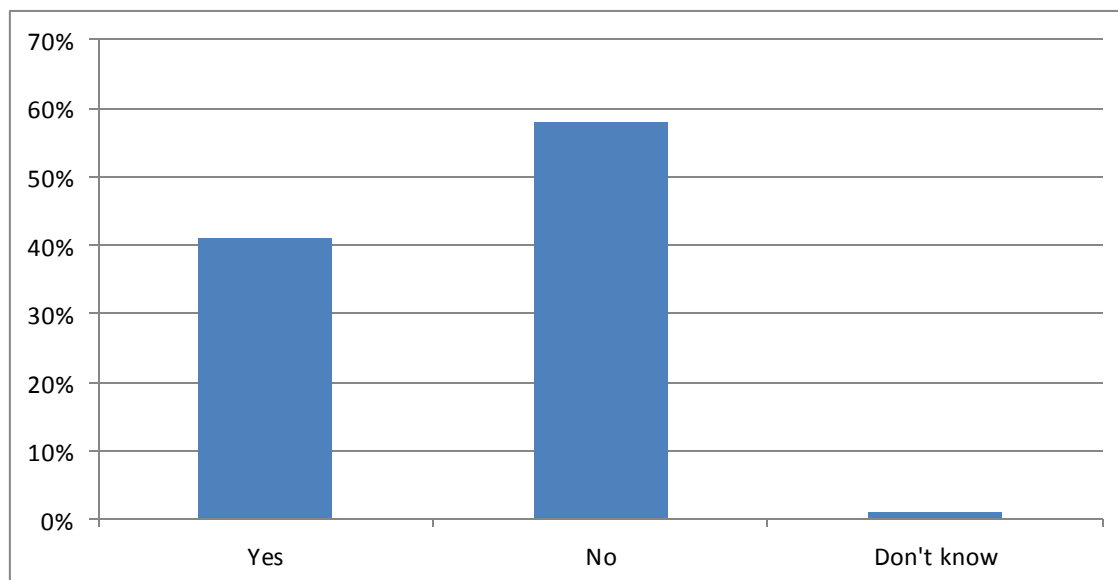
The majority of respondents (91%) answered No, while 8% answered yes and 1% did not know.

i. Equipment or adaptation to their home (such as wheelchair or handrails)



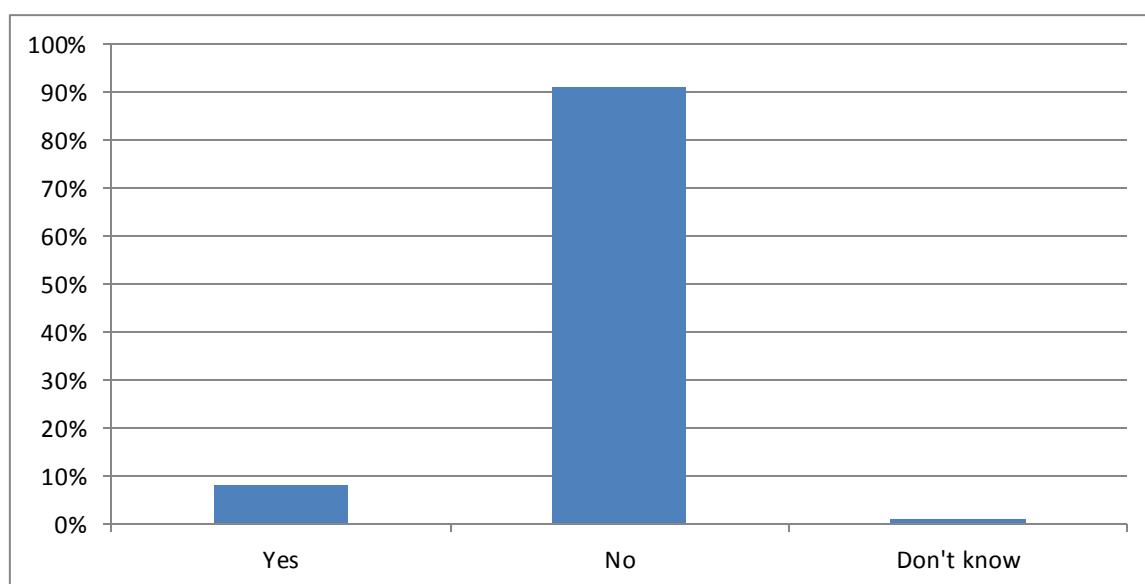
The majority of respondents (65%) answered yes, while 35% answered no and one person said that they did not know.

j. Lifeline alarm



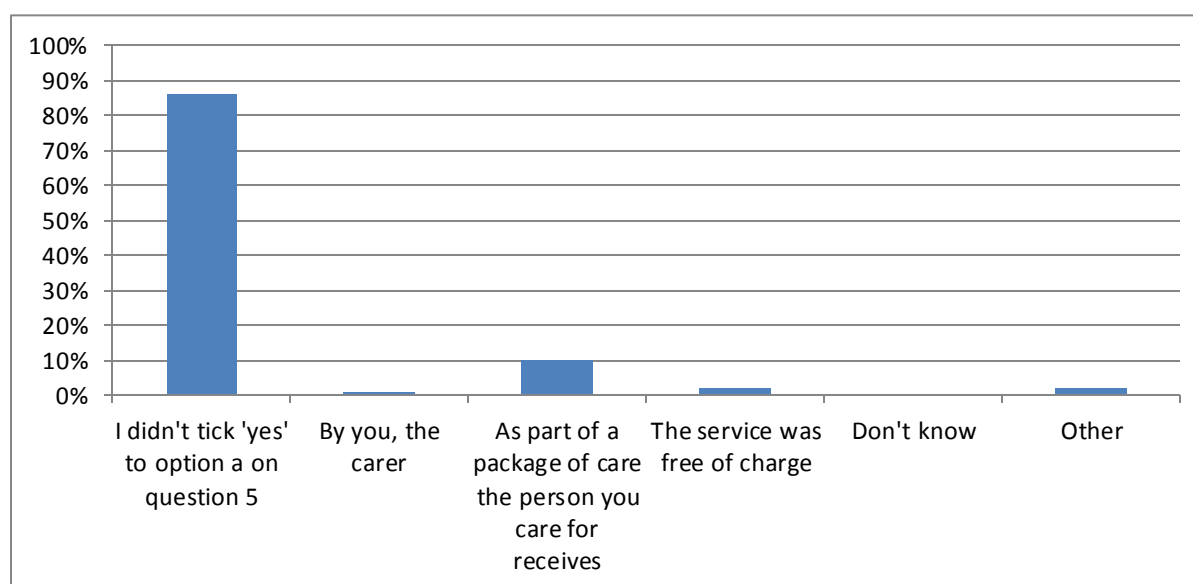
The majority of respondents (58%) answered no, while 41% answered yes and 1% said that they did not know.

k. Permanently resident in a care home



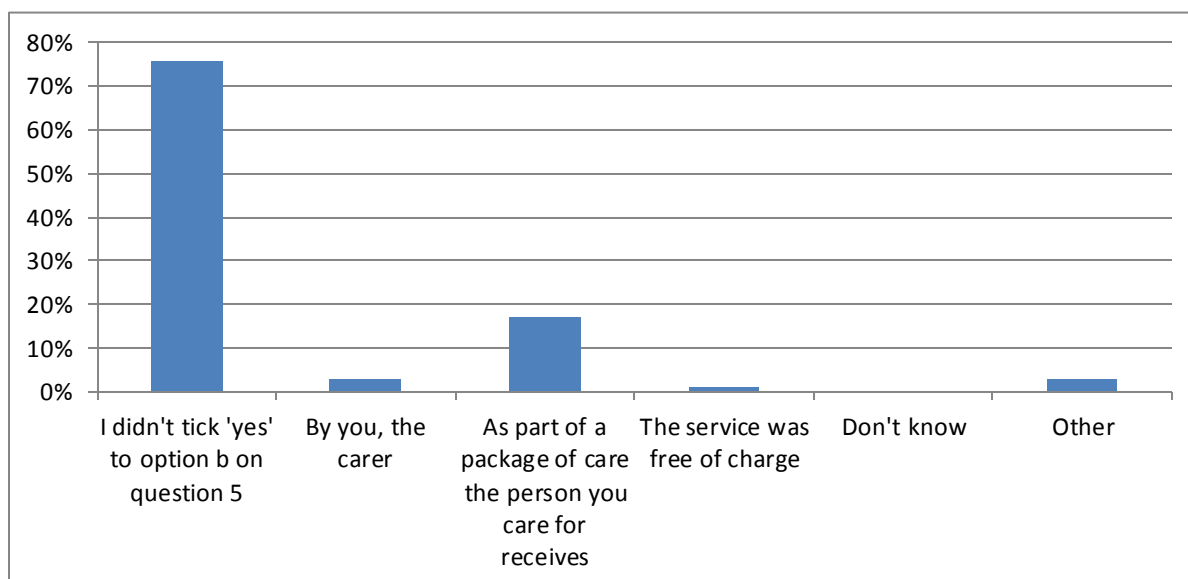
The majority of respondents (91%) answered no, while 8% answered yes and 1% said that they did not know.

Q5i If respondents answered yes to option a) on question 5 - support or services allowing you to take a break from caring a short notice or in an emergency; they were then asked how this service was paid for.



