

AMESBURY BRADFORD ON AVON CALNE CHIPPENHAM CORSHAM DEVIZES DOWNTON MALMESBURY
MARLBOROUGH MELKSHAM MERE PEWSEY SALISBURY TIDWORTH TISBURY TROWBRIDGE WARMINSTER
WESTBURY WILTON WOOTTON BASSETT & CRICKLADE WILTSHIRE'S COMMUNITY AREAS

WILTSHIRE CARERS' VOICE

September 2007 Survey Results

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CONTENTS

1. INTRODUCTION	5
1.1 Background.....	5
1.2 Panel Makeup.....	5
1.3 Returns Profile	6
1.4 Questionnaire Topics	7
2. WHAT DO YOU DO IN AN EMERGENCY SITUATION?	9
2.1 Recent Emergency Situations	9
2.2 Future Questions	15
3. MENTAL HEALTH	16
3.1 Carers of someone with mental health problems.....	16
3.2 Future Questions	21
4. CARERS' BREAK SERVICE.....	22
4.1 Opportunities to take a Carers' Break	22
5. CURRENT ISSUES.....	27
5.1 Current issues affecting Carers	27
6. CONCLUDING COMMENTS.....	28

Please Note

This report is a representation of the views and perceptions of members of the Carers' Voice panel and is not the representative opinions of all Carers in Wiltshire even though similarities may be present. In order for the results of future questionnaires to be better representative, recruitment of Carers to the Carers' Voice panel is ongoing.

1. INTRODUCTION

1.1 Background

- 1.1.1 Carers can be defined as people looking after or giving help or support to family members, friends, neighbours or others, because of long term physical or mental ill-health or disability, or because of problems associated with old age.
- 1.1.2 The 2001 Census revealed that in England and Wales, there are an estimated 5.2 million people providing **unpaid** care. This equates to 10% of the population. In Wiltshire, the 2001 Census indicated that there are 39,886 Carers, which accounts for 9% of Wiltshire's population.
- 1.1.3 Because voluntary or unpaid Carers provide services that in many cases would need to be provided by other agencies, it is essential to understand more about the needs of Carers and those they care for so that services and support mechanisms are available when needed.
- 1.1.4 In 2002, in recognition of the range of pressures that Carers can face, a new countywide initiative called Carers' Voice was launched. The aim of Carers' Voice is to enable a representative group of Carers to share their views, experiences and perceptions on the services and issues which affect them, in order for agencies to improve their services for the benefit of all Carers.
- 1.1.5 There is a steering group of the Carers' Voice project, which is made up of representatives from Wiltshire County Council, Carers' Support Agencies, and Carers themselves. The steering group meet to discuss issues relating to the running of the project, including the questions that will be asked in the surveys to the wider Carers' Voice Panel.
- 1.1.6 Carers' Voice is only possible because of the time voluntarily given to the project by Carers, both in terms of the Carers who sit on the steering group, and also the respondents to the surveys themselves.
- 1.1.7 This report analyses the results of the eighth Carers' Voice questionnaire, which was sent out to panellists in September 2007.

1.2 Panel Makeup

- 1.2.1 The Carers' Voice panel has been established to try and reflect the caring community across Wiltshire and consists of men and women from the age of 18 upwards. It includes Carers of adults and children and of people with a range of caring needs from physical and learning disabilities to mental health needs. Carers' Voice panellists include people who combine caring with paid employment, people who care for a few hours a week and those who care for someone all day and every day (the majority on the panel spend over 40 hours per week on caring tasks). The panel does not however include people who are employed to undertake caring tasks.
- 1.2.2 Currently over 70% of Carers' Voice panellists are female.

1.2.3 Around 70% of Carers' Voice panellists are aged between 45 and 74.

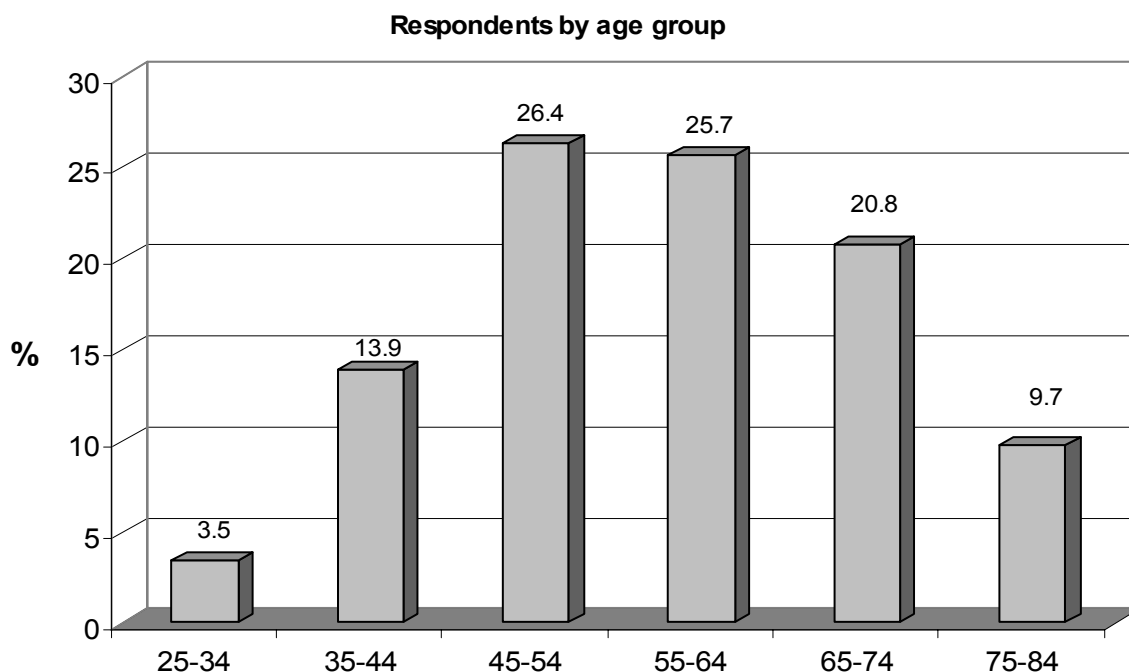
1.2.4 At the time of mailing this survey, the total number of Carers on the panel stood at 340.

1.3 Returns Profile

1.3.1 In early September 2007, panellists were sent the eighth Carers' Voice questionnaire. Due to the need for a swift response to Section 1: Emergency Planning, no reminders were sent and a relatively short window for returning the forms was given. By the end of September, this questionnaire had achieved a response rate of 44%, with 149 questionnaires received. Given the short window of opportunity and Carers' busy schedules, this is a good response rate.

1.3.2 In terms of gender, a higher proportion of Carers' Voice panellists are females, which was reflected in the gender split of all responses to the questionnaire; 24% of respondents to this survey were male, 76% were female.

1.3.3 The chart below shows the age distribution of respondents. The majority of respondents (56%) are aged 55 and over, which reflects the age structure of the panel.



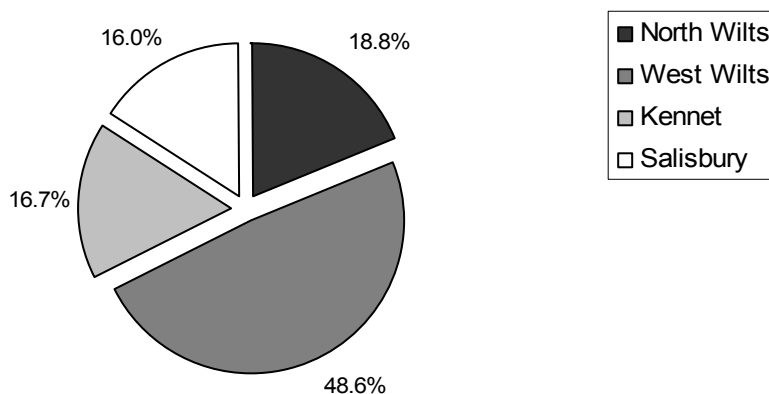
Base: 149

1.3.4 It should be noted that the age recorded for panellists is that recorded at the time of signing up to Carers' Voice, and therefore some respondents may, in reality, have moved across age brackets in the intervening time.

1.3.5 Responses were received from Carers' Voice members across the County. However the greatest proportion of responses was received from panellists living in the district of West Wiltshire; this reflects the make-up of the panel. The proportion of panellists from each of the four districts is not in line with overall

populations. Steps are being undertaken to reduce the disparity in the panel between West Wiltshire and the other districts.

Proportion of respondents by District



Base: 149

- 1.3.6 It should be noted that the base size to the questionnaire is a relatively small one, and some questions in this report are only answered by a fairly small proportion of respondents. Therefore results should be treated with caution, especially those where only a minority of respondents have given an answer, or where the response is split up rather than presented in total.

1.4 Questionnaire Topics

- 1.4.1 The members of the Carers' Voice Steering Group jointly decided upon the questions which appeared in the questionnaire. The questions in the eighth questionnaire covered the following topics, which were thought timely by members:

- What do you do in an Emergency situation
- Mental Health
- Carers' Break Service

1.5 Reporting the Results

- 1.5.1 In writing this report, the knowledge and experience of the Carers' Voice Steering group has been used to add insight to many of the findings. Their experience has been able to add explanation and background to the results and add to the understanding of what these figures say.

