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MARLBOROUGH MELKSHAM MERE PEWSEY SALISBURY TIDWORTH TISBURY TROWBRIDGE WARMINSTER
WESTBURY WILTON WOOTTON BASSETT & CRICKLADE **WILTSHIRE'S COMMUNITY AREAS**

WILTSHIRE CARERS' VOICE

Autumn 2008 Survey Results

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Wiltshire COUNTY COUNCIL

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Please Note
This report is a representation of the views and perceptions of members of the Carers' Voice panel and in this special case of the Carers receiving the Carers' Support Agencies newsletters in autumn 2008 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 meets 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 and to use their experience to provide an interpretation of survey findings.

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 tenth Carers' Voice questionnaire, which was sent out to panellists in September 2008. In addition to sending the survey to just the Carers' Voice panel, the questionnaire was distributed by the Carers Support Agencies in their autumn 2008 newsletters. Carers not on the panel were invited to complete the questionnaire and if this proved interesting, to become full members of the Carers' Voice panel.

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.

1.2.2 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).

1.2.3 The panel does not however include people who are employed to undertake caring tasks as their profession.

1.2.4 Currently over 70% of Carers' Voice panellists are female.

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

1.2.6 At the time of mailing this survey, the total number of Carers on the panel stood at 355.

1.3. Returns Profile

1.3.1 In a change to the normal distribution methodology, it was agreed by the Steering Group that in addition to sending the survey to the Carers' Voice panel, questionnaires would be distributed via the Carers Support Agencies' newsletters. This would circulate the survey to a further 4,000 Carers in Wiltshire and was intended to both boost the number of responses to this survey and to encourage Carers to join the panel after seeing what filling out the form entails.

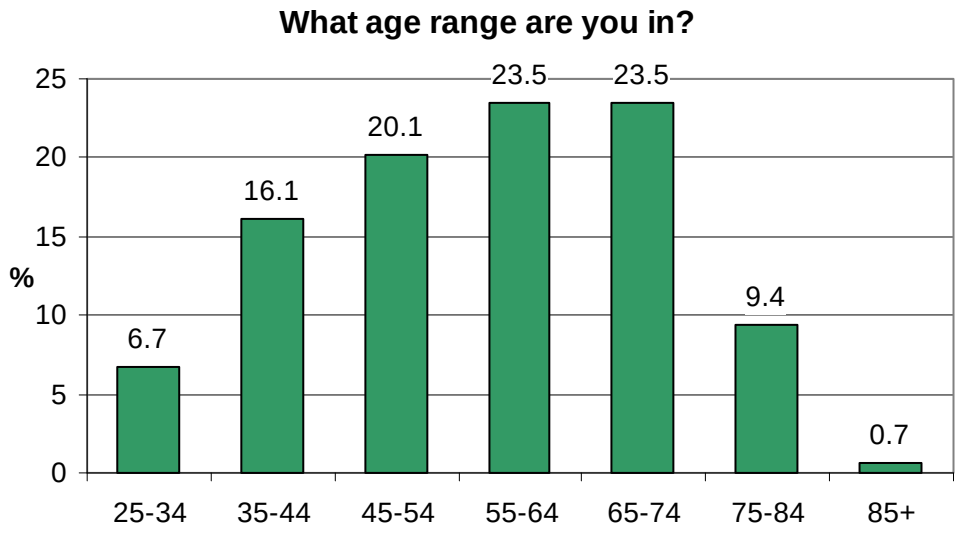
1.3.2 Panellists were sent the tenth Carers' Voice questionnaire at the beginning of September, 2008. By mid-November, this questionnaire had achieved a response rate of 43.1%, with 153 questionnaires received from panellists. Given that panellists had around over 8 weeks in which to return the survey, this response rate is slightly lower than that seen for other surveys, some of which had even shorter windows of opportunity to respond

1.3.3 A further 337 Carers not currently on the panel also returned completed questionnaires after having received them through the Carers' Support Agencies' newsletters. This brought the total of responses to 490. Although this does make the results more statistically reliable, it does bring other problems. As these respondents are not on the Carers' Voice panel, we do not know who they are or any other details about them. This makes analysis of the results difficult and could restrict detailed analysis (age,

gender, location, etc.) to the 153 panellists who responded.

1.3.4 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; 29% of respondents to this survey were male, 71% were female.

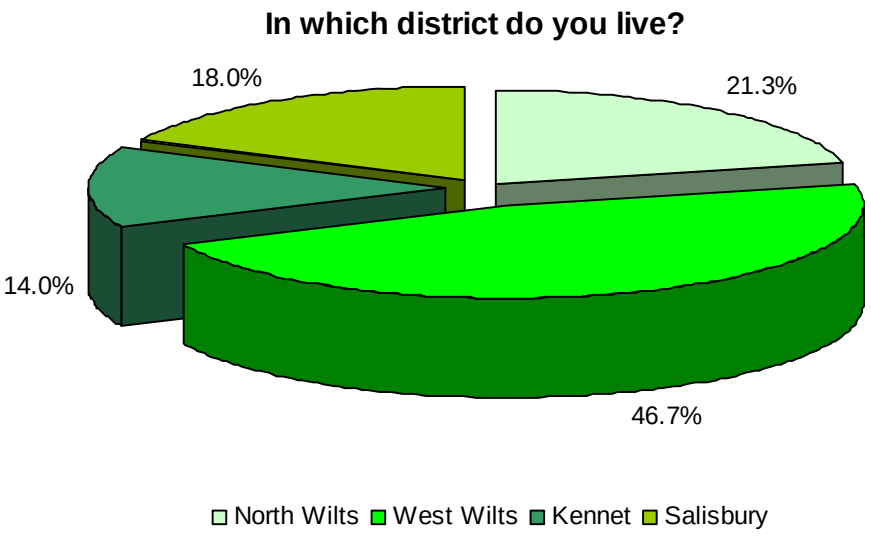
1.3.5 The chart below shows the age distribution of respondents. The majority of respondents (57%) are aged 55 and over, which reflects the age structure of the panel.



Base: 149

1.3.6 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.

1.3.7 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 as a whole. 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.



Base: 150

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 tenth questionnaire covered the following topics, which were thought timely by members:

- Potential Additional Services
- Work Status
- Wiltshire Libraries
- Carers' Assessments

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 used to add explanation and background to the results and add to the understanding of what these figures say.

2. Results

2.1. Additional Services

2.1.1. In discussion with the Steering Group, a list of possible and potential services that could be provided to Carers was developed. This was intended to cover practical issues that effected Carers personally, the skills they might need as Carers and further information that might help them in this role

2.1.2. Carers were asked to state how helpful they thought each of the suggested services might be to them. The chart below shows this list and how helpful carers thought these might be. It is ranked in terms of those thinking a service is helpful (Very helpful + Helpful).

2.1.3. Results show that the vast majority of Carers would like advice and information services extended – nearly 95% of respondents said they would find this helpful.