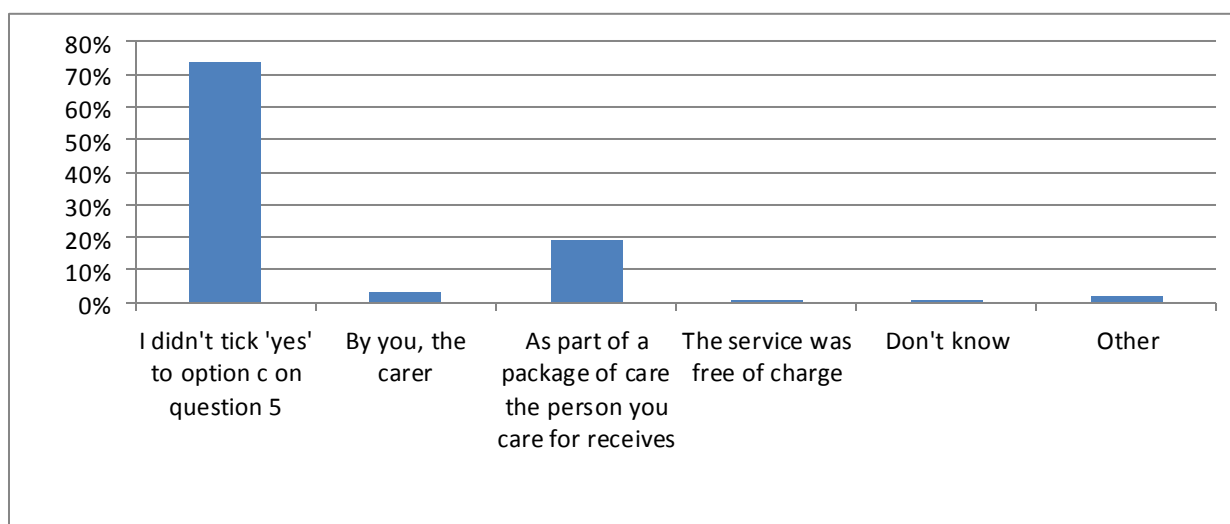
10% of respondents said that they paid for the service 'as part of a package of care the person you care for receives', 2% said that 'the service was free of charge', 1% answered that they paid for the service themselves and 2 % of said that they did not know.

Q5ii If respondents answered yes to option b) on question 5 - support or services allowing you to take a break from caring for more than 24 hours, they were then asked how this service.



17% of respondents said that they paid for the service 'as part of a package of care the person you care for receives', 3% said that they paid for the service themselves, 1% answered that 'the service was free of charge', while 3% said 'other'.

Q5iii If respondents answered yes to option c) on question 5 - support or services to allow you to have a rest from caring between 1 and 24 hours (eg. sitting service), they were then asked how this service was paid for

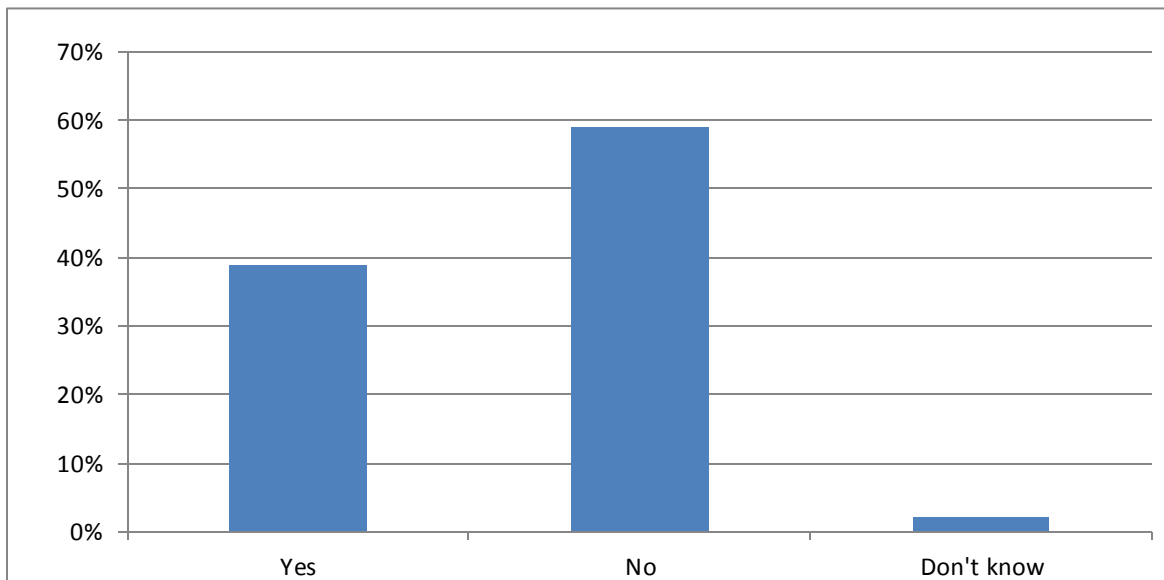


19% of respondents said that they paid for the service 'as part of a package of care the person you care for receives', 3% said that they paid for the service themselves, 1% answered that 'the service was free of charge', while 2% said 'other'.

Section 2: About your needs and experiences of support

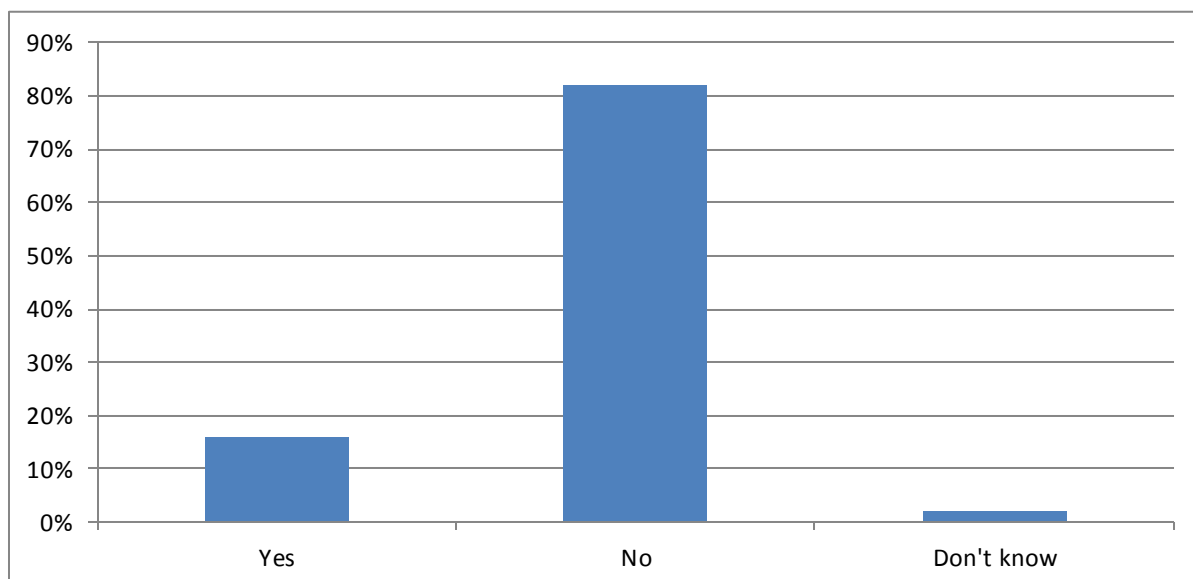
For question 6 respondents were given a list of support or services to help that help them as carers and asked if they had used any of them over the last 12 months.

a. Information and advice



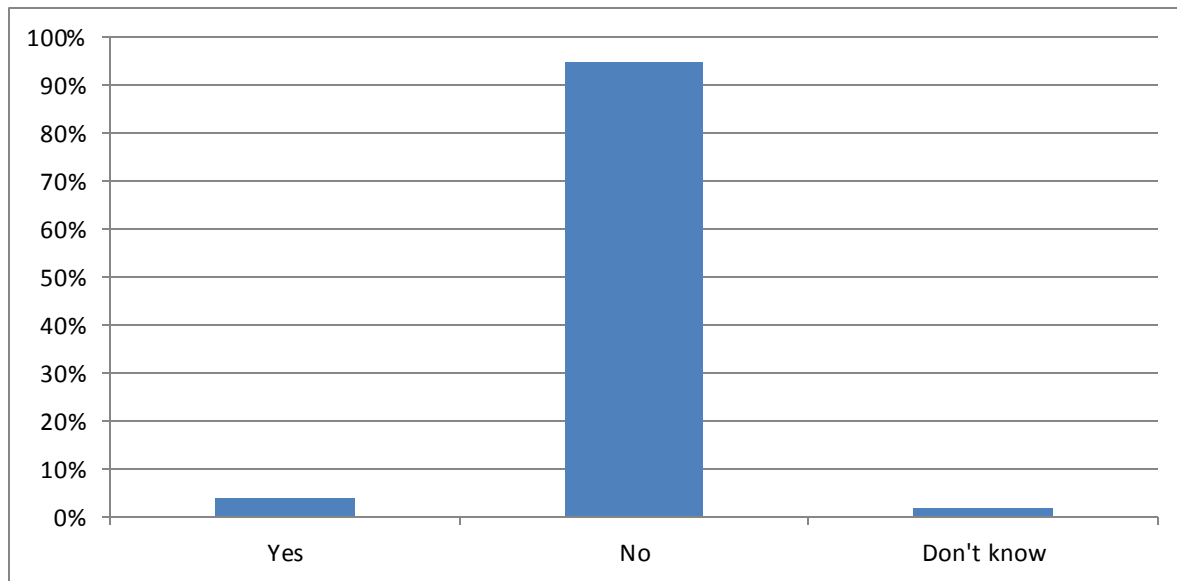
The majority of respondents (55%) answered yes, while 44% answered no and 1% said that they did not know.

b. Support from carers groups or someone to talk to in confidence.