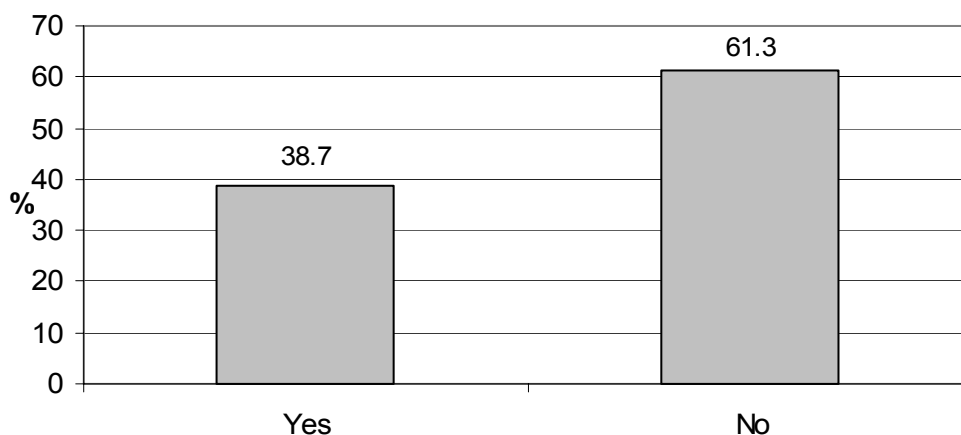
2. WHAT DO YOU DO IN AN EMERGENCY SITUATION?

2.1 Recent Emergency Situations

2.1.1 As the result of a personal situation affecting one of the steering group members, a series of questions was asked looking at whether panellists have ever been unable to carry out their caring role because of an emergency situation and how they have overcome this situation.

2.1.2 When asked whether there had ever been an unplanned or emergency situation where they had been unable to carry out their role as a Carer, the majority, 61%, said that they had not been in this position. That still meant that over one third of Carers had been left unable to continue caring:

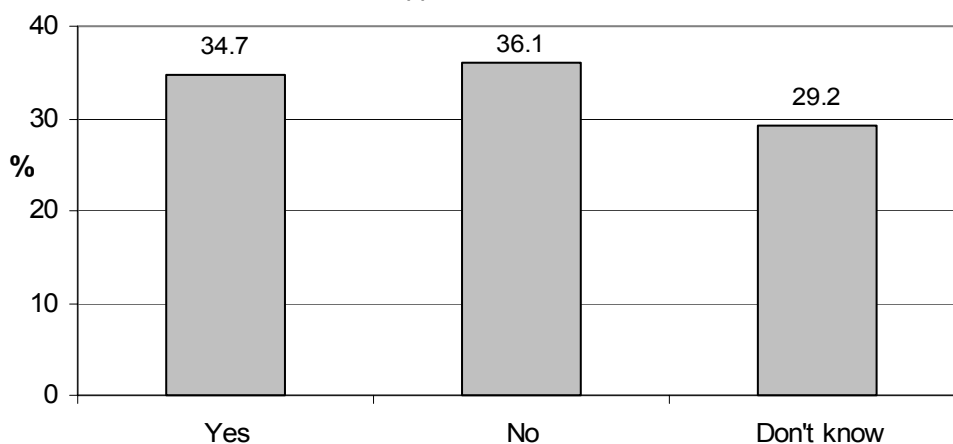
Q1 Has there ever been an emergency situation where you have not been able to carry on in your role of carer?



Base: 142

2.1.3 In order to judge the response of Wiltshire County Council's Department of Community Services (DCS) to these situations, panellists were asked whether they felt the support they received from DCS throughout their crises was adequate. Although the base size is a bit too small to be clear, the proportions saying yes and no were very similar:

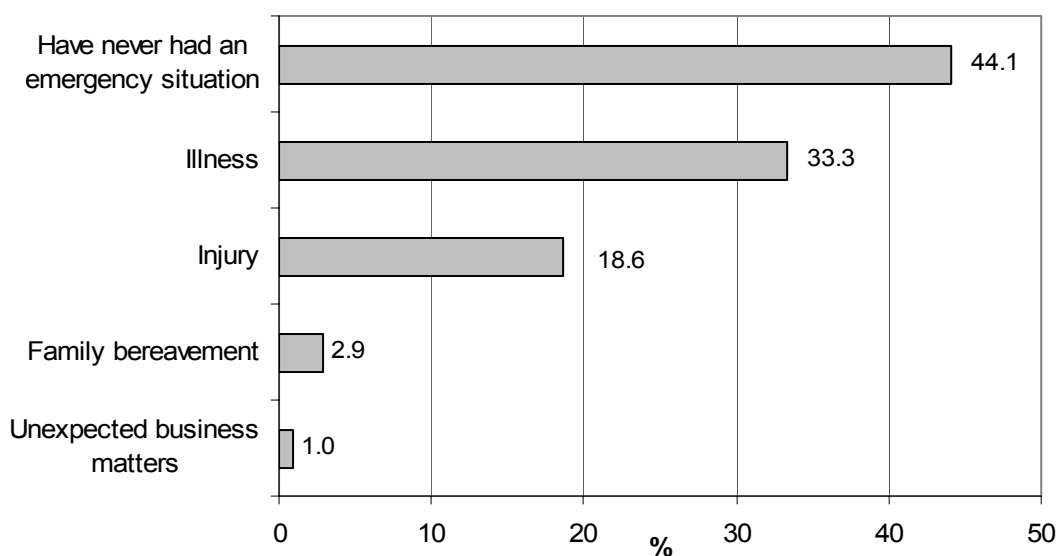
Q2 During this situation, did you feel you were given adequate support from DCS?



Base: 72

- 2.1.4 In discussion with the Steering Group, there were comments as to how many respondents to this question are actually in contact with DCS. The Carers Support Agencies are aware of many Carers who do not receive services from DCS. The Social Care Helpdesk was also mentioned as a possible cause for feelings of not having received adequate support. The fact that it is an automated service and issues of not knowing when a worker will call you back seemed to be problems. The change to no longer having a care manager has led to feelings of being lonely and isolated.
- 2.1.5 The reasons why Carers could not carry out their caring role were looked at in more detail. Panellists were asked what the cause of their emergency situation was:

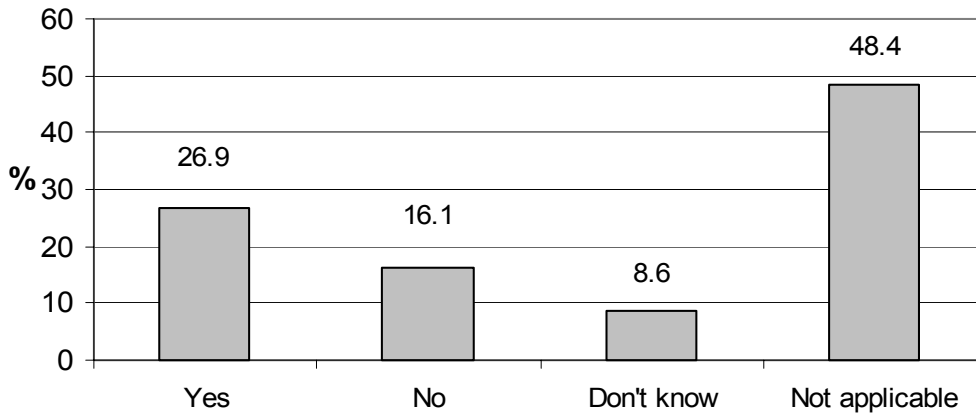
Q3. If there has been an emergency, what was the reason for this situation?



Base: 102

- 2.1.6 Of those respondents who said there had been an emergency situation, the most common reason was through illness, with over half of those who said there had been an emergency situation giving this as the reason. Injury was the second most common reason for not being able to care. With only 1% of panellists saying so, business matters was a very uncommon reason why a Carer could not carry out this role.
- 2.1.7 With illness and injury being the most common reasons for not being able to carry on caring, it would seem that support to get Carers healthy again following this crisis is an important factor. One suggested source of this support might be the care manager.
- 2.1.8 Panellists were asked whether, if the situation had been caused by personal illness or injury, they had been given enough support to get better speedily and so resume their caring role. Whilst not applicable to the greatest proportion of panellists, over a quarter, 27%, said they had been given enough support, compared to 16% who felt they had not.

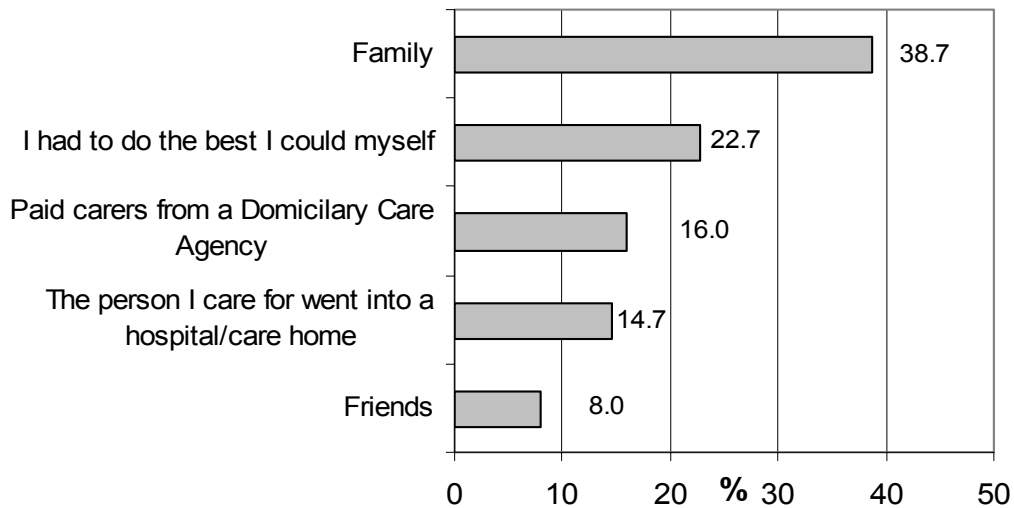
Q4 If this situation was due to personal illness or injury, did you feel you personally were given enough support to get better speedily?