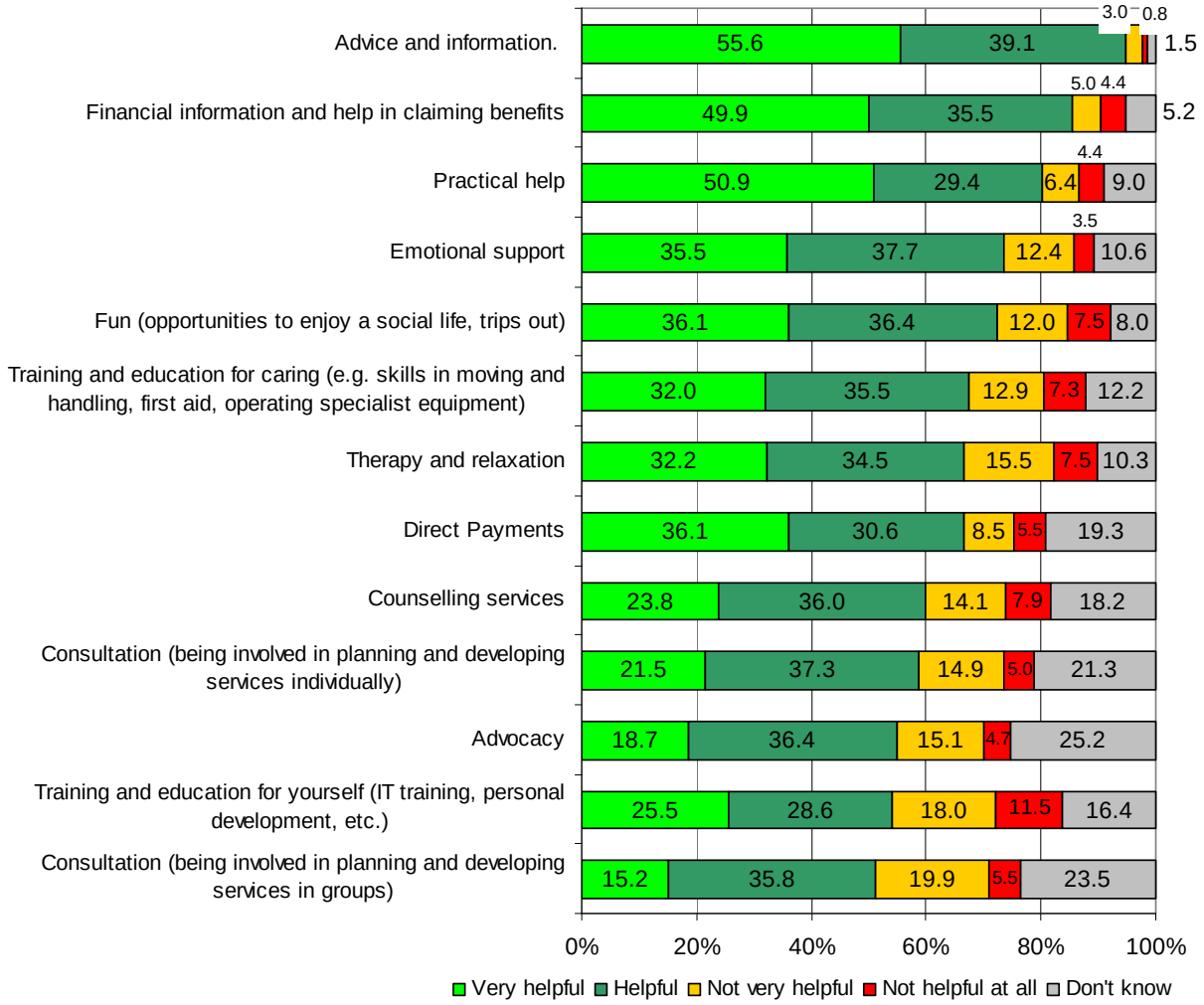
2.1.4. This service is followed by information about financial and benefits matters (85%), practical help (80%) and emotional support (73%). In all of these cases, well over two thirds of Carers say they would find them helpful.

2.1.5. It is interesting to see that the 5th most commonly chosen service is “Fun”, with 72% saying they would find this helpful. This shows that Carers look to find ways to socialise and enjoy themselves. This could be seen as both with the person they care for and on their own, possibly as a form of respite. It shows that Carers value opportunities to socialise and would like further chances to do so.

2.1.6. Of slight surprise to the Care Managers was the relatively low interest in information about Direct Payments, with 65% of Carers saying they would find this helpful. These are a one off sum of money to enable to purchase of care and services that might have been identified by a Carers Assessment. It was thought this might be due to the age of Carers, with older Carers preferring to provide care themselves and this Direct Payments and younger Carers opting to take Direct Payments and pay for care services.

2.1.7. Analysis of responses *from panellists* shows this not to be the case. Whilst 86% of panellists in the 35 – 44 year old group say this would be helpful, 73% of 65 – 74 year olds and 50% of 75 – 84 year olds also say Direct Payments would be helpful. As this analysis is of just the Carers’ Voice panellists, responses from Carers not on the panel, about whom we know nothing, might affect this.

Q1 Which of the following services, if they were to be introduced or extended, do you think you would find open



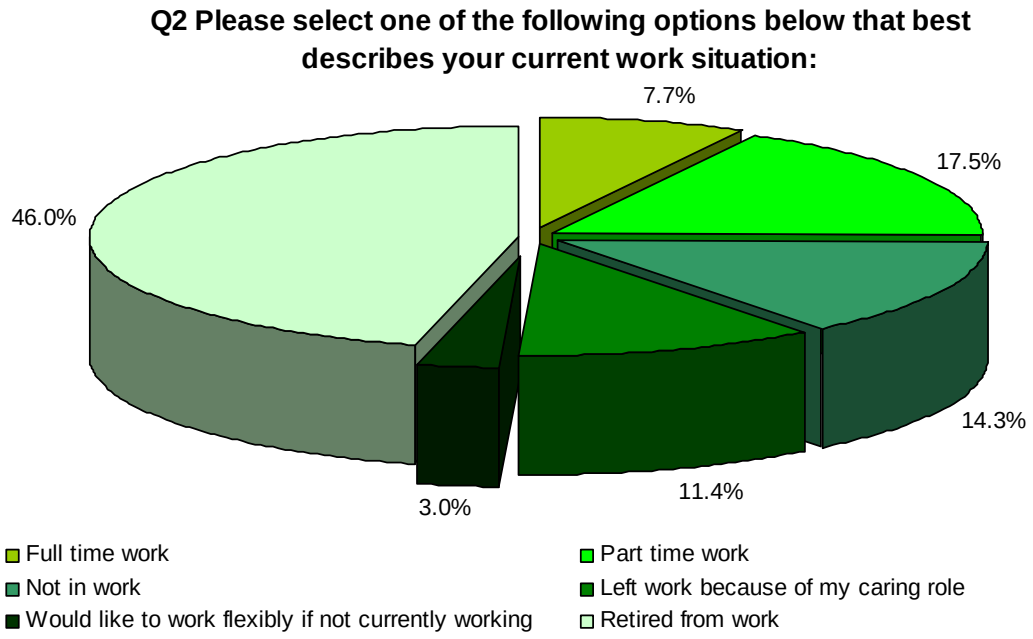
Base: 473

2.1.8. 50 respondents provided further suggestions for services. These included calls for more respite or time to themselves, opportunities for socialising, recognition as a Carer, better levels of support and easier access to different sorts of information. All comments are shown in Appendix A.

2.2. Work Status

2.2.1. The next section of the survey was designed to look at Carers' work status, how this might have changed when they started their caring role and what the impact of this has had on their financial situation.

2.2.2. The first question in this section asked Carers what their current work situation was. This included the option of having to leave work because of taking on their caring role.



Base: 428

2.2.3. This chart shows that the greatest proportion of Carers is retired. This is not surprising given the age of many panellists. With 57% of Carers' Voice panellists aged 55 or over, it is easy to see that 46% of all respondents will be retired.

2.2.4. The next most common status is working part-time, with 17.5% of respondents doing this. Together with the 7.7% saying they work full-time, we can see that just over one quarter of respondents are employed. Whilst this seemed to be high, discussion with the Steering Group showed that often, Carers look to get away from caring, for at least a while and going to a job, either full- or part-time, is an opportunity to do this.

2.2.5. 14% say they are not in work - presumably this is due to being a Carer and the time commitments this entails. A further 11% said they left work because of their caring role, again because of the many commitments this imposes. This means that a further quarter of respondents are not in work due to performing their caring role when they might have been in work.