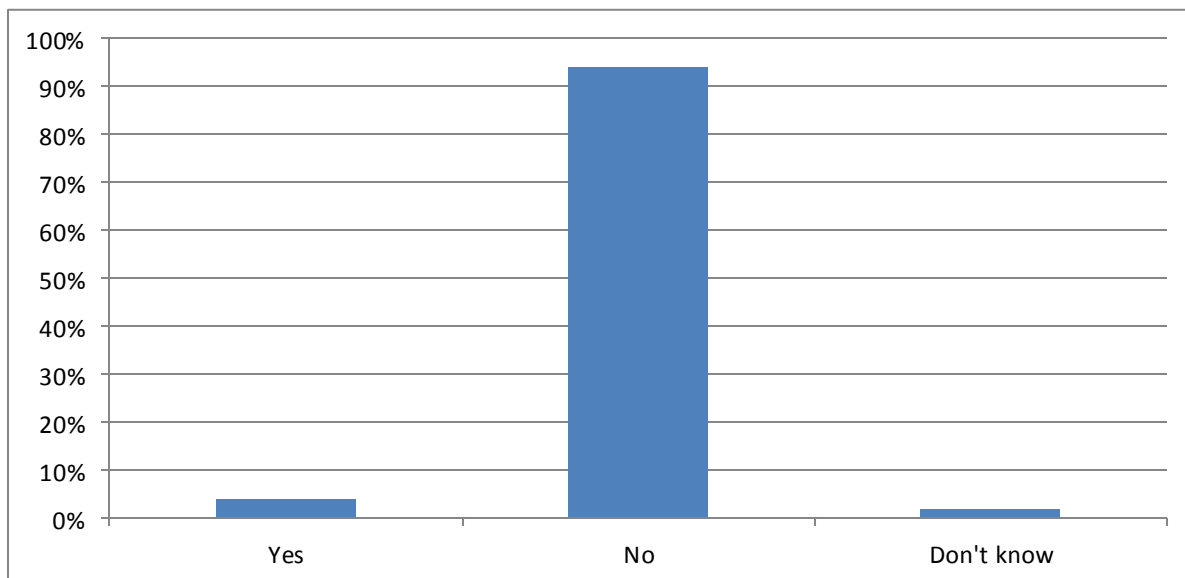
The majority of respondents (82%) answered no, while 16% answered yes and 2% said that they did not know.

c. Training for carers.



The majority of respondents (95%) answered no, while 4% answered yes and 2% said that they did not know.

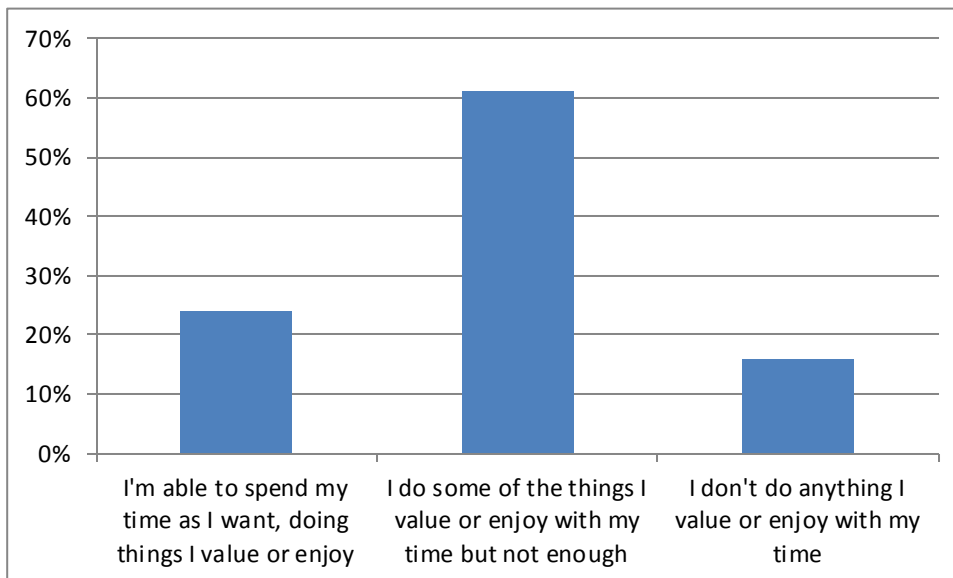
d. Support to keep you in employment.



The majority of respondents (94%) answered no, while 4% answered no and 2% said that they did not know.

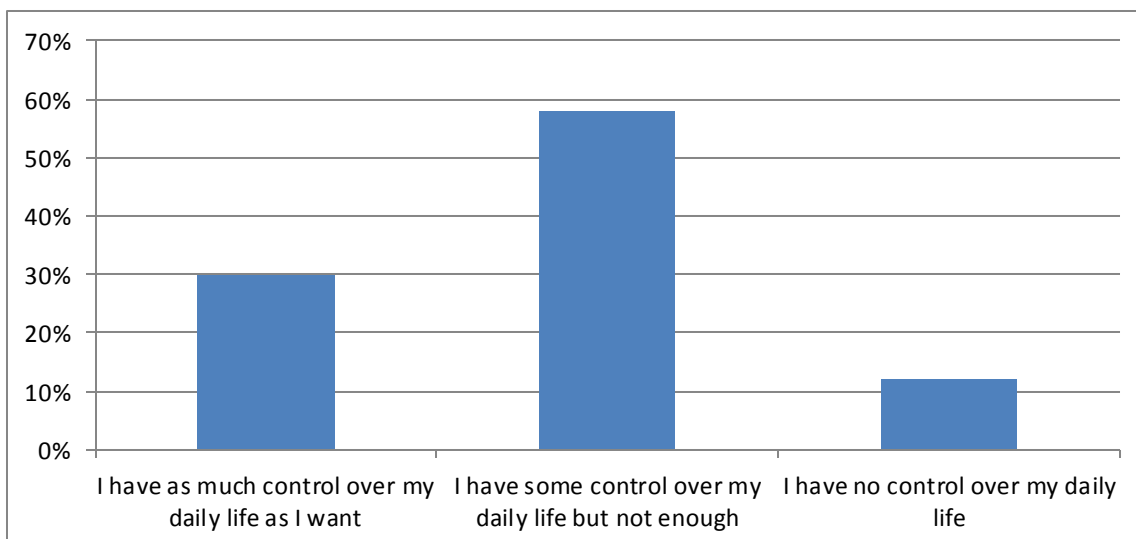
Section 3: The impact of caring and your quality of life

Q7. This question asked respondents which statement best described how they spent their time.



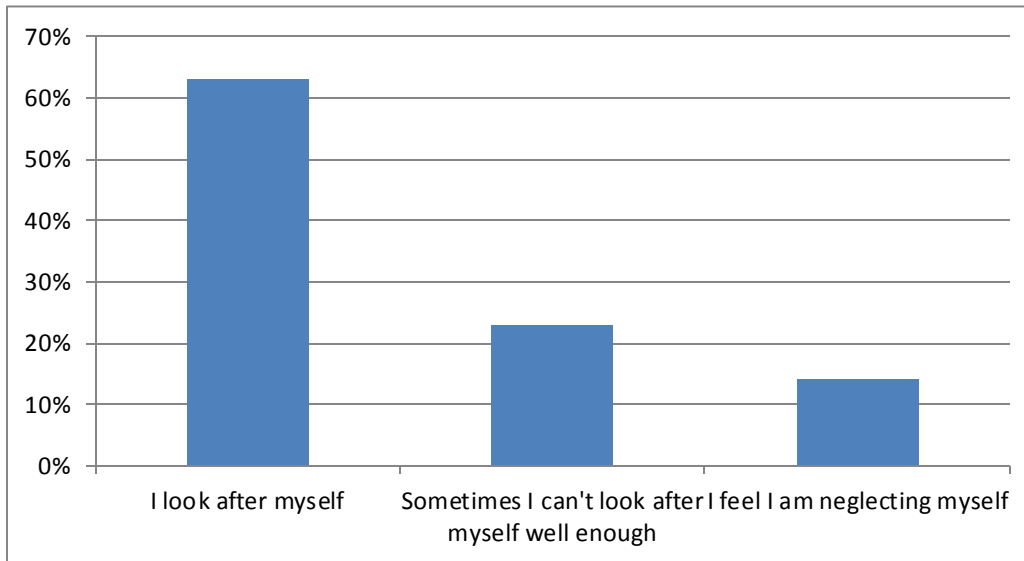
Over half (61%) of the respondents answered 'I do some of the things I value or enjoy with my time but not enough', 23% answered 'I'm able to spend my time as I want, doing things I value or enjoy' and 14% of respondents said that they 'Don't do anything I value or enjoy with my time'.

Q.8 this question asked respondents which statement best describes how much control they have over their daily life.