Base: 93

2.1.9 When asked who took over the role of Carer whilst the panellist was unable to, the most common response was a different family member. Next most frequently chosen was that the Carer had to do the best they could on their own. This is significant given that nearly a quarter of respondents said this, implying they received no additional help throughout a crisis situation. 16% of panellists found themselves in the situation where they had to pay domiciliary care agencies to help them:

Q5 During the most recent emergency situation, who provided the main care to the person you care for?



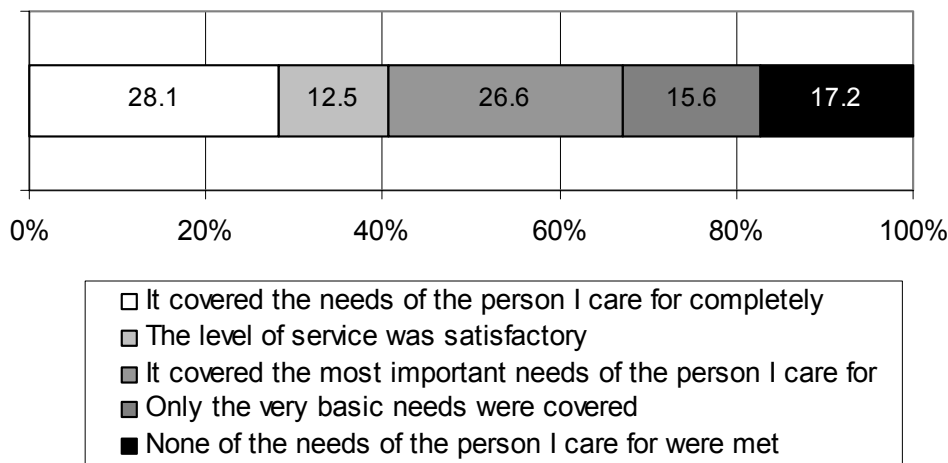
Base: 75

2.1.10 It was suggested that one possible reason for so many Carers having to continue by themselves or pay for additional help is that they are not in contact with DCS and so do not have care packages in place in order to support them. In this situation, there is not the statutory support to fall back on and Carers have to provide for themselves.

2.1.11 The next question asked about the level of any additional care that was given during this emergency and how it related to the needs of the person the panellist

cares for. It is encouraging to see that over one quarter of respondents stated that the needs of the person they care for were covered completely. However, just over one quarter also felt that only the most important needs of the cared for person were met by this additional help, implying it was only just good enough. Worryingly, 17% of panellists stated that the additional care that was given met none of the needs of the cared for person.

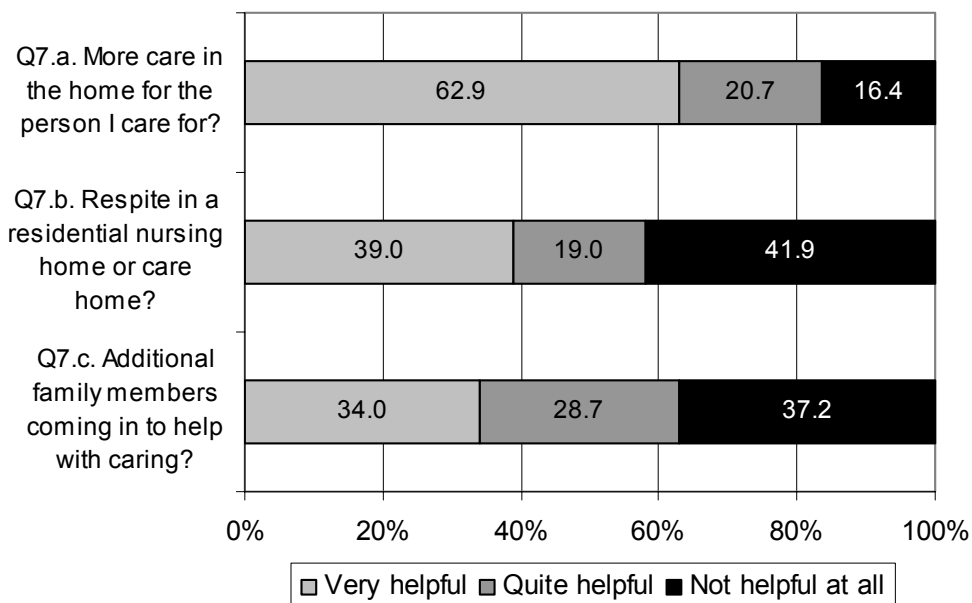
Q6 Please indicate how satisfactory any additional care was to the needs of the person you care for



Base: 64

2.1.12 In order to find out what sort of services Carers would find most useful in emergency situations, the next question asked panellists to rate the helpfulness of a short list of services:

Q7 Could you tell us how helpful you would find each of the following arrangements for short term back-up if you were unable to carry out your caring role

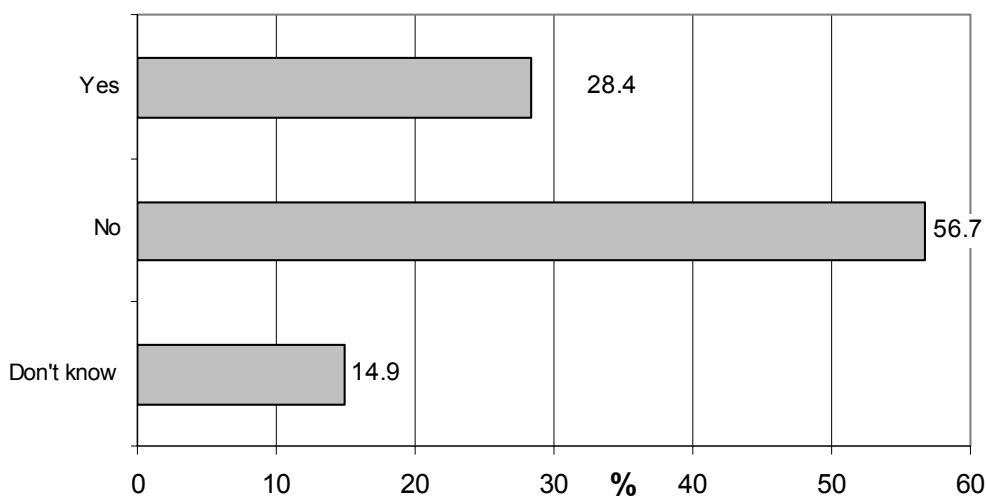


Base: 116

2.1.13 We can see that panellists find “more care in the home” by far the most helpful of these three services. More people thought this service would be Very helpful than those thinking either of the other two would be Very helpful and Helpful combined. In discussion with the Carers’ Voice Steering Group, there appears to be a number of reasons for these choices: linking the preference for more care in the home and Carers’ dislike of respite in a nursing home is the fact that if they exist at all, care homes are often found far away from where people live so there is a sense that the cared for person is being “packed off”. There is also the feeling that once the cared for person, particularly older people, is sent to a care home, they will not return to the family home. This question also links to question 5 where family members form the most frequent form of additional help. It was also pointed out that feelings and the results given might be different for the Carers of children.

2.1.14 The next series of questions concentrated on the Social Care Helpdesk provided by DCS and what panellists thought of the service they received from it. When asked whether they had ever been told the number for the Social Care Helpdesk, just one quarter of respondents, 28%, said that they had whilst over half, 57%, said that had never been told this number. This result might also link into the comment that there might be a significant number of Carers on the panel that do not have care packages or be in contact with DCS and so have not been told about the Helpdesk.