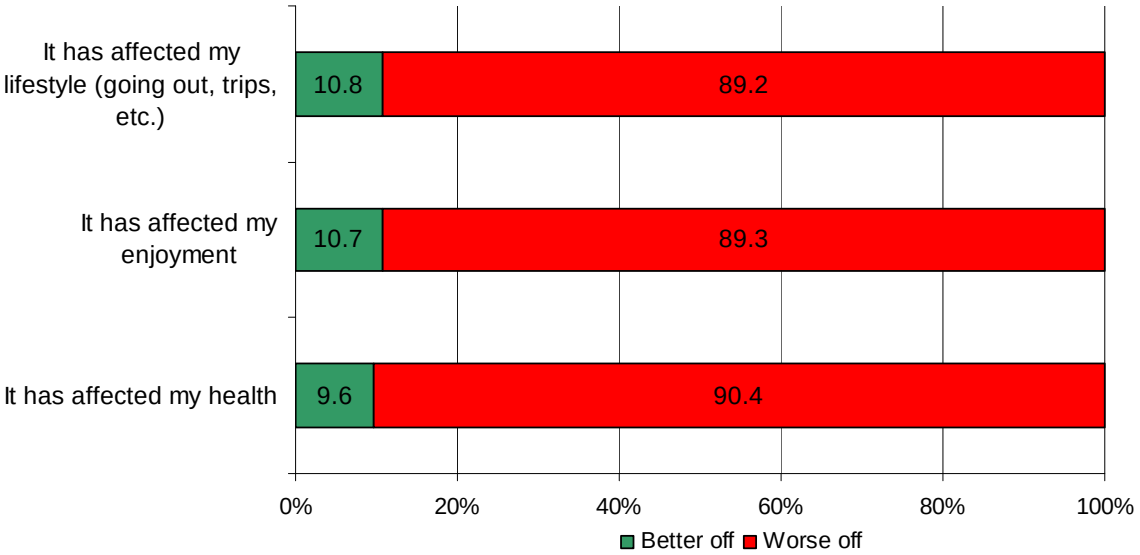
2.2.6. Results show that 3% of respondents say they would like to work flexibly if not currently working. Given the nature of caring and what has been said about Carers often looking to get a life outside of caring, to be able to work in a flexible way, which takes account of caring commitments could be seen as an ideal way of mixing both responsibilities.

2.2.7. The question also had an "Other" option. Many Carers noted here that they do some sort of voluntary work, that they consider their caring role as a full-time job and a few described how they were able to work from home

so still be able to provide care. All these comments are given in Appendix B.

2.2.8. The next question looked at the impact that Carers' financial situation has had on their caring role. Carers were asked to say whether they were "better off" or "worse off". The chart below shows this:

Q3 please tell us the impact that your financial situation has had on your caring role:



Base = 361

2.2.9. Just 11% of respondents say that being a Carer has affected their lifestyle and their enjoyment for the better and 10% say their health has changed for the better. The remainder, in every case the vast majority, say their lives have been affected for the worse in these three factors.

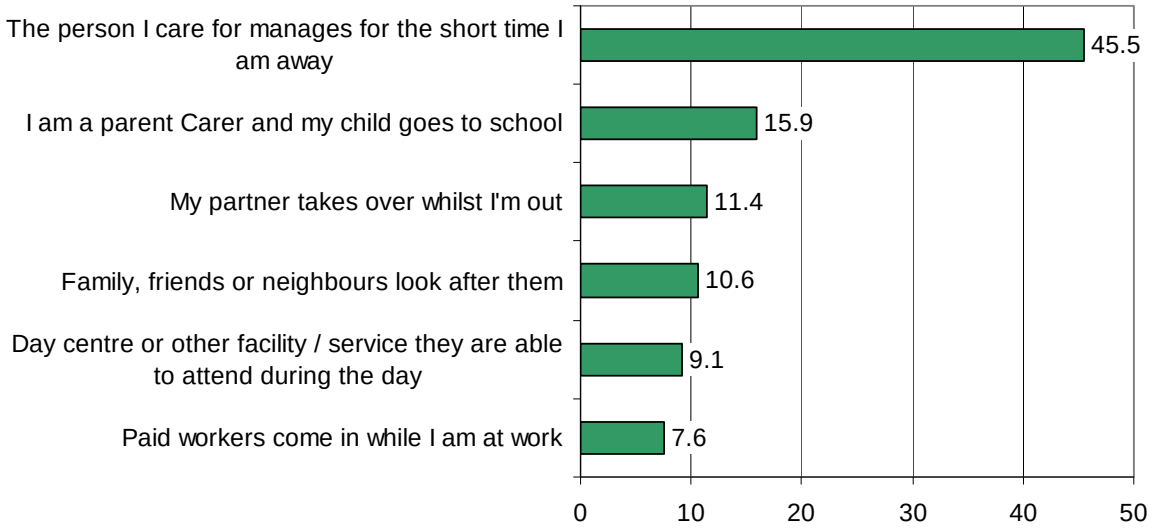
2.2.10. It was mentioned by the Steering Group that because of being able to access different benefits, some Carers might be better off financially after becoming a Carer. This could have led to feelings of being better off in terms of lifestyle and enjoyment. We know the some 11% of respondents left work to become a Carer. This could have given these people, and others, a bit more spare time and this could have had an effect on these factors making Carers fell better off.

2.2.11. Carers were asked to tell us more and to begin to explain their situation. This received over 150 comments. Many Carers used this space to describe their current situation. Many mentioned their own health problems, including issues around stress, constraints on their time, the mobility problems of the person they care for and themselves. Some

Carers also described how it affects everything and others said that there had been no change.

2.2.12. The final question in this section asked about the arrangements used by the Carers who worked to look after the person they care for whilst they were away at work. The chart below shows the most commonly used solutions:

Q4 If you work full or part time, please explain the arrangements you have in place to look after the person you care for whilst you are out



Base = 171

2.2.13. This question was answered by 171 Carers. Looking at the answers to the earlier question about work status, fewer Carers than this stated that they were in some form of work. The most common arrangement is that the person who is looked after manages for the short time that the carer is away. This was chosen by over 45% of Carers.

2.2.14. The next commonly used arrangement was that the Carer is a parent and their child goes to school thus giving some free time to go to work, etc. This is used by some 16% of Carers who work. The third most commonly used arrangement is for a partner to take over whilst the main Carer goes to work.

2.2.15. The least commonly used arrangement for looking after the cared for person was for paid care workers to come in whilst at work. This was chosen by 7.6% of Carers. This was seen by members of the Steering Group as low, bearing in mind there is an obligation to allow Carers to work if that is what they want.

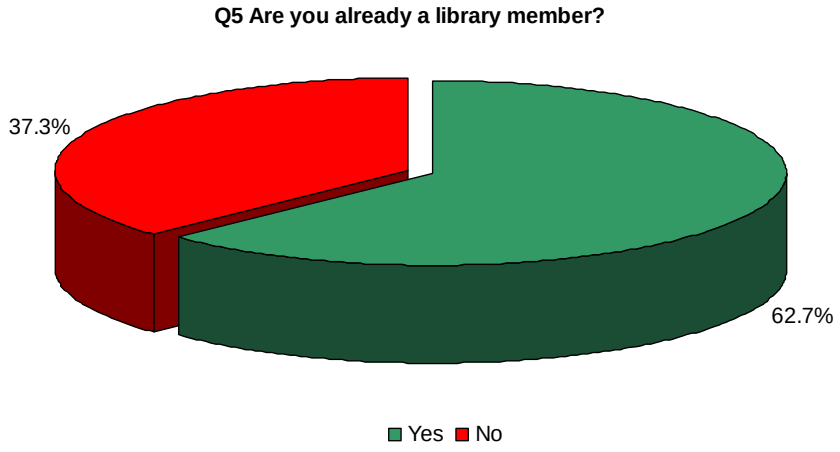
2.2.16. Again, this question gave respondents the chance to add other comments. Comments again mention working from home, using other family members to help, that the person cared for has residential help – this could be some

form of boarding school or college or a nursing home. Other comments include that the Carer is only able to work at times convenient to their caring commitments and that the person who is cared for is quite independent and is able to look after themselves for these periods.