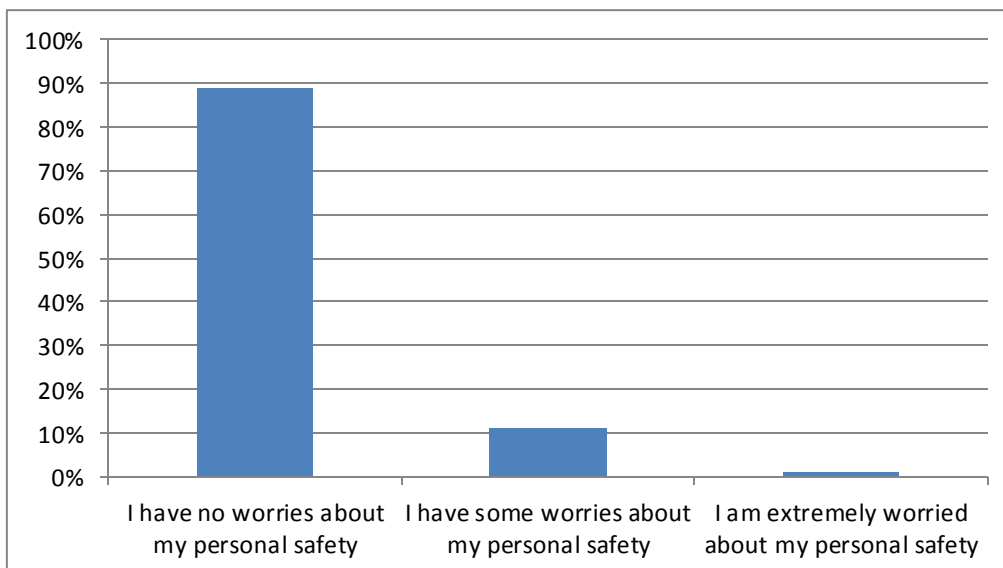
Just over half of respondents (58%) said that they 'have some control over their daily life but not enough'. Nearly a third of respondents (30%) answered 'I have as much control over my daily life as I want'; while 12% of respondents said that they 'have no control over their daily life.'

Q.9 This question asked respondents which statement best describes how much time they have to look after themselves - in terms of getting enough sleep or eating well.



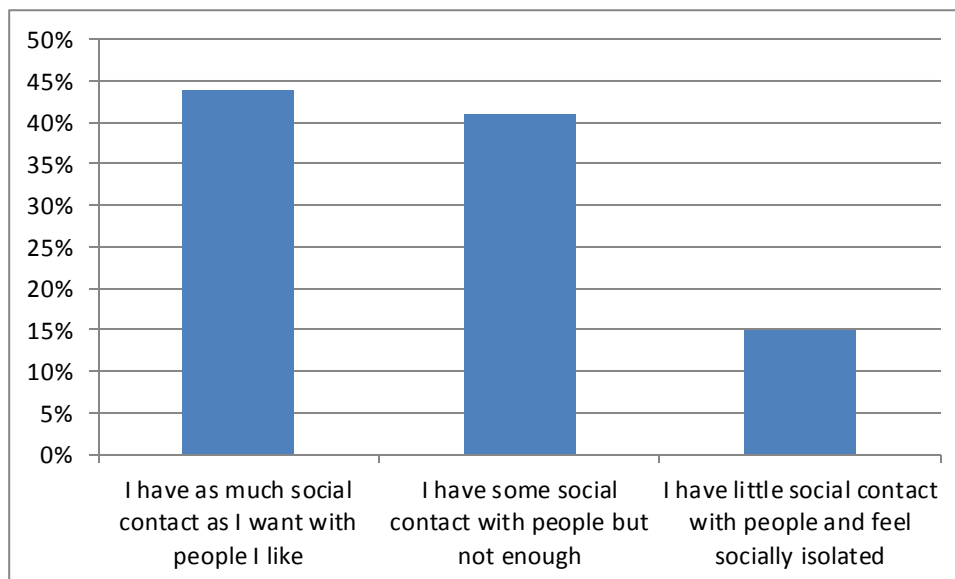
The majority of respondents (63%) answered 'I look after myself', with 23% saying 'sometimes I can't look after myself well enough' and 14% answering that 'I feel I am neglecting myself'.

Q. 10 This question asked respondents which statement best describes their present situation when thinking about personal safety.



The majority of responses (89%) answered 'I have no worries about my personal safety', 11% of respondents answered 'I have some worries about my personal safety and 1% answered 'I am extremely worried about my personal safety.'

Q 11. This question asked respondents to think about how much social contact they've had with people they like and which statement best described their social situation.



44% of people said that they 'have as much social contact as they want with people they like', while 41% said that they 'have some social contact with people but not enough' and 15% answered they have 'little social contact with people and feel socially isolated.'

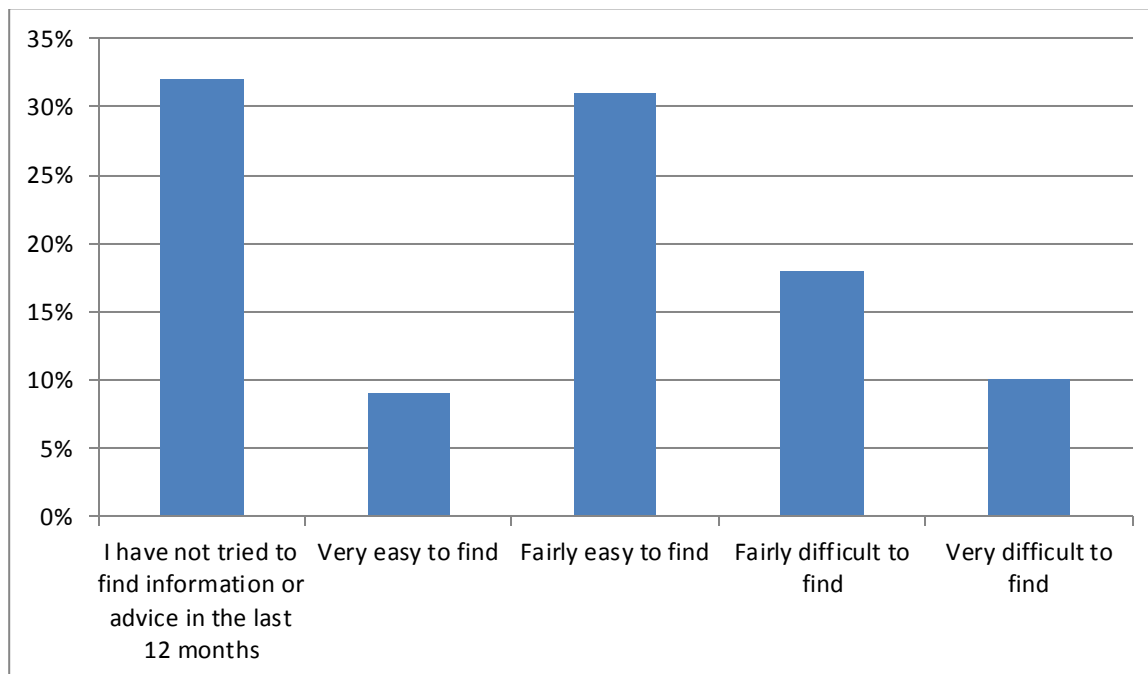
Q.12 This questions asked respondents to think about encouragement and support in their caring role and which statement best described their present situation.



41 % of respondents said that they felt they have 'encouragement and support'; similarly 40% said that they felt like they had 'some encouragement and support', however 20% answered that they felt they have 'no encouragement and support'.

Section 4: Information advice and quality

Q.13 This question asked respondents if in the last 12 months, they have found it easy or difficult to find information and advice about support, services or benefits.



Out of the 500 respondents 32% said that they had not tried to find information or advice in the last 12 months. Over a third of respondents said that they find it fairly easy to find information and advice, with 9% saying that they found it 'very easy'. In comparison 18% of respondents said that they find it 'fairly difficult' and 10% said that they found it 'very difficult' to find information and advice.

If respondents had found it difficult to find information and advice, they were asked why and what can be done to make it easier.

A number of respondents highlighted that they found it difficult to find the right information and advice, with one respondent commenting that *"It is a struggle to find the right help to get the correct care for my daughter."* And another commenting that it is *"hard to know who to speak to as department/roles appear to change."* Another issue of concern related to just not knowing where to find the information, one person commented that they have *"no idea of entitlement"* and another commented that they *"Did not know who to contact with my problem and where to get the information I wanted."* One respondent suggested that it would be useful for social services staff to have knowledge of the area in which they work so that they *"know what help and services exist in the local area"*.

A key issue that was highlighted related to the fact that there is no one-stop place for information. A few people made suggestions that there should be one place that you can go to for all your adult social care needs, one person commented there should be, *"pop up carer's help shops."* And another suggesting *"there should be an advisor who has the experience to point me in the right direction."* Others commented that although they were told where to find information and advice they just simply *"have no time to do this."* And another person commented that *"There is no time*

to spend looking for info either online or by phone, everything is press button – on hold- call back.”

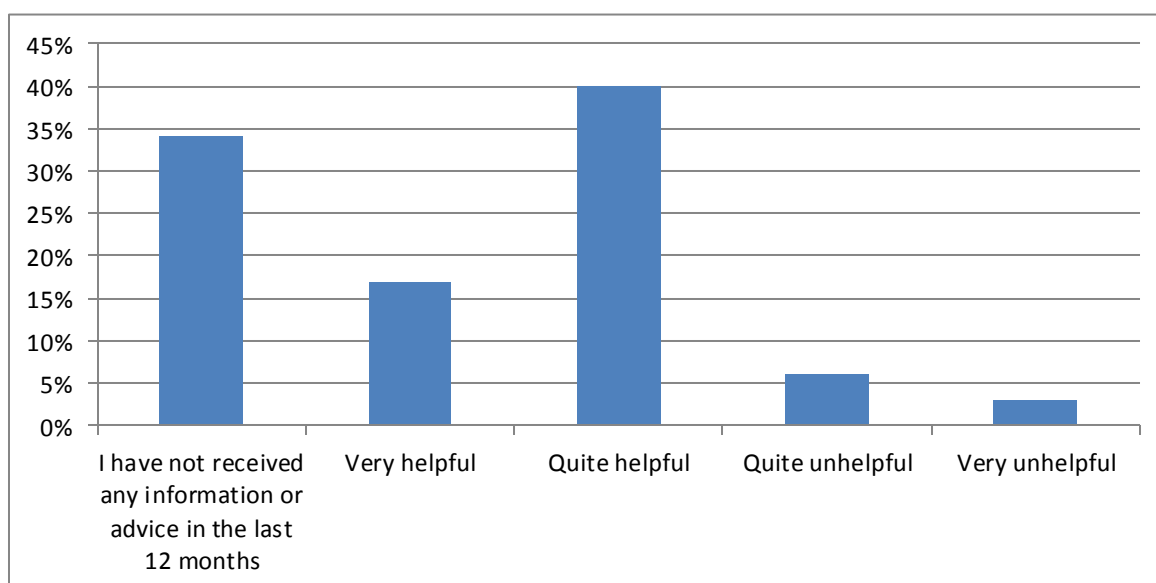
Issues concerning the telephone services seemed to be a common theme with many respondents saying that their phone calls are rarely returned, with one person commenting *“I leave messages and no one rings me back.”* And another respondent said *“High telephone demand = too long waiting to be answered because of queues.”*