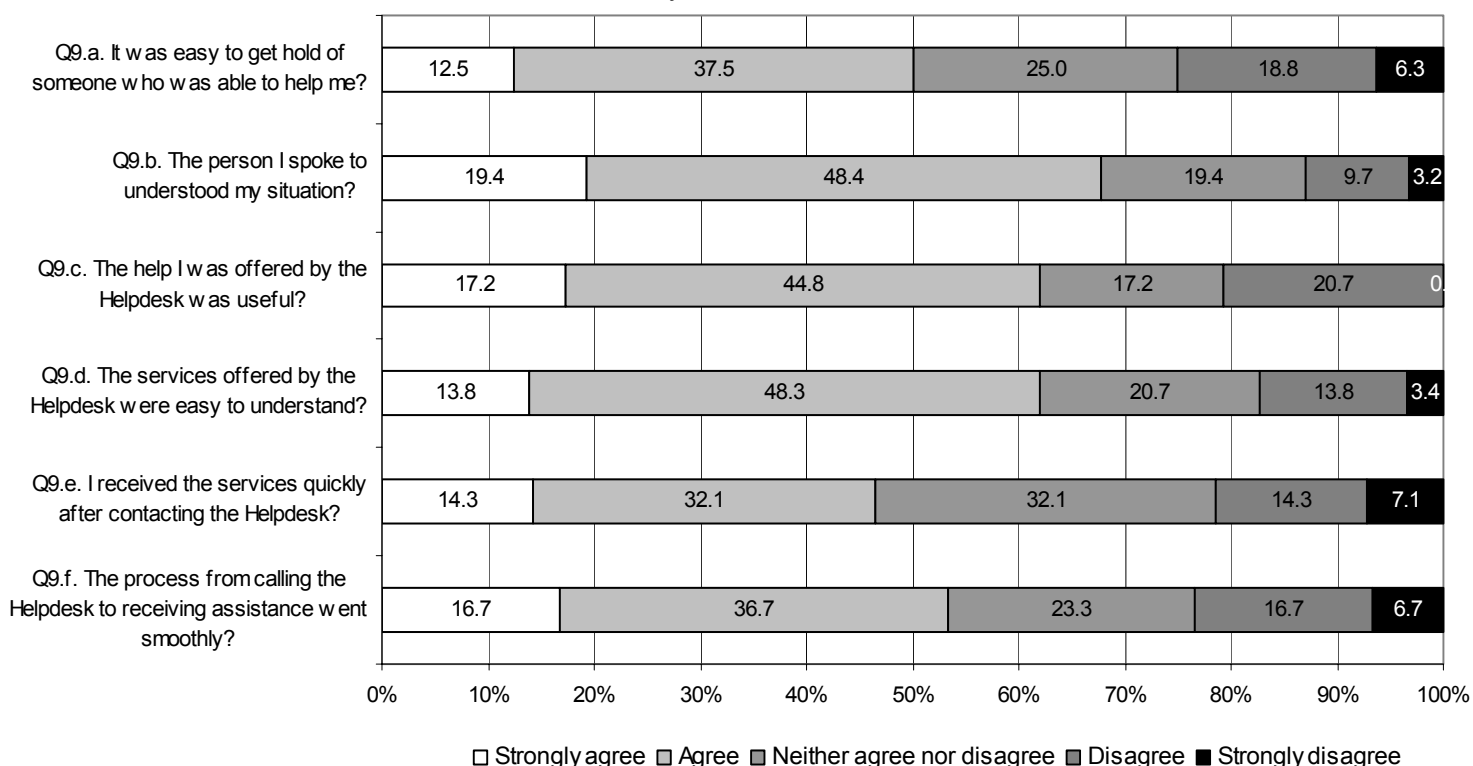
Q8 Have you ever been told the number of the DCS Social Care Helpline?



Base: 134

2.1.15 At the next question, asked to gauge what panellists thought of the service they received from the Social Care Helpdesk, the base size was very low; just 32 panellists answered this. This may be a reflection of the numbers of Carers who have been made aware of this service and its contact number (see Q8 above). This low base means that these results are unreliable and should be taken as indicative only.

Q9 If you have ever had to call the Social Care Helpdesk, please tell us what you thought of the service you received



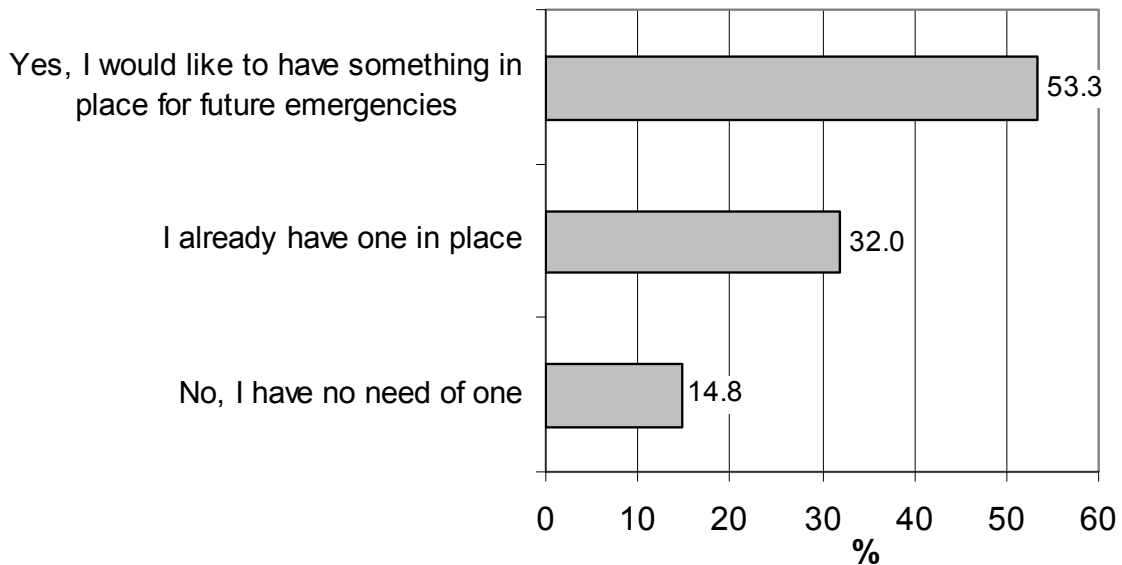
Base: 32

2.1.16 It is worth noting that overall, half of all respondents agreed (Strongly agree + Agree) that it was easy to get hold of someone on the Helpdesk; nearly 70% agreed the person they spoke to understood their situation; over 60% agreed the help they received from the Helpdesk was useful; over 60% agreed the services offered by the helpdesk were easy to understand and that over half agreed that the process of calling the Helpdesk to receiving the services went smoothly.

2.1.17 On the down side, less than half of respondents agreed that they received services quickly after contacting the Helpdesk. 25% of panellists disagreed that it was easy to get hold of someone on the Helpdesk. The statement that had the 2nd highest level of disagreement was that the process of calling the Helpdesk went smoothly, with 23% disagreeing.

2.1.18 The final question in this section described how having a Carers' Assessment can help plan for any emergency situations. Panellists were asked whether they had thought about having a plan for any such situations. Whilst only 32% of respondents stated that they currently have a plan in place, it is encouraging to see that over half replied that they are interested in having a plan in place for the future. Nearly 15% of respondents replied that they did not need a plan. Possible reasons for not having a plan in place is that Carers may not want the cared for person going into respite for some of the reasons mentioned earlier or they might simply want to continue caring for that person themselves.

Q10 Have you thought about having a plan for emergency situations?



Base: 122

2.2 Future Questions

- 2.2.1 This section of the survey returned some interesting results showing Carers' reliance on family members to help with additional caring and in certain other situations to provide respite. In order to find out more about the reliance on family members, questions looking at this topic could be asked in future Carers' Voice questionnaires.
- 2.2.2 Several of the questions in this section also showed that many Carers on the panel seemed not to be aware of certain DCS services and information. It was pointed out by Steering Group members that this may be because some panellists are not in touch with DCS and do receive services from them. Again the extent to which panellists have contact with DCS and to a lesser extent with the Carers' support agencies can be looked at further in future questionnaires.

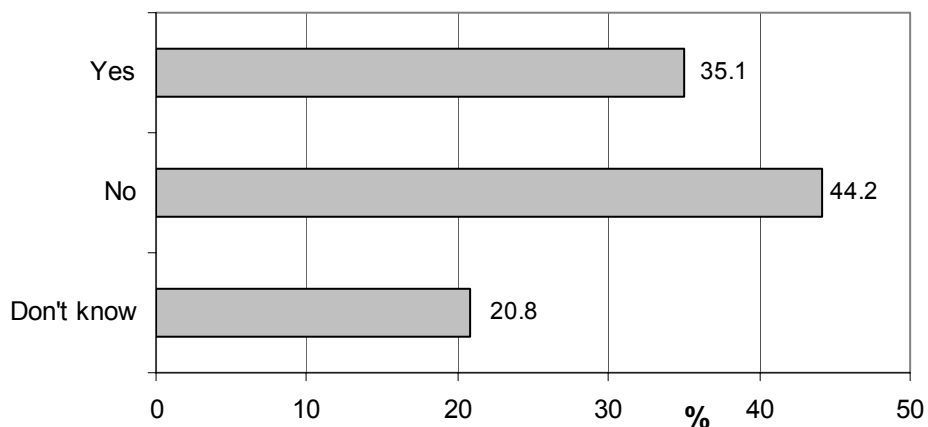
3. MENTAL HEALTH

3.1 Carers of someone with mental health problems

3.1.1 In the last Carers' Voice survey from November 2006, 30% of respondents said the main provider of services they received was Mental Health Services. As a follow up, this section asked questions around support, information and services for Carers of someone with mental health problems.

3.1.2 Carers were asked whether they felt they were given enough information and support in their caring role. Whilst over one third of respondents said that yes, they do receive enough support, nearly half, 44%, said that no they do not. Answered by 77 respondents, these results should be viewed as indicative only.