2.3. Wiltshire Libraries

2.3.1. This next section of questions was suggested by Wiltshire Library Services. They are looking to provide more services for Carers and were looking to test ideas and gauge Carers' reactions to some suggestions

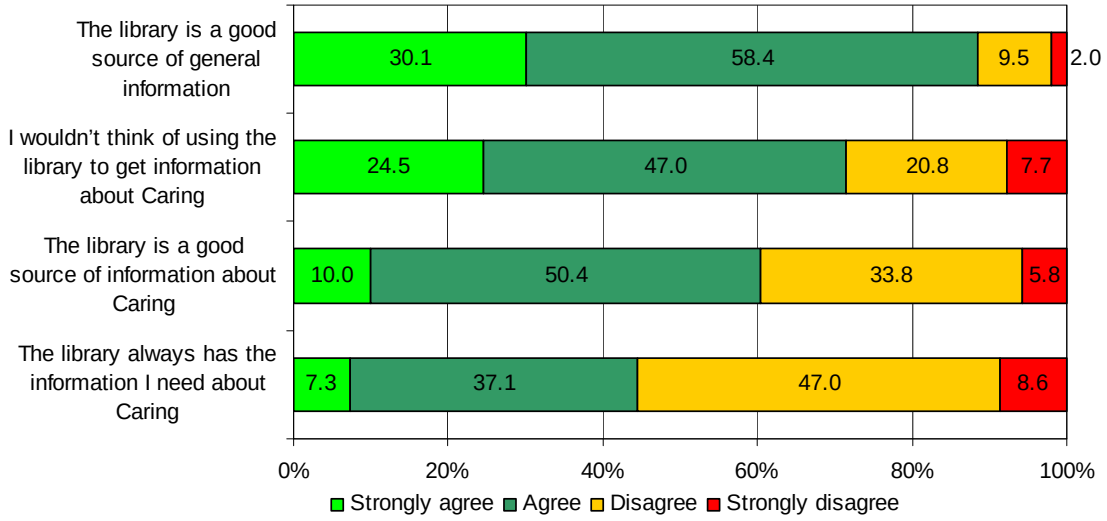
2.3.2. The first question looked at current library membership amongst Carers. The chart below shows that nearly two thirds of respondents are already library members:



Base = 464

2.3.3. Next, Carers were asked about what they thought of the library as a source of information specifically for Carers. Nearly 90% of respondents agreed that the library was a good source of general information but fewer than two thirds (60%) agreed that the library was a good source of information specifically about Caring.

Q6 How would you view the library as a source of information for you as a Carer?



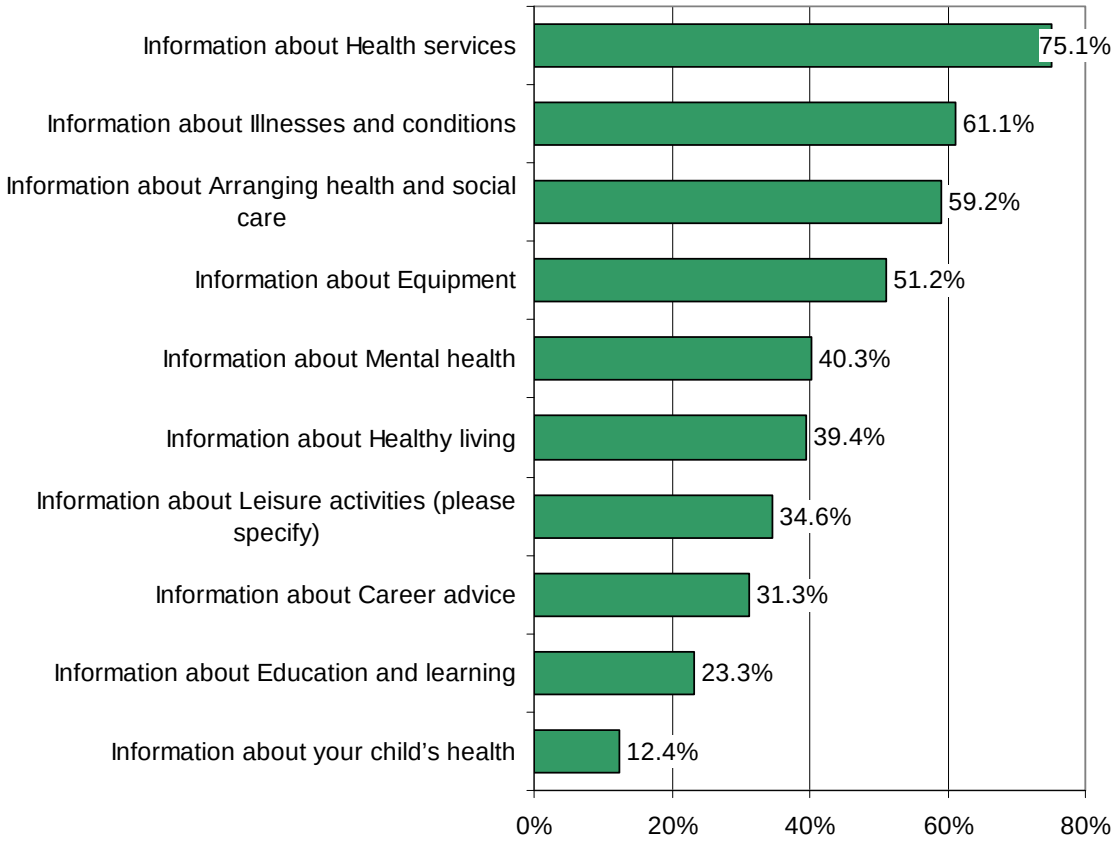
Base = 379

2.3.4. More than half of respondents, 55.6%, disagree that the library always has the information they need about caring. This still leaves an encouraging 44% of respondents who agreed that the library did always have the information they needed to help in their caring role.

2.3.5. A couple of the results here could be seen as contradictory. Whilst 60% of respondents say they agree that the library is a good source of information about caring, more than 70% agree that they would not think of using the library to get information about caring. In light of this, it would seem that these two results must be treated with caution

2.3.6. Next, Carers were asked to choose the five different types of information, from a list provided, that they thought they would find most useful if it were held by the local library. The most commonly chosen types are shown in the chart below:

Q7 What information would you find useful?



Base = 434

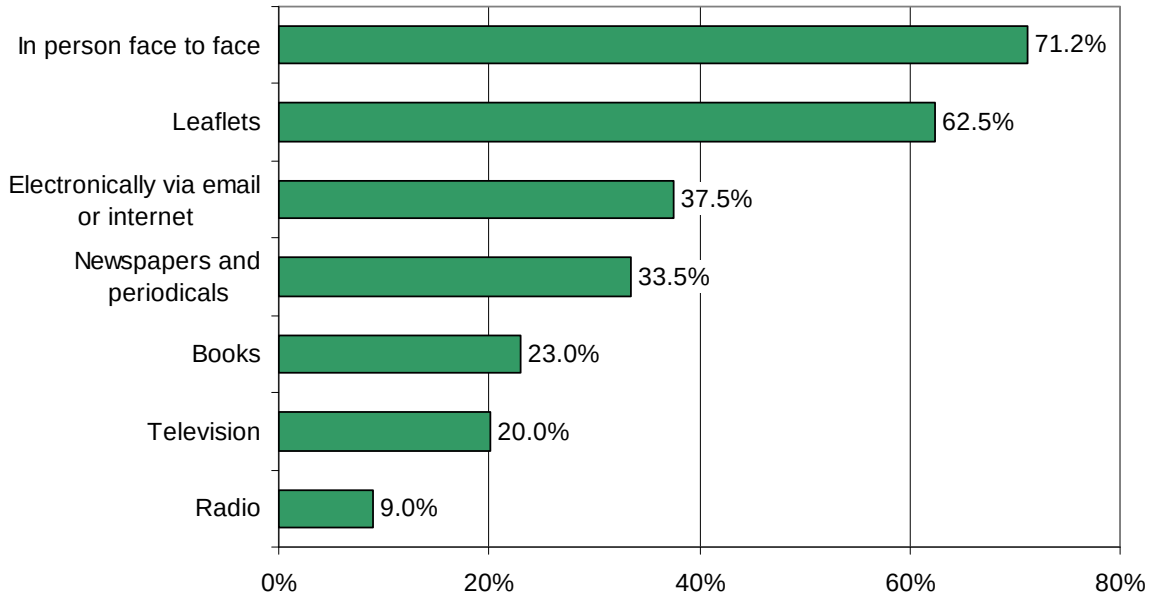
2.3.7. This showed that the information respondents would find most useful would be about health services, with three quarters of respondents choosing this, followed by information about illnesses & conditions (61%), arranging health & social care (59%) and information about equipment (51%).