A number of respondents have highlighted the issue of being pushed and pulled between different departments, with one person commenting *“I am being pushed between three different services, each then passing me back to the other.”* With another saying that they *“felt like we were passed from one service to another.”*

Listed below are issues people found difficult to find/get information on;

- Not knowing what equipment to buy or request
- Dementia
- Financial aspect on home help/carer from social services
- CAB limited open hours
- Finding alternative activities for cared for person to attend
- Benefits and allowances
- Respite care
- Support and services entitlement
- DLA
- Mental health

Q14. This question asked respondents in the last 12 months how helpful has the information and advice that they have received been



Out of the 495 respondents over a third (34%) said that they had not tried to find information or advice. For those that did, 40% said that they had found it ‘quite helpful’ and 17% said that they had found it ‘very helpful’. In comparison 6% of respondents said that they found it ‘quite unhelpful’ and 3% said that they found it ‘very unhelpful’.

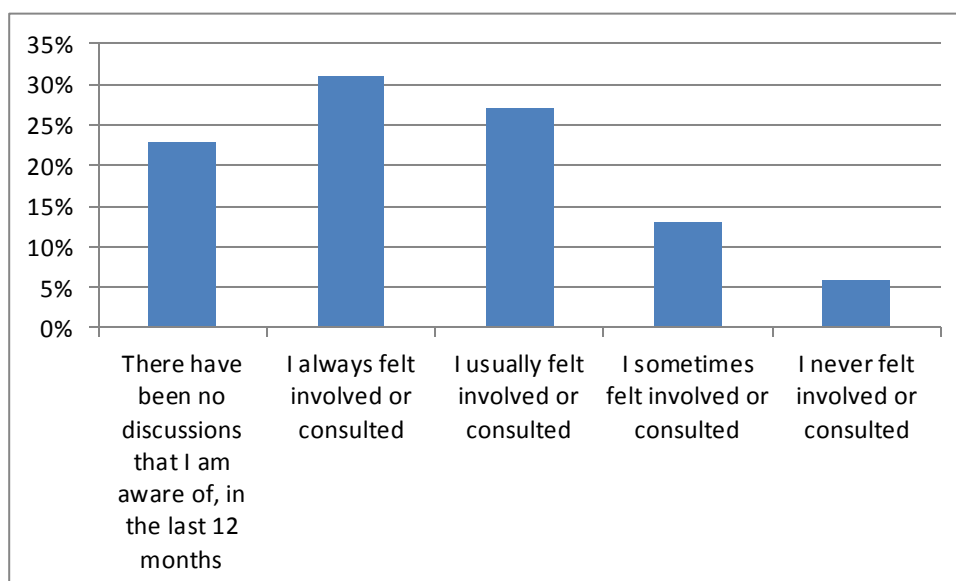
If respondents had found the information and advice that they received unhelpful then they were asked why and what could be done to make it more helpful for them.

One of the key issues highlighted by respondents related to the information and advice provided not being relevant, up to date and useful. One person commented, *"Information about dementia only told me what I already knew"* and that the information from the OT was not relevant or helpful as they had *"not thought about activities or past times for someone with memory loss."* Another commented that the leaflets she receives are out of date and not relevant to her son's condition, saying that they *"imply that either all children had ADHD or Autism, my child has neither,"* and *"are a complete waste of paper, envelope, postage and my time."* Others commented that they do receive good information but the issue is that this information is not passed on to relevant professionals and there is a lack of communication amongst services. One person commented that *"Because agencies do not share information between each other adequately, we say the same thing to each service."* and that no one *"takes responsibility for my questions"*

Another key issue involves the time it takes to receive information, one person commented *"Got advice and information from a voluntary organisation but even then still took a long time to get it."* Comments would also suggest that initially information is provided or first contact made but this is rarely chased or followed up by the professionals, one person commented *"All information that I have received has been by me chasing it."* And another said *"I have had a carer's assessment but have had no feedback."*

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

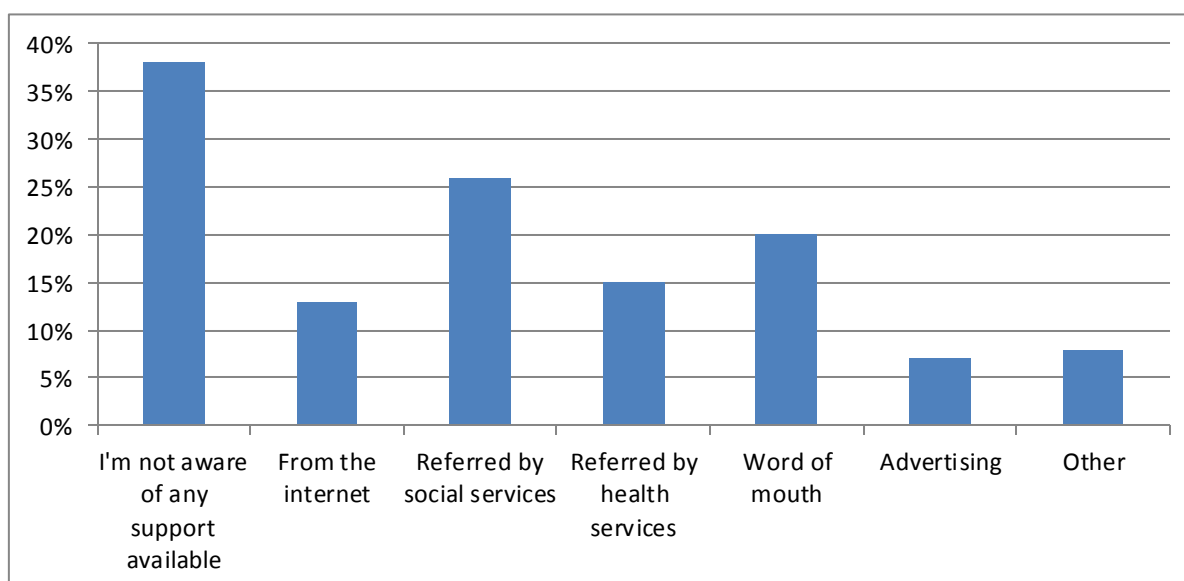
Q15 This question asked respondents in the last 12 months, if they felt that they had been involved or consulted as much as they wanted to be, in the discussions about the support or services provided to the person they care for.



Nearly a third (31%) of respondents said that they ‘always felt involved or consulted’, while just over a quarter (27%) said that they ‘usually felt involved or consulted’. In comparison, 13% of respondents said that they sometimes ‘felt involved or consulted’ and 6% said that they ‘never felt involved or consulted’. Just under a quarter (23%) said that there have been no discussions that I am aware of, in the last 12 months’.

Section 6: Voluntary Organisations

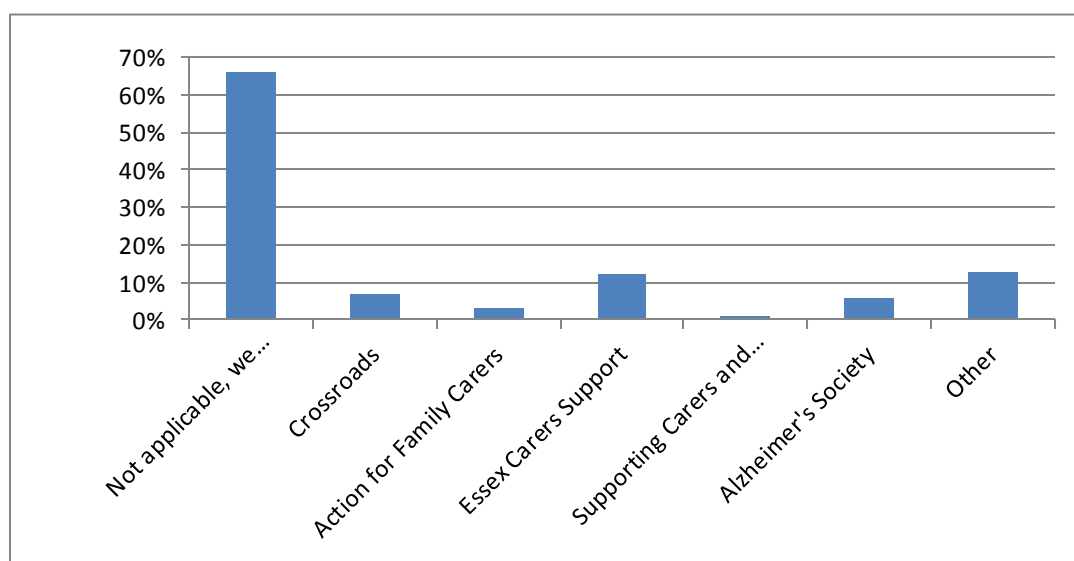
Q16. This question asked respondents how they found out about support available for carers from voluntary organisations in their local area.