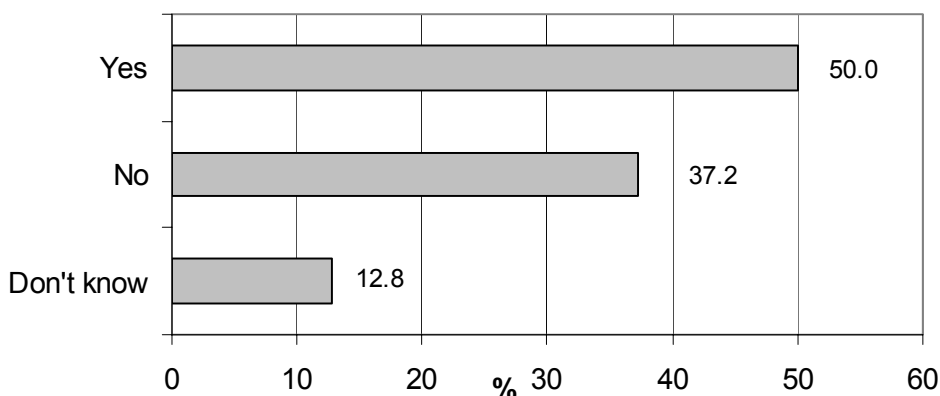
Q11 Do you feel that you have been given enough information and support



Base: 77

3.1.3 To follow this question, Carers were then asked if they know where to go to get practical or emotional support. 78 respondents answered this question, so again, the result should only be viewed as indicative, but here, exactly half of respondents said yes, they do know. Just over one third said they do not know where to get this sort of support.

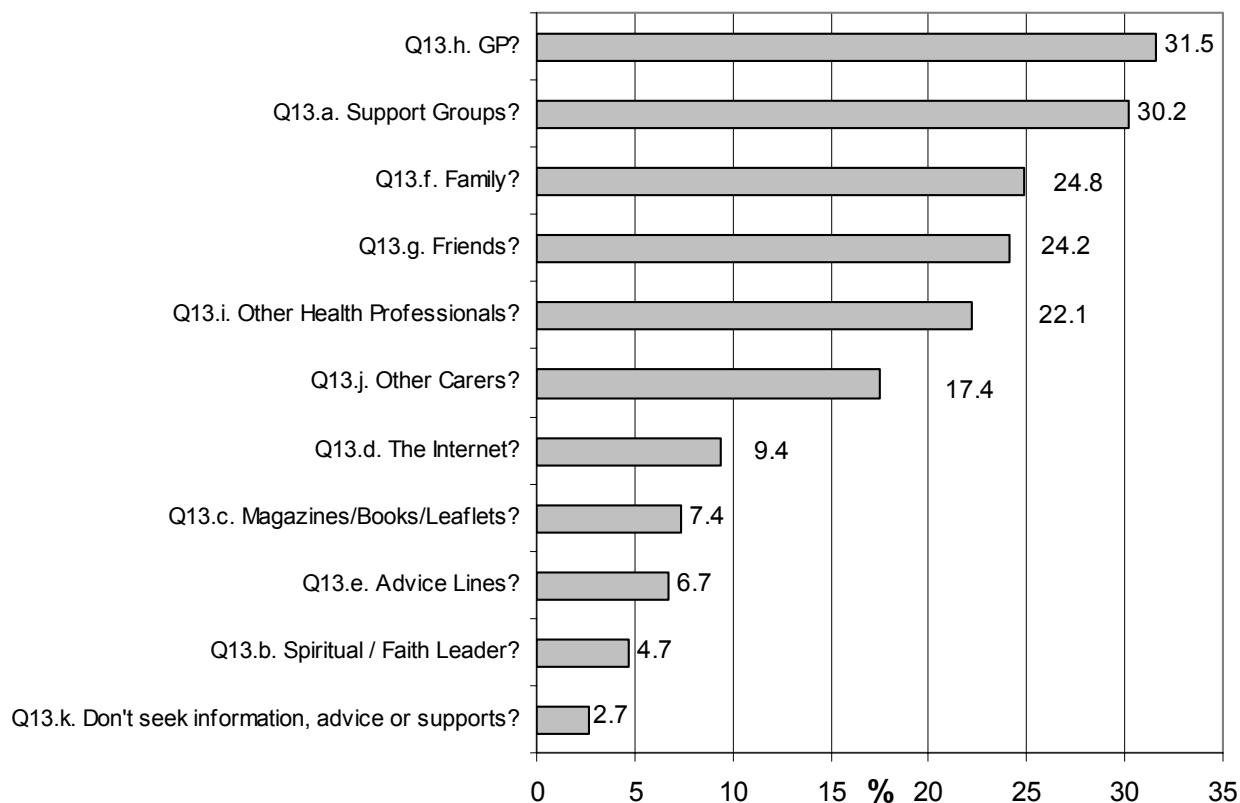
Q12 Do you know where to go for practical / emotional support



Base: 78

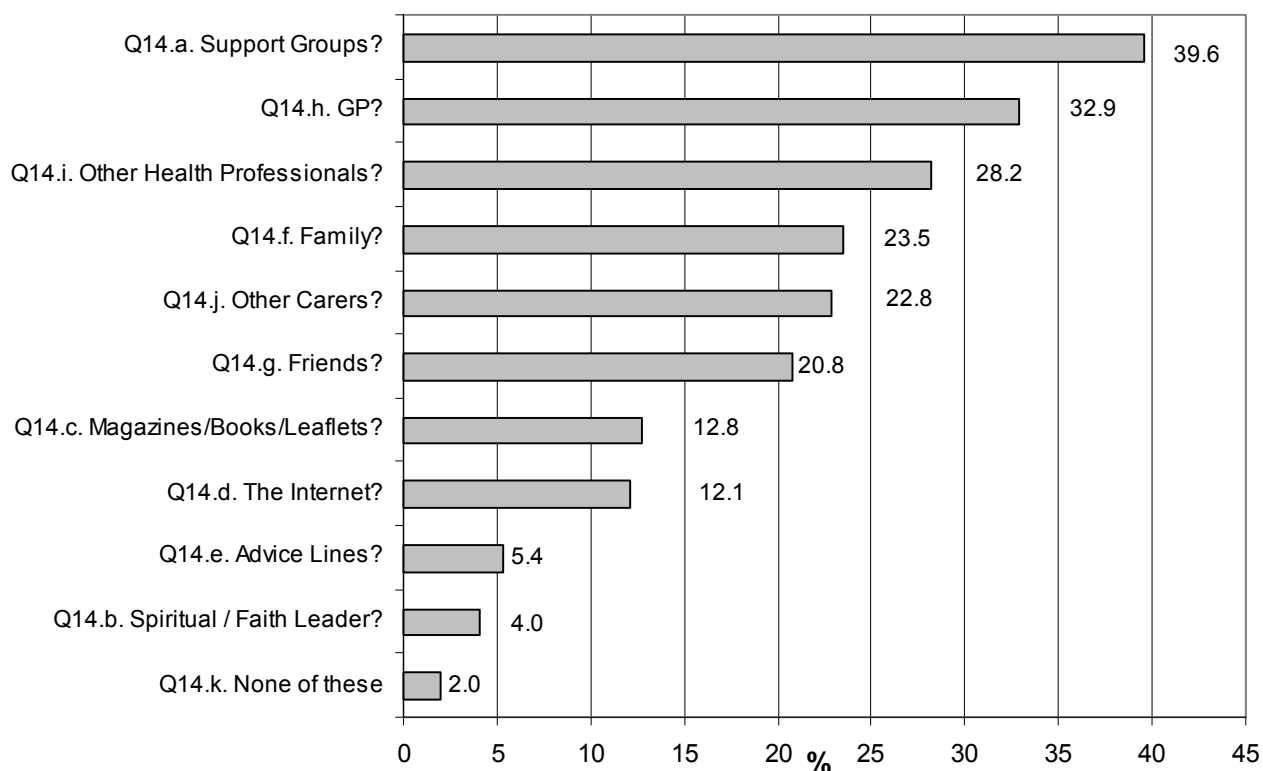
3.1.4 Carers were then asked where they go to get this information, support and advice. Panellists were asked to choose from a list, the sources that they normally turn to. The most common response was to get advice from the GP, followed by help from support groups. It is interesting to note that only 7% of respondents turn to advice telephone lines for information and advice. Also of note, and quite reassuring, just 2.7% of respondents say they do not seek any form of help.

Q13 Where do you normally turn when you need information, advice and support?



3.1.5 The next question follows up Q13. Panellists were asked which of the sources of information they mentioned in Q13 they found to be the most helpful. Whilst respondents most commonly turn to their GP for advice in Q13, here, the GP is chosen as being helpful by only the second greatest proportion of respondents. Support Groups were chosen as being helpful by the greatest proportion of Carers. As was seen above in the level of use of advice line, just 5.4% of respondents said that this form of information was useful to them. Also reassuring was to see that only 2% of panellists said that none of the sources on this list were useful.

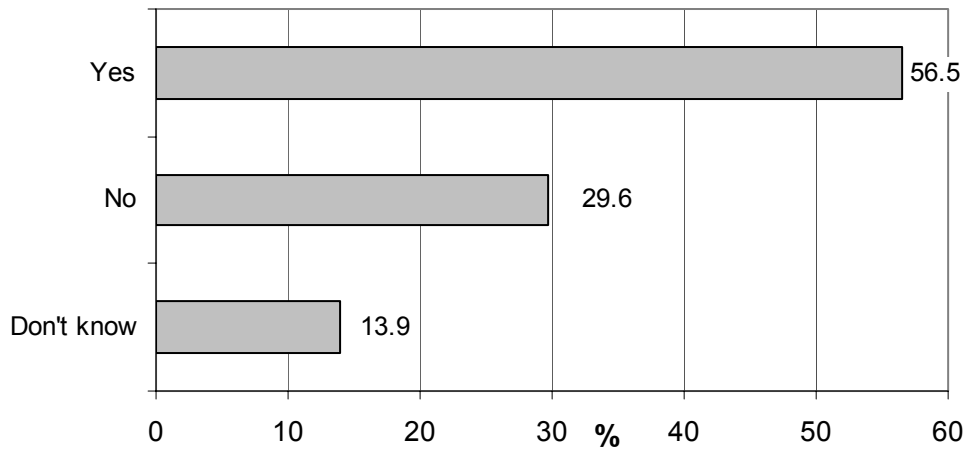
Q14 Which of the following do you think are the most useful sources of information, advice and support to you?