2.3.8. The types of information least chosen were about careers advice (31%), education & learning (23%) and about children's health (12%). We have already seen from earlier questions that nearly half of respondents say they are retired and a further 25% do not work for a variety of reasons. This would account for the low interest in careers advice. We also know that many Carers have very limited amounts of free time and this could account for the low interest in information about education and learning. Finally, we know from a previous Carers' Voice survey that only 8% of Carers' Voice panellists say that Children's Services provide the most services to the person they look after. This is a way of showing that very few panellists are parent carers and might explain why information about children's health received the lowest level if interest.

2.3.9. Respondents were also asked to provide other suggestions for types of information required. Comments made included information about benefits and other financial advice, about IT training and information about respite and other forms of break.

2.3.10. Next, Carers were asked how they prefer to access information. They were asked to choose the three most preferred options from a list or to make a further suggestion. The chart below shows this:

Q8 How do you generally prefer to access information?



Base = 469

2.3.11. This question showed that respondents prefer to receive information by face to face means, with 71% saying this. It was not made clear where this face to face contact takes place or with who. It is easy to see why this method is most popular – specific questions can asked and further detail requested, as and when the Carer chooses.

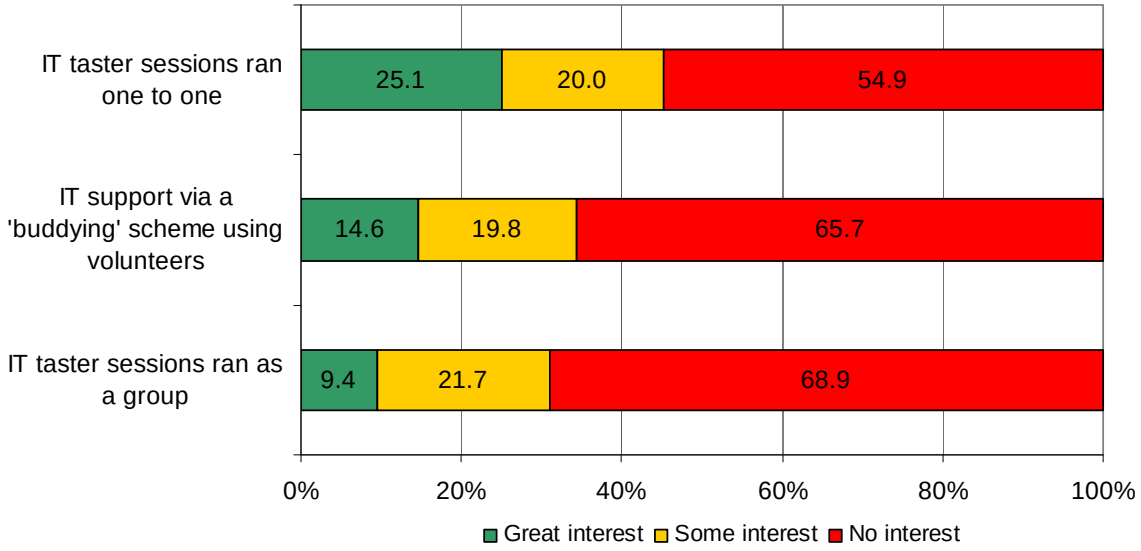
2.3.12. Next most popular was receiving information via leaflets, with 62.5% of respondents choosing this method. It is again easy to imagine Carers choosing to get information this way – leaflets can be read, understood and easily kept for future reference.

2.3.13. Of interest is that the third most popular way of getting information is via email and the internet, with over a third of respondents (37.5%) saying this. Looking at the age profile of the Carers' Voice panel and many of the comments received about IT literacy and internet usage, it would be very easy to assume that Carers won't want to use the internet or receive information, etc. electronically. This response shows that there is a significant proportion who would like to access information in this way.

2.3.14. Again, respondents were given the opportunity to add comments on other sources of information that they found useful. These comments included sources such as through groups and workshops, including through the Carers Support Agencies, through word-of-mouth, especially with other Carers and through the GP. One comment of note stated that information was not necessarily forthcoming and had to be asked for. All these comments are reproduced in Appendix F.

2.3.15. Wiltshire libraries provide free access to computers and the internet for all library members. In the next question, Carers were asked how much interest they thought a range of different IT training options might be to them. The chart below shows the levels of interest in each option:

Q9 The library provides free access to the internet and other online services. How much would the following be of interest to you?



Base = 370

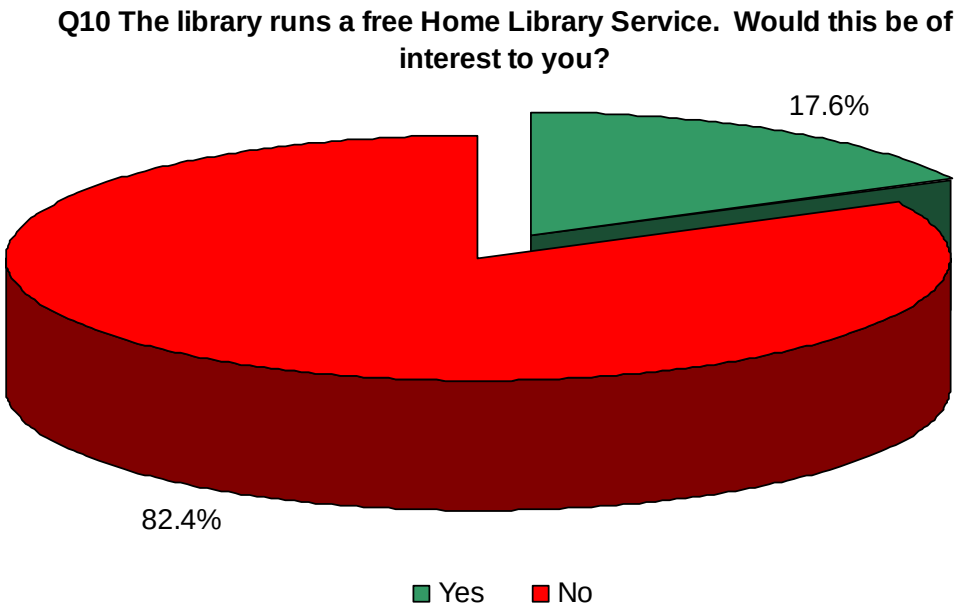
2.3.16. This shows that the form of IT training of most interest to respondents is to have taster sessions run on a one-to-one basis. A quarter of respondents said this would be of great interest to them and a further 20% said it would be of some interest.

2.3.17. The least popular form of IT training amongst respondents were sessions run as a group, with just 31% saying this would be of any interest (great interest + some interest) to them.

2.3.18. Given what we know about Carers and Carers' Voice panellists, they tend to be older and all have little free time. Choosing IT training run on a one-to-one basis might be seen by many Carers as the most effective way for them to learn about IT quickly and easily.

2.3.19. This question also had an "other" box where respondents could suggest other methods of training. There were in fact few suggestions about actual ways of being trained in IT, although one comment did suggest training in the learner's own home. Other comments suggested topics for training, such as use of the internet and how to access information, such as council services. Many comments stated that the respondent was already IT literate.