Over a third (38%) said that they were ‘not aware of any support available’, just over a quarter of respondents (26%) said that they were referred by social services, 20% by word of mouth, 15% referred by health services, 13% from the internet, 7% through advertising and 8% answered ‘other’. If respondents answered ‘other’ they were asked to specify, a few examples of these included:

- Action for carers, Age UK, Alzheimer’s Society, Armed forces charities Essex Carers, The stroke club, Mencap, Homecare and Farleigh Hospice
- GP, doctor at Hospital
- Library
- MENCAP magazine
- “Leaflets and posters in the GP”
- “Internet from other relative who has computer ”
- “I asked a friend to google info for me”
- “The only person who could help me at any time was the receptionist at my mother’s GP”

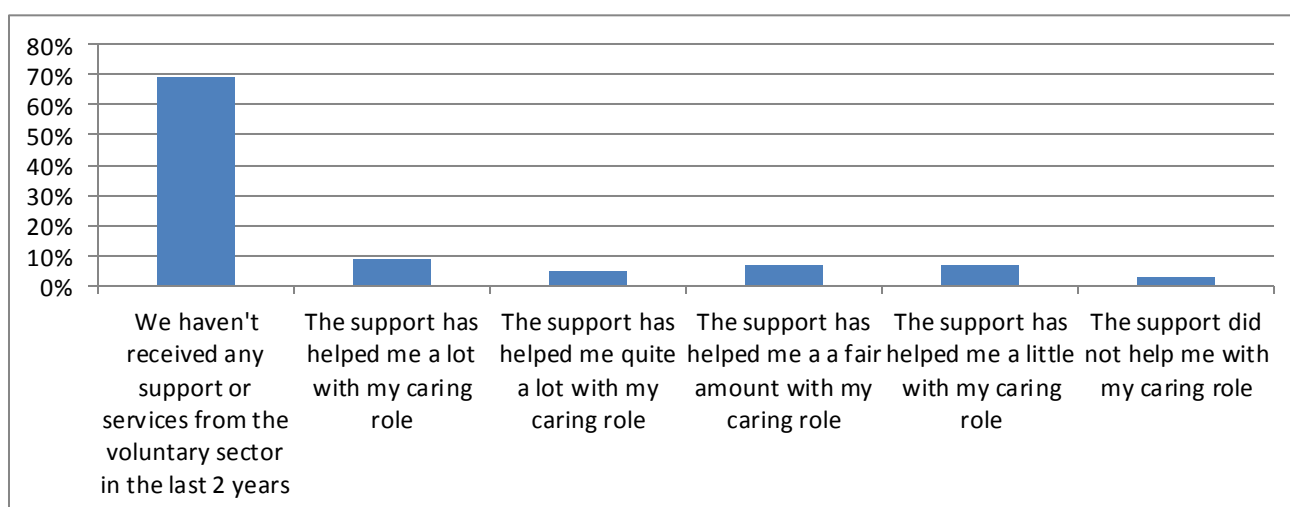
Q17. This question gave respondents a list of voluntary sector organisations and asked which ones they have approached for support in the last 2 years.



The majority of respondents (66%) said that they hadn't approached the voluntary sector for any support. Out of the 502 respondents 12% answered Essex Carers support, 7% Crossroads, 6% Alzheimer's Society, 3% Action for Family Carers, 1% Supporting Carers and Families Together and 13% answered other. If respondents answered other they were asked to specify, a few examples given were:

- Action for carers, Age UK , Care UK, Dementia support service, Downs Syndrome Association, Essex Dementia, Essex Cares, Essex Pass, GP care advisor, Headway, Home Instead, iBasis, London Care, Macmillian Cancer Nurses, MENCAP, Mosaic, MS Society, SNAP, Parkinson's support group, Rethink, RNIB and social services.

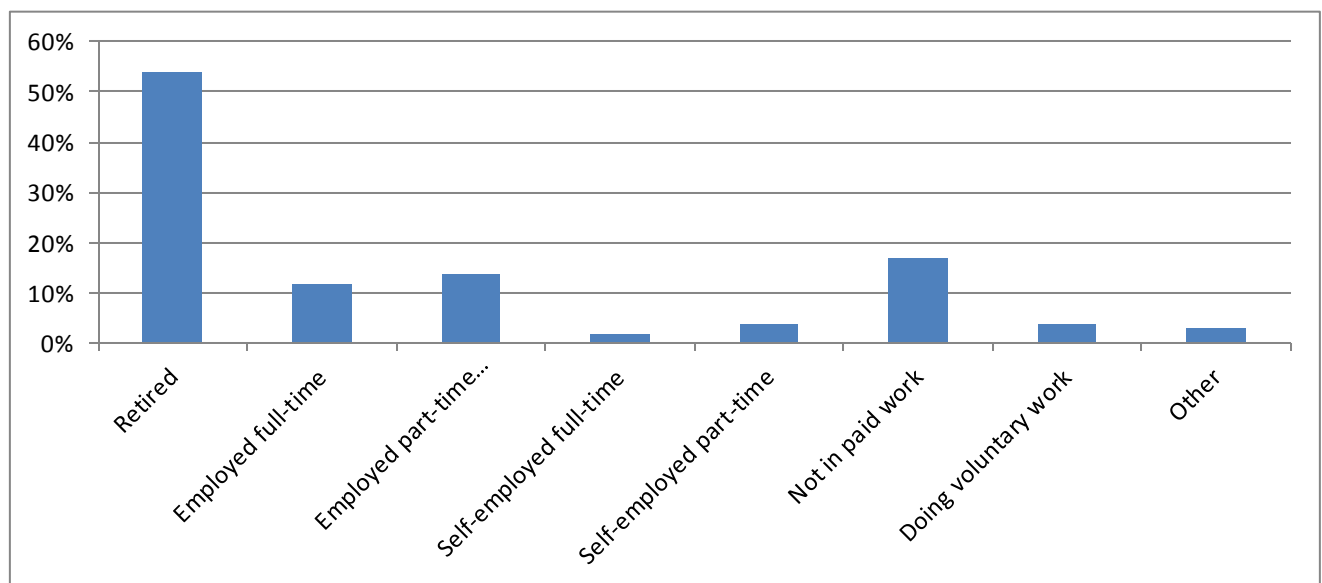
Q18 This question asked respondents if they had approached voluntary sector organisations for support in the last 2 years, did the support help them to carry out your caring role.



Out of the 458 people that answered this question the majority said that they had not received any support or services from the voluntary sector in the last 2 years, 9% of respondents said that the support has helped them 'a lot' and 5% said that the support has helped them 'quite a lot'. 7% of respondents said that the support has helped them a 'fair amount' and similarly for 'helped me a little', while 3% said that the support 'did not help' with their caring role.

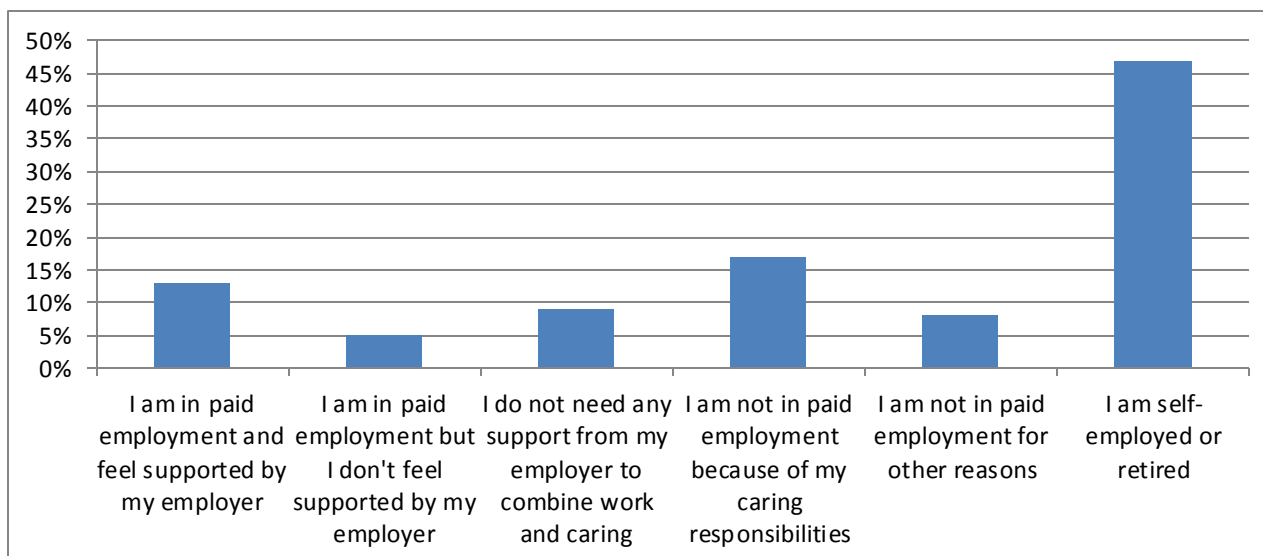
Section 7: About yourself

Q19 In addition to their caring role, respondents were asked which employment status applied to them.