3.1.6 Of note in these last two questions is the relative rank of “Other Health Professionals”. Question 13 showed that this group is the 5th most commonly turned to, whilst Carers in fact find them the 3rd most helpful source of information and advice in question 14. In discussion with the Steering Group, it was noted that the advice and assistance of professionals such as psychiatrists are valued by Carers but that it can be difficult to get placed on their case-load, hence the lower ranking at question 13.

3.1.7 The next question continued the theme of having information available and looked at whether Carers knew where to go or who to contact in the event of a crisis. Over half of respondents said that yes, they did know who to contact. However, this still leaves over 40% of Carers not knowing exactly who to contact in the event of a crisis.

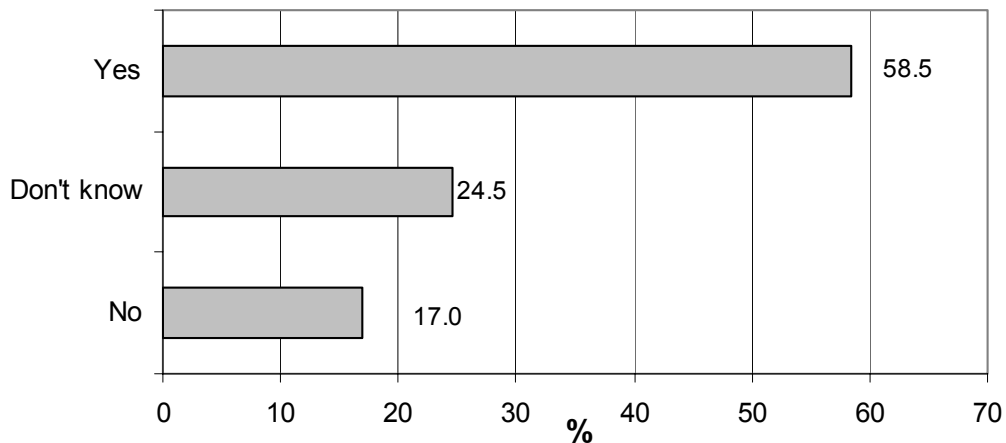
Q15 In the event of a crisis, do you know who to contact for help



Base: 108

3.1.8 Carers were then asked whether they thought reviews or reassessments of care services should be carried out more frequently. Nearly two thirds of respondents thought that they should be carried out more frequently. One quarter stated they did not know and 17% thought reviews did not need to be carried out more frequently. This “no” proportion might follow on from the observation that there may be many Carers not in touch with DCS.

Q16 Do you think reviews / reassessments should be carried out more frequently



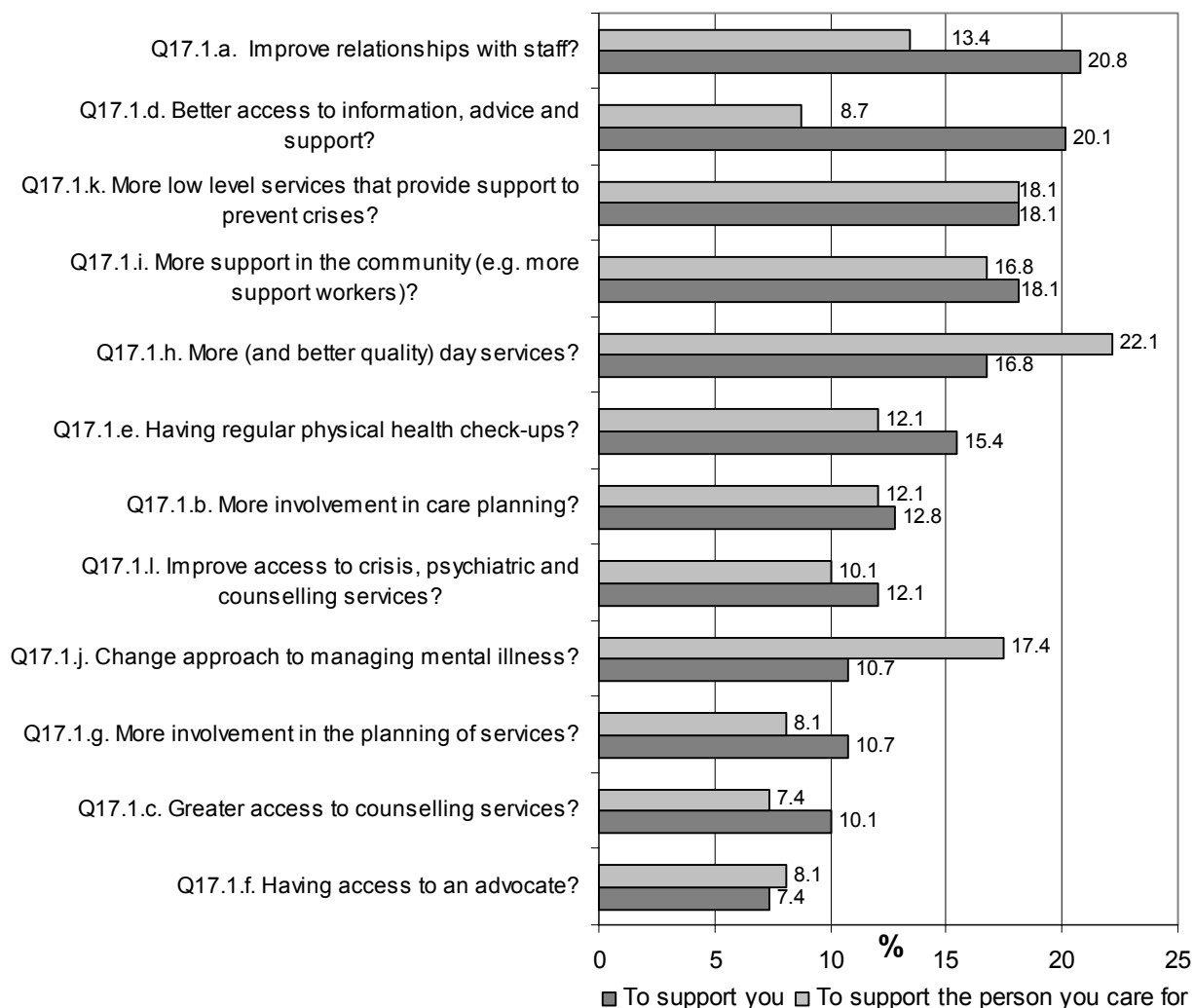
Base: 106

3.1.9 Carers were then asked what improvements they would like to see to the service they receive. They were asked to think about which would be most important to themselves and which would most support the person they care for.

3.1.10 Respondents most commonly stated that in order to better support themselves, they would like to see an improvement in relationships with staff; 21% said this. This was closely followed by having better access to information and support. At the other end of the spectrum, just 10% said they would find greater access to counselling of use to themselves and least frequently chosen of all, 7% thought having access to an advocate would be useful.

3.1.11 Carers thought that of most support to the person they care for would be more (and better quality) day services; 22% chose this service. Next most commonly chosen was to provide more low level services that provide support that prevent crises. Interestingly, the third most commonly chosen action to support the cared for person was a change in approach to managing mental illness. The services least frequently chosen to support the cared for person were having access to an advocate (8.1%) and greater access to counselling services with just 7.4% selecting it.

Q17 As a carer of someone with mental health problems, what improvements would you like to see in services?