2.3.20. Wiltshire libraries run a free home library service for people who find leaving their homes difficult. Question 10 asked whether Carers would be interested in this service:

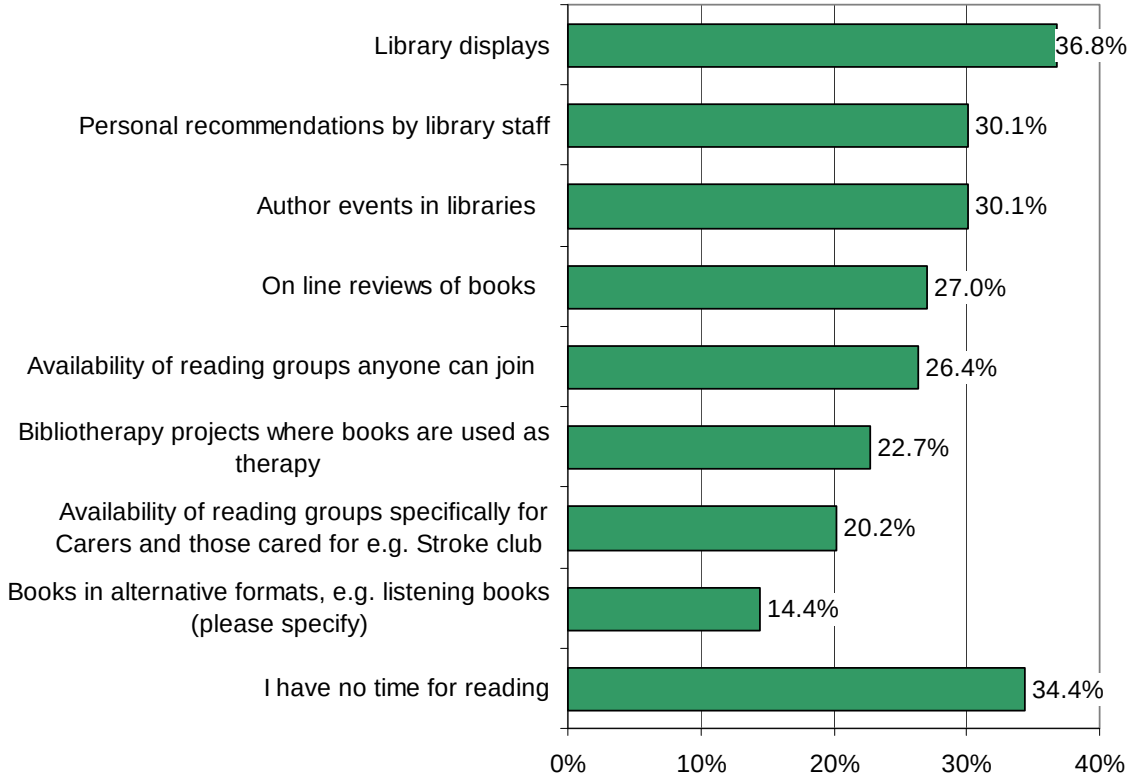


Base = 438

2.3.21. An overwhelming 82% of respondents said they would not be interested in this service. On the one hand this result is surprising: given that many Carers have little spare time, it would be easy to think that many Carers would be interested in the opportunity to receive the books they would like to read without having to actually go to the library. However, in discussion with the Steering group, it was mentioned that a visit to the local library is more than just a way to collect a new book. It is a chance for social contact and to receive further information whilst at the library plus the journey there could be a form of exercise and a way of getting out of the house for some fresh air. This is as true for the Carer as it is for the person cared for.

2.3.22. 2008 is the National Year of Reading. Question 11 asked Carers how the library could make reading more enjoyable. Respondents were asked to choose from a list of services and other things the library might be able to provide. The chart below shows these preferences:

Q11 How could the library help make reading more enjoyable for you?



Base = 326

2.3.23. The most commonly chosen activity was for there to be displays in libraries. Over a third of respondents (37%) said this would make reading more enjoyable. This was followed by personal recommendations of books from staff and author events (both 30%) and to be able to access on-line reviews of books (27%). All of these choices seem to show that respondents would like some direction in their choice of new books.

2.3.24. The suggestions of different types of reading groups were not particularly well supported. Reading some of the open comments that came with this question shows that many Carers do not have the time to attend these groups or that they would have difficulty in finding someone to look after the person they care for during these groups

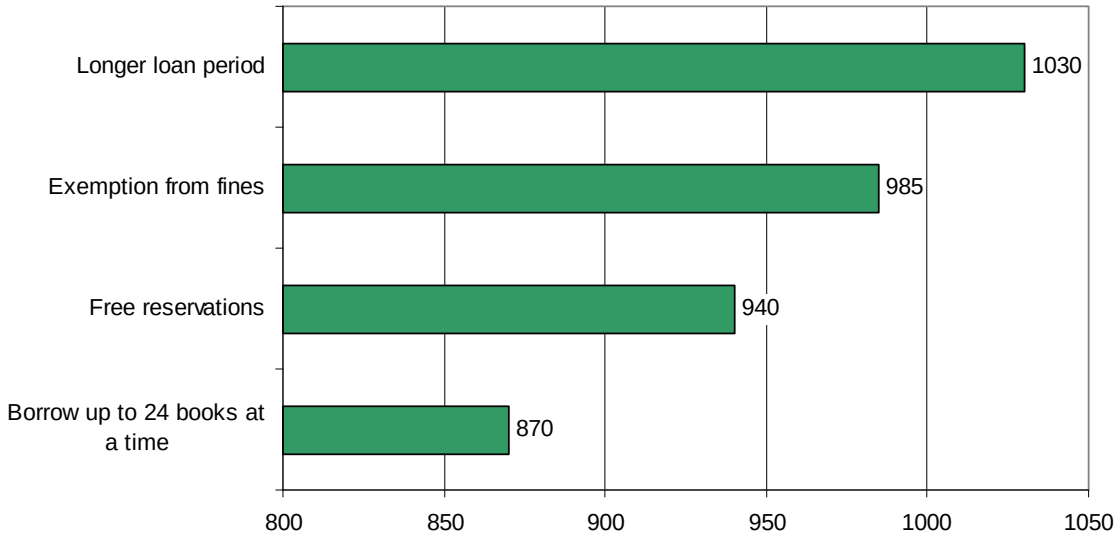
2.3.25. Of note is the figure that one third of respondents, 34.4%, said they do not have time for reading. This could follow on from the observation above about a lack of time due to the Caring role. Again, looking at some of the comments provided, many respondents back this up; others mention their own health and/or eyesight problems as being a reason for not reading. Interestingly, many respondents chose to use the open comments box as a way to describe how often they read and how much they enjoy it.

2.3.26. Suggestions for new services or activities given here included having a broader range of fiction books, more large print books, a drop-off and

collection service (although this service has already been offered above), longer opening hours, inc. evenings, having an on-line catalogue and ordering service plus not having to pay to order these books and better awareness of when books are in stock. All comments are reproduced in Appendix H.

2.3.27. The library service is considering making it easier for Carers to use the library. Question 12 asked respondents to state how helpful they thought a list of extra services might be. Respondents were asked to rate the services, where 1 is the most helpful service and 5 is the least helpful. In order to analyse these results, a score of 5 points has been given to the most helpful service where the respondent gave it a 1 and a score of 1 point given to the least helpful service where a respondent gave it a 5. These scores have then been added together to give a total score for each new service. The one with the greatest score can be seen as the most helpful or most popular:

Q12 Please rank the options below in terms of helping to use the library



Base = 279

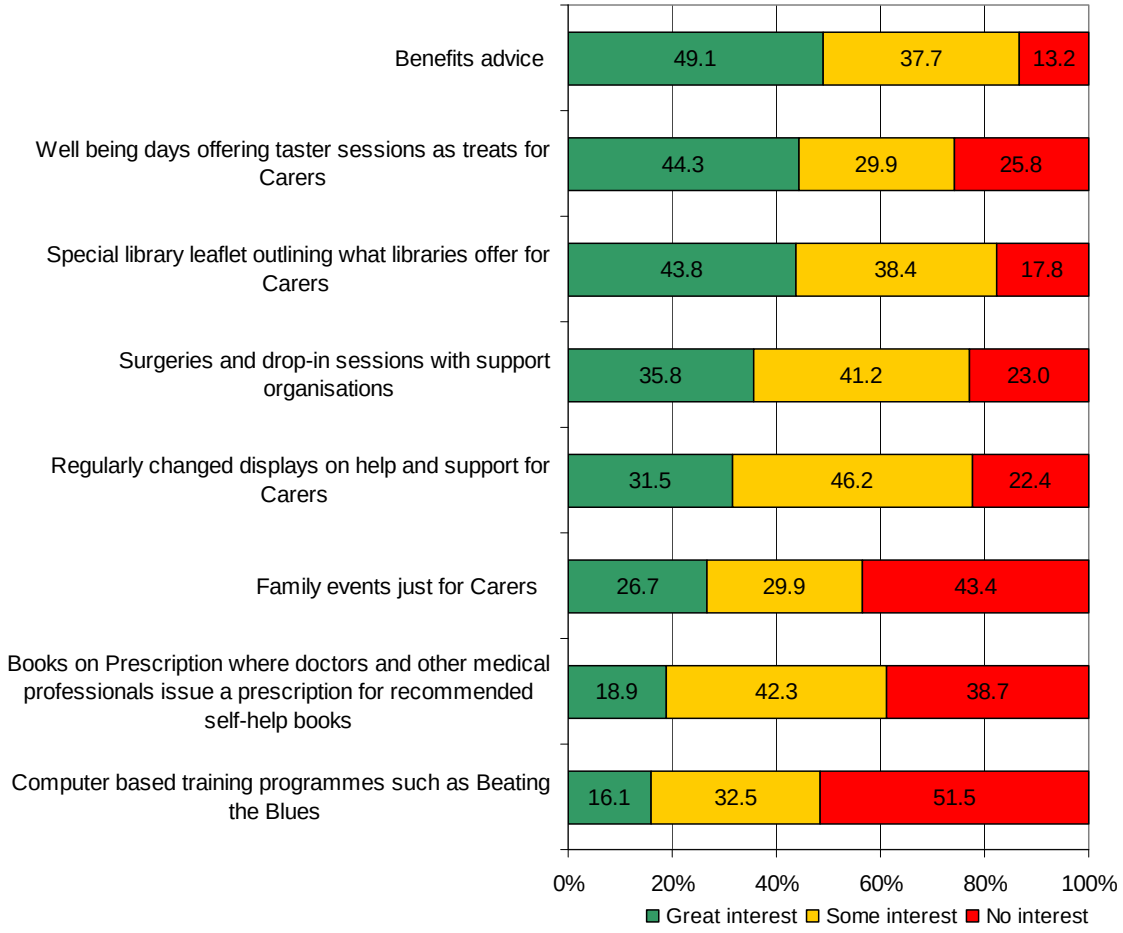
2.3.28. Analysing the results in this way shows that having longer loan periods would be the most helpful of these ideas to respondents. This is followed by being exempt from fines. These are the same sort of benefit. It shows that many respondents may not be able to read all of their books in the current three week loan period and do not want to be fined accordingly. The third option, of free reservations, also tallies with Carers' situations. It makes sense if busy Carers are able to choose the books they would like in advance, reserve them and collect them when they are able to without necessarily the need to browse and without having to pay for this.

2.3.29. This question also asked for open comments. Those received included having longer opening hours, being able to have other people to collect

reserved books, being able to reserve books on-line and being able to receive a 'phone call reminding that books are due back.

2.3.30. The final question in this section asked how much interest a range of services and events aimed specifically for Carers would be. The chart below shows this level of interest:

Q13 Libraries can offer or host additional services and events for of benefit for Carers. Would any of the following be of interest to you?



Base = 371

2.3.31. We can see that benefits advice was the most popular of these services offered: nearly half of respondents said this would be of great interest to them and a further 38% said this was of some interest to them. This tallies with what was said in Question 1 of this survey, where respondents said that "financial information and help in claiming benefits" was the second most helpful service from a different range of things. However, there was evidence from members of the Steering Group that when courses had been run in the past on this same topic, the take up from Carers had actually been low.

2.3.32. The service showing the next greatest level of interest was wellbeing days for Carers. The example used in the question mentioned reflexology. These were meant to be treats for Carers and a way to relax and take a break. Nearly three quarters (74%) of respondents said they were interested (Great interest + Some interest) in this service.

2.3.33. The service showing the least interest from respondents was taking part in computer-based courses that would help Carers in their role. Only 16% of respondents said this would be of great interest with a further 32% saying it would be of some interest. The description of the service used in the question might not have helped respondents know just what was on offer. It did not make clear that the courses on offer were not IT courses but kinds of "self-help" courses that used a computer to present the material. It might be that in future, different publicity and explanation around this type of course might lead to greater interest.

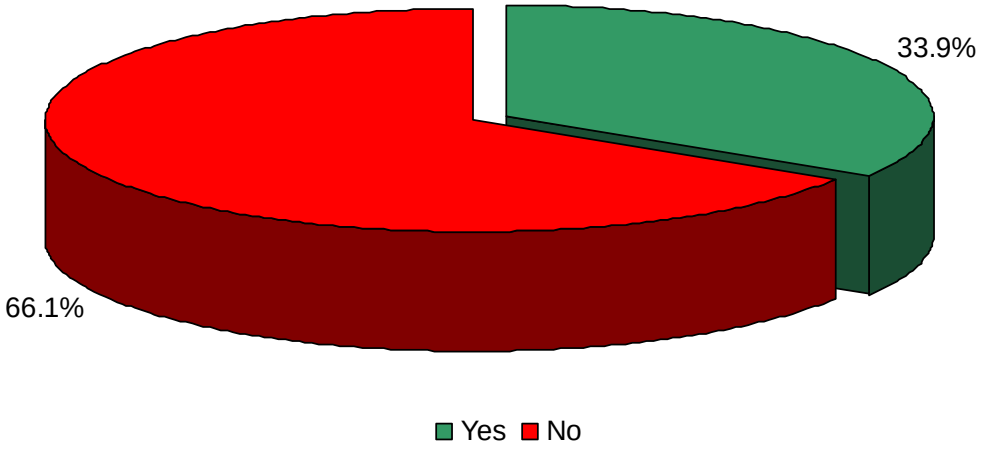
2.3.34. In the open comments box for this question, additional services suggested included offering services on a one-to-one basis depending on what they were, support sessions with dedicated library staff (although this could be with other, trained staff), better information about groups for Carers, Family days in the library and sessions with the funders of certain services. One respondent raised concerns about the level of privacy in the (small) local library. If discussing sensitive issues, such as benefits or personal finances, a high level of privacy and confidentiality would be important.

2.4. Carers' Assessments

2.4.1. The final section of the questionnaire looked at what Carers thought of having a Carer's Assessment. With a review of the Carer's Assessment process underway, the answers to these questions can help influence the future form of the Carer's Assessment.