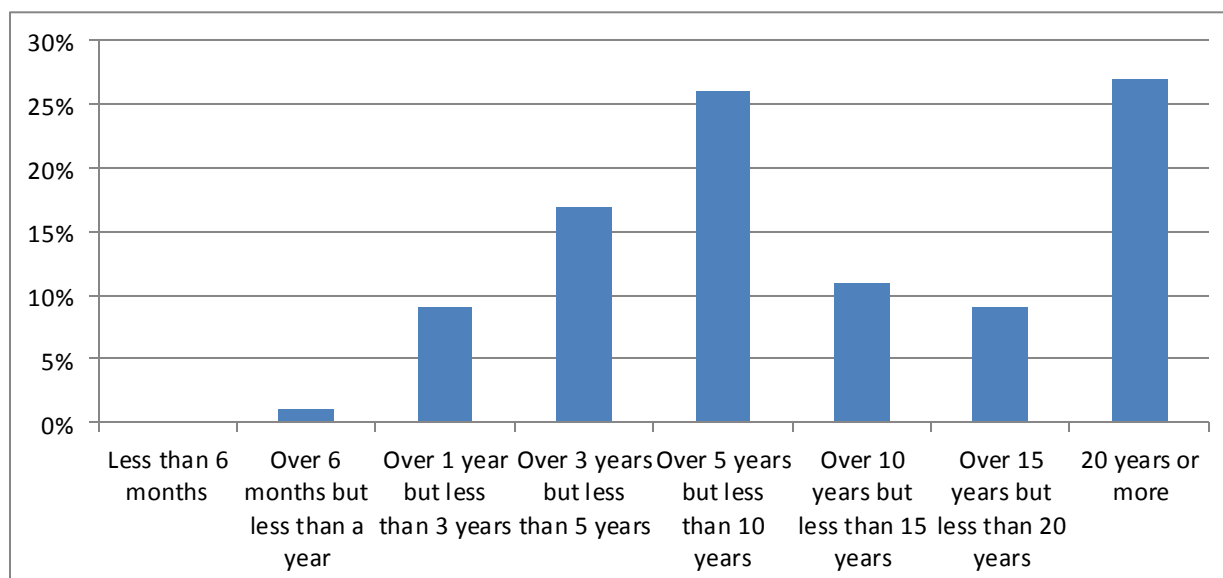
Over half (54%) of respondents said that they were retired, 12% in full-time employment and 14% in part-time employment (working 30 hours or less). 17% of respondents said that they were not in paid work and 4% said that they were in voluntary work, while 2% said that they were self-employed (full-time) and 4% that they were self-employed (part-time). 3% of respondents answered 'other'.

Q20 This question asked them to think about combining paid work and caring and which statement best described their current situation.



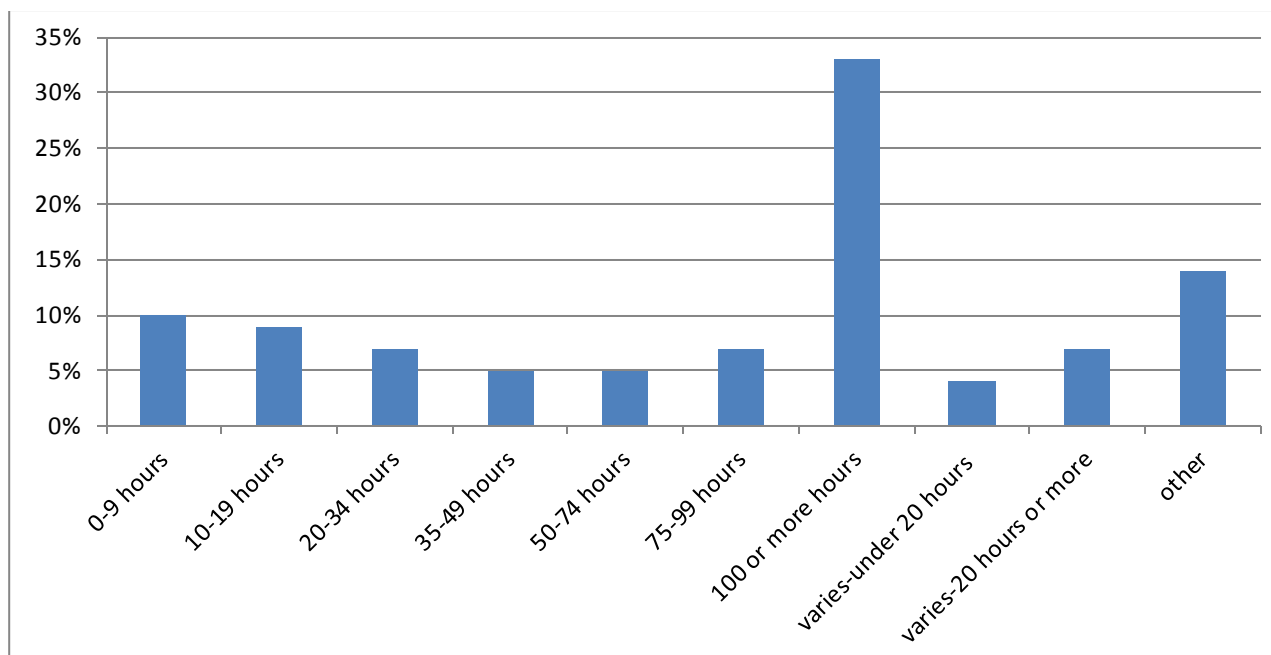
Nearly half of respondents (47%) said that they were self-employed or retired, 13% said that they were in paid employment and felt supported by their employer while 5% said that they were in paid employment but didn't feel supported by their employer. 17% of people said that they are not in paid employment as a result of their caring responsibilities and 8% said that they did not need any support from their employer to combine work and caring.

Q21 This question asked respondents about how long they have been looking after or helping the person that they care for.



The two highest responses were for over 5 years but less than 10 years (26%) and 20 years or more (27%). 17% of respondents said over three years but less than five, 11% said over 10 years but less than 15, 9% over 15 years but less than 20 years. 9% said over one year but less than three years, and 1% for over six months but less than a year.

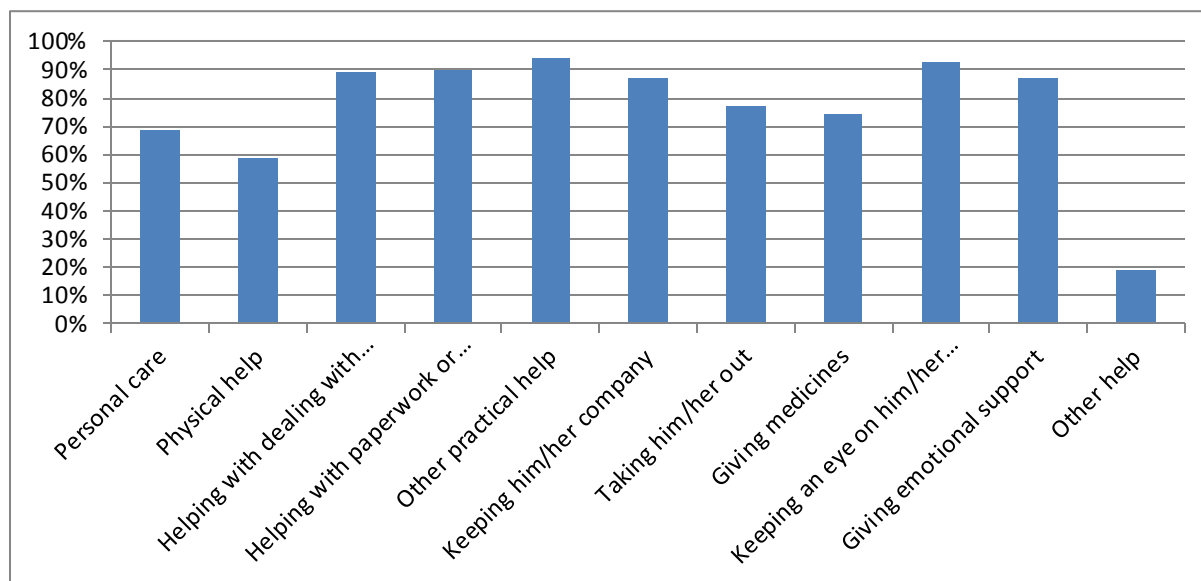
Q22. This question asked respondents about how long they spend each week looking after or helping the person that they care for.



A third of respondents said that they looked after the person that they care for more than 100 hours a week, 14% of respondents answered other and were asked to specify.

Some respondents commented that the time they spent caring was dependent on the health or mental state of the person that they care for, one person said *“it depends on my daughter’s mental state.”* Another commented that the time they spent caring varied as the person they cared for was a diabetic. Other people commented that the person they care for is still in full-time education and therefore the time that they spent caring varied during term time, school holidays and weekends, one person commented *“depends, 50-74 hours in term time and 75-99 hours in school holidays.”* Another said that they only see their son *“every fortnight”* but care for them *“24/7 during school holidays.”* A large number of respondents commented that they spend 24 hours a day seven days a week looking after the person that they care for, one person said *“full time”* while a few respondents said *“all week”*.

Q.23 This question gave a list and asked what kind of things they did for the person they care for over the last 12 months.



Nearly all answers given had high response rates, the highest rated answers being 'other practical help' (94%), 'keeping an eye on him/her' (93%), 'helping with paperwork or financial matters' (90%), 'helping with dealing with care services and benefits' (89%) and 'giving emotional support' (87%). The lowest rated answers were 'physical help' (59%) and 'personal care' (69%), while 19% said that they gave 'other help' that wasn't listed.

Section 8: Comments and feedback

The last section of the survey asked respondents to describe any experiences that they would like to talk about, or to provide any other feedback. Overall 233 comments were made, both positive and negative, with some key themes and issues arising, including: Not getting enough help or support 34 comments (15%), time and efficiency of services and support 30 comments (13%), quality of the services provided (staff) 26 comments (11%) and lack of information and advice 20 comments (9%).