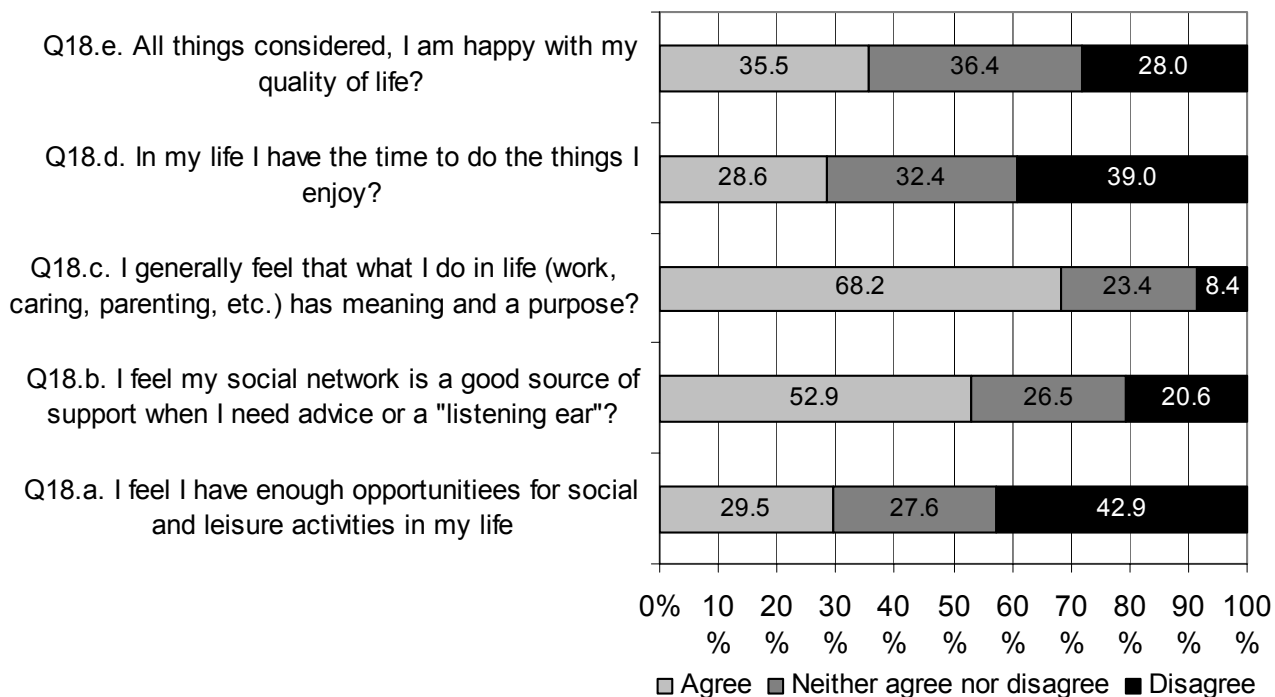


3.1.12 Finally in the section on mental health, Carers were asked about their emotional health. They were asked if they agreed or disagreed on several statements about their quality of life and the way it makes them feel.

3.1.13 Carers most commonly agreed with the statement “generally I feel that what I do in life has a meaning and a purpose; nearly 70% of respondents agreed with this. The next most commonly agreed with statement was “I feel my social network is a good source of support when I need advice or a ‘listening ear’”, with 53% agreeing to this. Just 29% of respondents agreed with the statement “in my life I have the

time to do the things I enjoy”. This is not however the statement that received the greatest level of disagreement. 43% of respondents disagreed with the statement “I feel I have enough opportunities for social and leisure activities in my life”

Q18 To what extent do you agree with the following statements?



Base: 107

3.1.13 Generally speaking, these results seem to show that Carers are satisfied with what they do in life and with the social networks around them (parts b & c) although it is apparent Carers have little time to themselves for their own interests and activities (parts a & d). Overall, the feeling of being satisfied with their quality of life (part e) is mixed between Carers: equal proportions, 36%, agree and are unsure about this statement. A slightly smaller proportion of Carers, 28%, disagreed, showing they are unhappy with their quality of life.

3.2 Future Questions

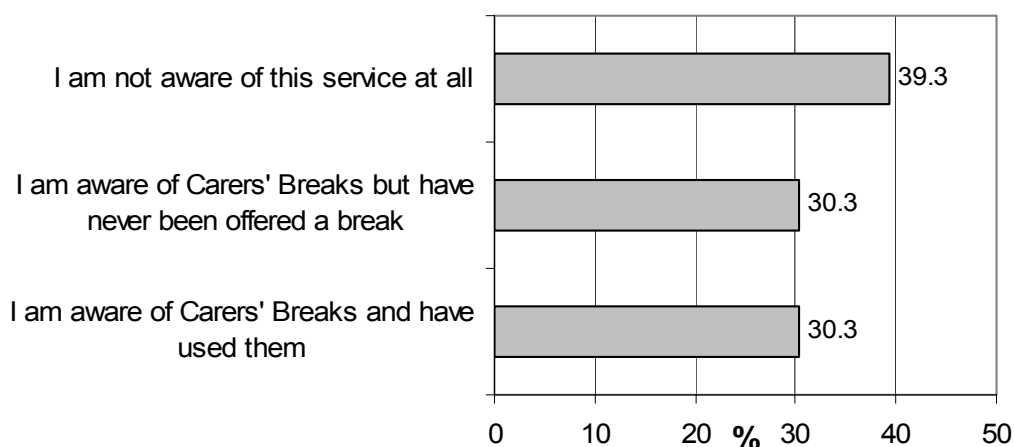
3.2.1 Following on from the topline results of the survey, there has been a request for some of these questions to be repeated regularly in order to monitor the effects of any changes to services and to provide a regular way of judging how Carers feel about their role.

4. CARERS' BREAK SERVICE

4.1 Opportunities to take a Carers' Break

- 4.1.1 The final section of the Carers' Voice survey looked at the services that were on offer through opportunities to take a Carers' Break and how they can be of most benefit to Carers. Questions looked at the take up and type of breaks that are used, what services are most useful to Carers and how best to find out about them.
- 4.1.2 The first question in this section asked panellists whether they were aware of the Break service and whether they made use of it. The largest proportion of Carers, nearly 40%, said they were not aware of Carers' Breaks and the opportunity to get away. 30% of Carers were aware of the opportunity to take a break but had never been offered one, whilst another 30% of Carers were aware of this service and had used this service. These results show that 70% of respondents have never been given the opportunity to take a Carers' Break.

Q19 Are you aware of the opportunity for you to take a Carers' Break?

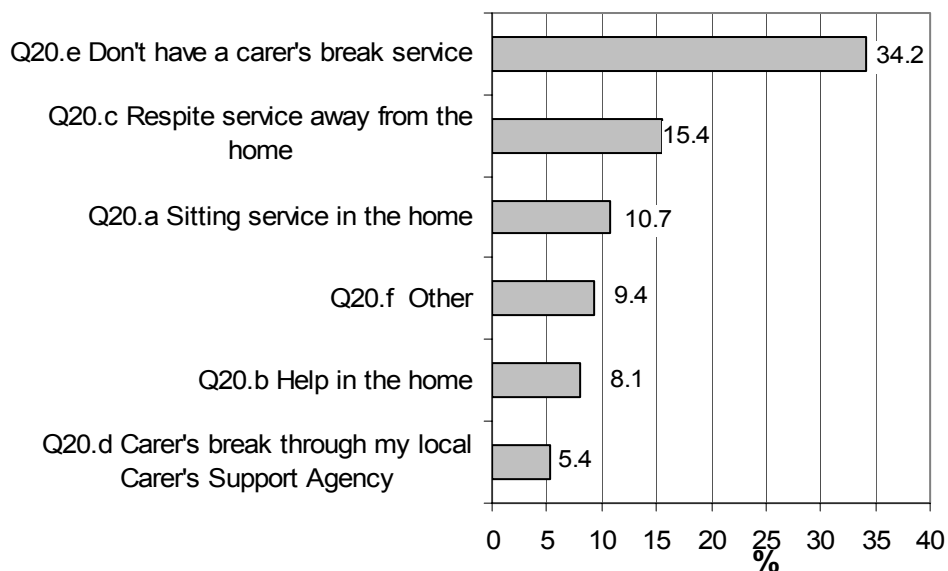


Base: 122

- 4.1.3 Following discussion with the Steering Group, it appears there is some ambiguity over the phrase "Carers' Break" in that there are many different services that fall under this umbrella term that Carers may receive without being aware that it is a "Carers' Break". This could account for there being such a low proportion of Carers who say they have used one of the services. A description of the different services under this heading within the survey might have allowed Carers to realise that they had in fact used a Carers' break service.
- 4.1.4 The next question asked about the types of services that Carers received. As we have just seen, very few Carers are actually able to take up this service so the numbers answering this question are very low and cannot be taken as reliable
- 4.1.5 Carers were asked which services they currently received from a list. The most common response, with 34% ticking this one was "don't have a Carers' break". Of the respondents that do receive a service, the most frequently received was "respite services away from the home" with 15% of Carers receiving this; although

it must be pointed out that in terms of numbers, only 23 Carers received this service. This was followed by “sitting services in the home” with 11% or 16 Carers, receiving this.

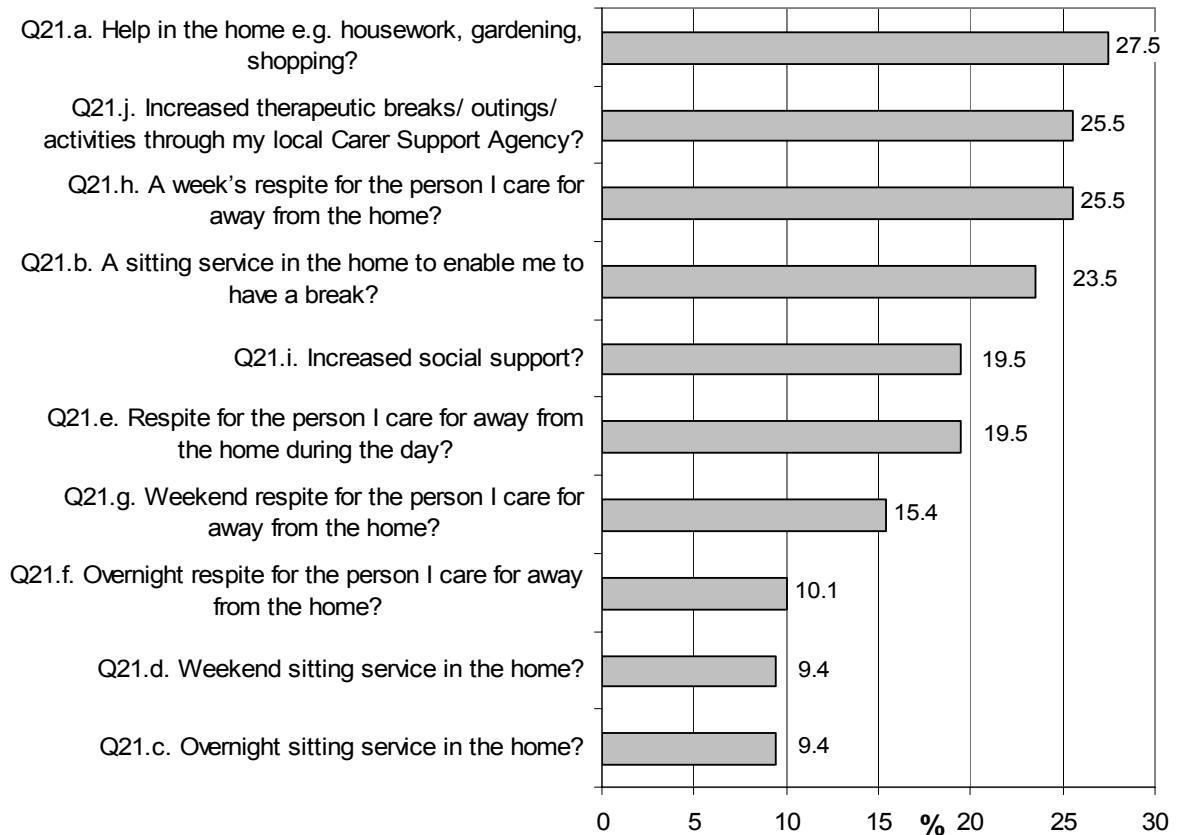
Q20 What type of Carers' Break service do you currently have?



4.1.6 Carers were next asked about what services they would like a Carers' Break to be able to offer them. The most common service that Carers would like to see is for help in and around the home. The next most common services related to services away from the home, with an equal proportion choosing “increasing therapeutic breaks & outings” and “a week’s respite for the person I care for away from the home”. Both options that incorporated a sitting service were the least frequently chosen options, with just 9.4% feeling the overnight and weekend services would be useful to them.

4.1.7 Several respondents took time to suggest “Other” services they would find useful. These comments included ideas such as the ability to take a break somewhere along with the cared for person, help in finding agency care staff, knowing that breaks will be covered by specialist staff and help with transport.

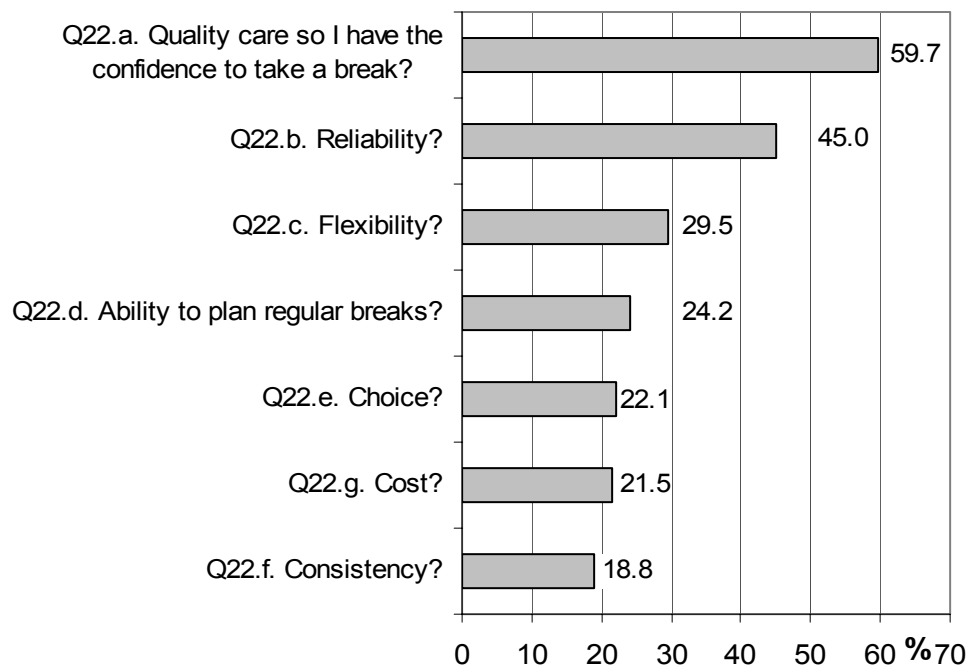
Q21 What would you like a Carers' Break service to be able to offer you?



4.1.8 In Question 22, Carers were asked about the qualities they felt were important to them in a Carers' Break service. They were asked to select a range of qualities from a list. Nearly two thirds of respondents felt that quality care was important, giving them confidence to take a break. The next most common quality was reliability, chosen by 45% of Carers, followed by flexibility, chosen by 30%. The least frequently chosen quality for a Carers' Break was consistency, chosen by 19% of respondents. The theme of Carers having confidence to take a break ran through many of the results here. The Steering Group noted that qualities such as choice or cost were of little importance if the Carer did not have the confidence to leave the person they care for.

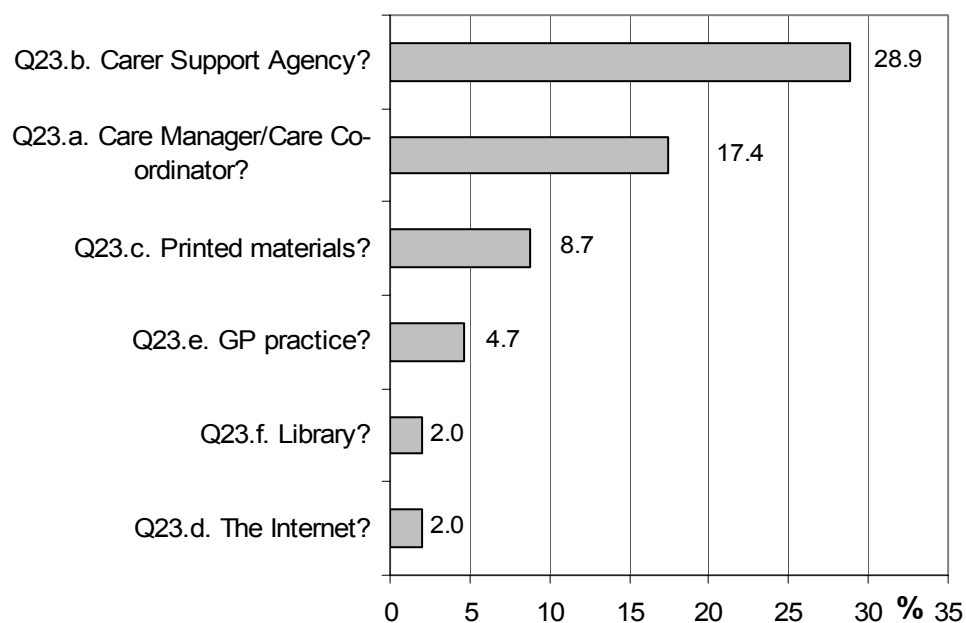
4.1.9 Again, panellists took the time to mention several other suggestions that they thought important. Some of these were similar to those mentioned in Q21, such as being able to take a break together as well as simple suggestions such as being easy to arrange or for the availability of very short breaks – just 2 - 3 hours.

Q22 What do you feel is important in a carers' break service?



4.1.9 In the final question in the survey, panellists were asked where they go to get information on Carers' Break services. 29% of Carers said they get information about breaks through the Carers support agency. The next greatest proportion said the information came from their care manager or co-ordinator. The sources that the least people used proved to be the GP's practice, the library and over the internet.

Q23 Where do you get information on carer's breaks services?



- 4.1.10 Some 25 panellists made comments detailing an “other” option as to where they get any further information. These comments were made up of several “don’t know” and other ways of saying the respondent does not access information about breaks. Several panellists mentioned social services, social workers and WCC as the source. Others comment that they have to pay for breaks themselves.
- 4.1.11 In this and other sections of the survey, Carers’ views about the use of the internet has consistently been very low, both in terms of Carers choosing to use it for information and the perceived usefulness of that information. The Steering Group commented that many Carers simply do not have the time available to use the internet. This low usage may also be due to the make up of the Carers’ Voice panel, being as it is made up of mostly older residents who are less likely to have home access to ICT and use it.

5. CURRENT ISSUES

5.1 Current issues affecting Carers

- 5.1.1 This survey asked for the first time whether Carers have any issues that are currently affecting them. A box for open comments was provided to allow Carers to let us know what their problems might be. Because of the number and range of comments they have not been analysed as part of this report. However, they have all been passed on to the relevant DCS officer to be used as appropriate.

6. CONCLUDING COMMENTS

- 6.1 Carers' Voice is an invaluable method of collecting information about the opinions of Carers living in Wiltshire by providing an insight into the experiences and views of the members of Wiltshire's Carers' Voice Panel.
- 6.2 This survey has produced results which will be useful to Wiltshire County Council and Carer Support Organisations in the development of better services for all Carers in the county.
- 6.3 The results of this survey should be seen as a way of supporting decision makers by helping them to understand the needs, opinions and priorities of Carers living in Wiltshire.
- 6.4 This report will be disseminated among the partner organisations and service providers. Copies will be made available in all of Wiltshire's libraries and an electronic version of this report will be available to download online from the Wiltshire and Swindon Intelligence Network (www.intelligencenetwork.org.uk).