Out of the 233 comments, 16 respondents made positive comments about social services and agency personnel, one person saying that he found all staff at worst, "polite and civil and usually helpful, cheerful and charming". While another said that they have always found social services personnel "very helpful and good listeners." One person said:

"I think the care my mother receives is fantastic. She is a very difficult person, probably because of her mental illness and I think the carers who attend her should be given a medal."

For some respondents the care packages and support services that they have in place allows them to have a break from caring and continue with their normal routines. One person said that they “appreciate the visits I get from Essex Carers, social services and others, they do a good worthwhile job, it’s hard work caring for my husband, but up to now I manage ok.” While another commented, “My mother attends a day centre twice weekly leaving my father and I free for six hours to catch up with shopping, chores etc.” One respondent said:

“Social services provided a budget for respite which was a true help for me. They also provided a sitting service from crossroads. The lady was fantastic with my wife; it helped her so much and has benefited me greatly.”

Out of the 233 comments, 12 people described how family support plays a huge part in their caring roles. One respondent said “My brother supports me in the care and this allows me to have a social life as well as providing care as stated.” And another said “Both my sister and I looked out for and care for our mother, for some time she was cared for by ourselves and care agencies.”

A number of respondents made positive comments about personal budgets, one person saying that “we are very grateful for the personal budget, which we feel helps my son lead a more full life.” While another commented that:

“My son has a personal assistant supported by a personal budget; this has been invaluable and not only supports me and my husband but really enhances my son’s social life as well.”

There were quite a few positive comments made about the speed and efficiency of setting up services, one respondent commented, “I got in touch with a social worker, just before Christmas 2012 and she put a care package together within days.” Another said that once her husband had been discharged from hospital after stroke rehab “I just didn’t know how to deal with the situation and I made a call and was helped with, speed, efficiency and compassion.”

However just over a third (34%) of all comments made criticized the quality of social care services, with 30 people criticizing the length of time that it took to put services in place or find out information. One respondent said that although once social services were involved “the equipment provided was excellent and good quality,” that it took “a long time for social services to start the process.” Another respondent commented that “Cogs turn very slowly in terms of setting up a support structure for the person cared for.” And another said. “It has taken three years to get my mother to the level of support and activity that she now enjoys.” One person praised the support that her Mum now receives but criticised the length of time it took, “It took 6 months to get up and running.”

A fairly common criticism from respondents (26 comments in total) related to the quality and efficiency of the care that was given. There were several comments made about carers not arriving on time or not turning up at all:

"The care agents were an absolute waste of time... they were always late, couldn't do what was needed and caused more worry and stress."

"Have carers come in but don't come on time."

"Carers vary the times that they come and often ignore instructions."

"When a carer is delayed by a previous emergency they should phone to let the next person on the list know that they will be late, often late at night my mother thinks they have forgotten her, this has also happened when she has been left off rotas."

"The care company is not terribly reliable and mum gets upset that the carers are constantly changed and arrive at all different times, there is nothing regular and static and with an elderly person you need to have things constant and regular."

There were also several negative comments made about the quality of the care provided by the carers both in their own homes and in care homes (permanent and respite):

"My time is spent clearing up the mess left by the carers eg. Coffee granules spilt on the side and floor, coffee (liquid) spilt, crumbs and jam dropped on the work surfaces."

"Our main issue is finding a care home where Albert's fluid intake is carefully monitored. When he goes in for respite he generally comes out dehydrated and ends up in hospital."

"The carers are mostly very good, although sometimes they seem a bit slapdash – eg. Poor quality washing up."

"My mother has carers morning and evening but some are not good, it's the little things really, not cleaning up properly... making my mum's breakfast with the gloves on that they used to wash her with... not making the bed properly... mum's nails are always dirty so they are not helping her to clean them- I have to do it etc."

"Care firms are useless. The employ people who do not care about patients; they are only interested in MONEY."

There were 34 comments in total made about receiving little or no help for the person that they care for:

"I am so angry about the treatment, or lack of it, I have received since 2011."

"Following a stroke in 2003 my wife was discharged from hospital with severe memory loss and was confirmed later with vascular dementia, during the 10 yrs. of her illness we received little or no help from the NHS or social services."

"I became my husband's carer and took a career break from work. I've tried to contact the Essex Young carers for help and support with my 11 year old daughter who helps me a lot but they never contact me or offer any help."

"I consider my wife is not getting enough mental health support."

"I fear there is not enough support available for my father as he falls in a bracket that he has some savings but is required to spend all of this on his care, whilst others who have made no provision for the future have a wide range of help and facilities available to them for no cost."

"I have found that as my mother was paying privately for her care I had no support from social services except for OT."

Other respondents (20 comments in total) criticised the lack of information and advice, with one person commenting that the *"Information is out of date."* And another commenting that, *"I am saddened that at the age of 30 with disability from birth that there has not been sufficient information or help to enable my daughter to live truly independently."* One respondent commented that is difficult to find correct and up to date information saying *"I have no idea what sort of help I can get and I don't know where to look or who to contact."* Another said *"I would like to know what support services are available for myself and my mother but have no idea where to start."*

There were 12 negative comments made regarding social services assessment processes, with people saying that they found that assessment processes *"takes a very long time"* and are very difficult to complete. One respondent commented that the assessment process for the carer's package and carer's support *"requires simplification... and Carer's plan should be completed and monitored by the same social worker, giving one point of contact."* This issue of consistency was common, with five people commenting that there often too many different carers and social workers and that this made it difficult to build up trust and for the carer to understand their needs without having to keep explaining, *"You would always get different people who would not understand his needs."* One respondent commented that *"Social workers come and go"* and that *"Social workers do not inform when cases are being transferred/banked/relocated/reallocated."* Another commented that the main issue re social services is the *"constant changing of staff so no consistency."*

There were also comments regarding social services being *"too fragmented"* and poor coordination and communication between different services, one person said that they had a *"terrible job"* of getting their father released from hospital following a fall mainly because *"The hospital OTs and social workers don't talk to each other."*

There were also issues raised around understanding the carer's needs, one person commented that, *"Being a male and a carer is not always recognised and referred to and some services, not all, can override your decision making."* Another respondent said that *"people do not understand the problems of the deaf,"* and agencies have not understood that the person she cares for cannot speak down the phone. There have also been issues with letters and forms that have been sent out from agencies written with *"language well above her understanding despite knowing who they are writing to."*

There were nine negative comments made relating to respite care, some around the quality of care when receiving respite services, one person explained that her husband had gone into respite while she was away on holiday but when he returned home he had two grade two pressure sores and also a cough which turned into pneumonia, after this she feels that she *"cannot go on holiday with no worries."* There were several comments made about reductions in respite care, one respondent said that respite for her son had been *"cut down from 36 days to 28 days"* and that this was *"not a lot"*, commenting that carers *"need to have respite so we can recharge our batteries so as to give the support we need"*. Others have found difficulties in requesting respite, one person commented that *"requests for respite have not been possible"* and another that *"the care service we use fails to understand my own limitations,"* and that he does *"not get any break from caring"*.

One respondent said *"without my respite and my daughters day services I wouldn't be able to maintain my job as a full time carer."* But with *"budget cuts to services"* and many agencies closing due to *"lack of funding"* this is leading to even more *"stress and anxiety"*.

One person commented that *"when we lived in London our daughter could have respite, so we had a break."* However since moving to Brentwood they have had only *"2 respites in the last 6 years."*

There were also several comments that would suggest a level of anxiety and worry regarding leaving the person cared for in respite, one person commented that *"Social services have suggested respite but I am worried about leaving my husband."* Another speaking about their daughter said that it would of *"no use us having respite as she wouldn't settle away from us and be very distressed."*

Six respondents highlighted issues around their carer's allowance and in most cases saying that this was inadequate and had a huge impact on their own personal well-being and quality of life; one respondent commented that *"my carer's allowance is £30 per week; I suffer from depression and arthritis. I feel tired and worn out most of the time and obviously my benefits do not stretch to doing anything for myself."* Another person said that their carers allowance of *"£60 a week is so inadequate, it does not even begin to cover the bills,"* and highlighted that *"working elsewhere to earn extra money is impossible as there are not enough hours in the day."* This was a common criticism with many people explaining that they felt they could not work extra or get part-time jobs as they were too busy caring. Many respondents commented that *"carers should be given more support"* as they *"are saving the government so much money."* One person explained that they

made a 60 mile round trip to care for their father and this *"takes all of my carer's allowance."* And *"there should be help with carer's travel expenses."* There were also several comments made around carer's allowance in regards to limits on what the carer can earn, with one person commenting that the government should *"let them earn a decent wage while claiming carer's allowance."* Another commented, *"we should have a proper wage."*

A large number of respondents (29 comments in total) spoke about the effects of caring for someone else and the support that they receive as a carer. Many respondents highlighted that they felt isolated, stressed or depressed. Some comments described the impact that it had on their own families and lives, with some carers feeling that support services are only interested in the person being cared for and not the carers themselves:

"I would like to get out of the house and meet other people; I feel very isolated and feel like I don't have a life of my own."

"Being a carer is a full time and lonely life; you sometimes lose sight of yourself and become totally overpowered by your caring role. You have little or no social life"

"Caring for someone is very demanding."

"I am finding it increasing difficult and feel very isolated."

"I am so stressed I cannot even go into it at this moment."

"My life is very mundane, I do the same thing every day and "I do not receive any advice"

"Most of the time I feel totally stressed out."

Having a disabled child one respondent explained, was now the "whole focus of her life" and has had a "profound effect on family", explaining they feel like they are living on a "Knives edge" fearful that the care package that allows for them to work will change and they are uncertain about what the future could hold.

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