2.4.2. Question 14 asked if respondents had had a Carer's Assessment within the last 12 months or a review of their current assessment. Just one third of respondents said they had:

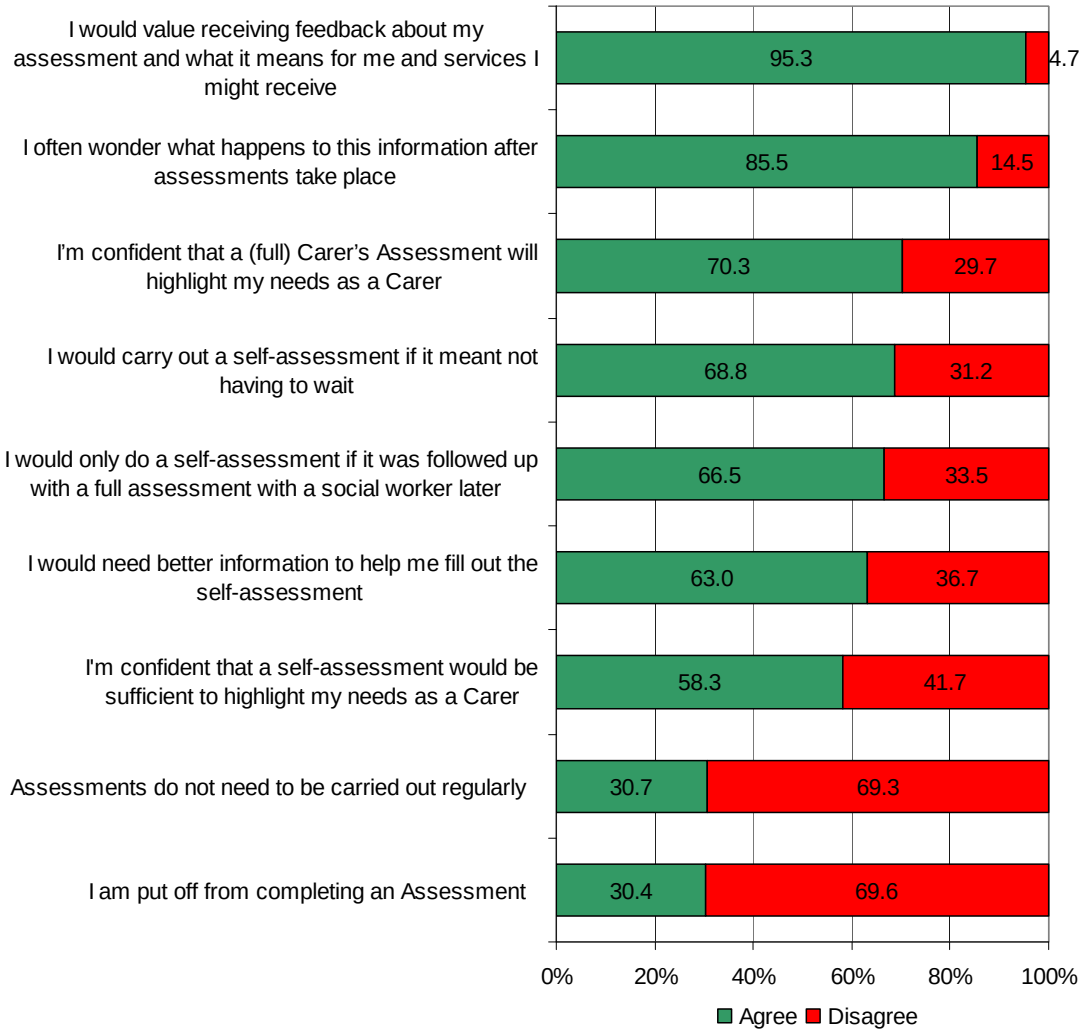
Q14 Have you had a Carer's Assessment and or a review of your Carer's Assessment in the last 12 months



Base = 443

2.4.3. Question 15 posed a number of statements about Carer's Assessments as asked respondents to agree or disagree with them:

Q15 Carers are able to carry out a self-assessment. Please tell us if you agree or disagree with the following statements about this process:



Base = 380

2.4.4. The statement that gets the highest level of agreement shows that respondents would value feedback from their Carer's Assessment and an explanation of what it then means in terms of the services they might receive. Discussion with the Steering Group shows there is a feeling amongst Carers that the information from their Assessment goes off into the ether and they are not informed of what this means for them. The strength of feeling shown by this result will hopefully go to alter this situation.

2.4.5. The statement with the second greatest level of agreement echoes that first. 85.5% of respondents agree that they "often wonder what happens the information after their assessment takes place". This again highlights there is a high level of confusion and misunderstanding about what the assessment is for and how it then helps the Carer.

2.4.6. Having mentioned that Carers are uncertain of what happens to the information after their assessment, 70% of respondents then agree that they are confident the Carer's Assessment will "highlight their needs as a Carer". As the only way of showing their situation to "social services" (Dept. for Community Services), Carers have to trust that their assessment gives them the services they need.

2.4.7. Nearly 70% of respondents (68.8%) agree that they would be happy to carry out a self-assessment if it meant avoiding waiting for an assessment with a social worker. This was then qualified with a similar proportion, 66.5%, saying they would only do a self-assessment if this was followed up later by a full assessment with the social worker at a later date. It is encouraging to know that many Carers would be prepared to do self-assessments in order to get on and be assessed.

2.4.8. Only 30% of respondents said that they were put off from completing a Carer's Assessment. This shows there is the belief that assessments are worth doing and can provide services to help the Carer. Respondent who replied they were put off doing an assessment were given the chance to say why. Some 90 comment were received back. These covered a few similar topics such as not liking filling out forms, not understanding them and needing help to fill them out, so not being confident they are answering properly and not having the time to complete them. Also several respondents said they were not aware of assessments. Several said they did not like asking for help or felt they could cope on their own anyway. Finally, some comments mentioned they felt that assessments would not reflect their status as a Carer properly, that they would not be able to claim certain benefits or services or that they were concerned they would miss out on some entitlements having had an assessment

2.4.9. The final question in the survey was an open question asking what Carers thought they would like out of an assessment. About 250 comments were received. Whilst covering many different points, the following is a summary of the main ones:

- Training for the Carer
- Understanding of the Carer's circumstances & viewing their situation as a whole
- One social/care worker who can coordinate between departments
- Support
- Social outings/occasions for the whole family
- Respite / breaks
- A list of available services; a straight forward care package; awareness of eligibility
- Assessment needs to be flexible and reviewed regularly to capture changes
- Action during a crisis
- Recognition of the Carers and their caring role
- How to get an assessment

- Proper equipment to carry out caring role
- Further information on a range of caring subjects

A complete list of the comments made at this question is included in Appendix L.

3. 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).

4. APPENDICES

4.1. Appendix A

Q1. Which of the following services, if they were to be introduced or extended, do you think you would find helpful? Other:

'ME TIME' TO DO SOMETHING FOR MYSELF + NOT WORRY OR FEEL GUILTY ABOUT DOING IT
ADVICE ON FINDING A CARE HOME
ADVISORY FOR CARERS NOT JUST THOSE CARED FOR.
ALL THSESE SERVICES NOW.
AS A FULL TIME CARER, I DON'T HAVE TIME FOR THE THINGS YOU PROPOSE
BEING "AT THE END OF THE PHONE" - WHEN THE WORRY AND ANXIETY IS OVERWHELMING. THE "TICKS" ABOVE FOLLOW THAT INITIAL REACHING OUT.
CARING FOR DEMENTIA PATIENTS IN PARTICULAR.
CONTACT WITH OTHER PARENT-CARERS
CREATION OF A CARERS REGISTER & NETWORK GROUP HOSTED BY COUNCIL OFFICERS WITH FUNDING TO AIM FOR 90%+ REGISTRATION.
DUE TO FINANCES CANNOT SET UP ON-LINE EQUIPMENT AT HOME. (USE LIBRARY WHEN NECESSARY). WOULD APPRECIATE A GRANT OR HELP TO SET UP AT HOME.
FREE TRAINING TO HELP GET BACK INTO WORK IF/WHEN YOUR ADULT CHILD GOES INTO SUPPORTED LIVING OR SIMILAR
GENERAL DISCUSSION
I AM A 1 YEAR OLD PENSIONER AND A LOT OF THIS DOES NOT AFFECT ME.
I AM CONSTANTLY STUDYING AS A RETIRED SENIOR ENGINEER IN TELEVISION ELECTRICAL ENGINEER ON RADIO TRANSMITTING. I INDULGE IN ALL BOOKS IN THIS, YOU SEE I STARTED MY CAREER IN THE 130S TRAINED BY FATHER, UNCLE BBC ENGINEER, THE EARLY DAYS OF CRYSTAL
I GET NO HELP IN ANY WAY
I HAVE ANSWERED DON'T KNOW A LOT BECAUSE I WAS UNAWARE OF THESE SERVICES.
I HAVE FOUND SPIRITUALITY IMMENSILY HELPFUL - HOW ABOUT OFFERING REIKI?
I HAVE NOT HAD ANY RESPITE IN THE PAST 18 MONTHS FULL TIME CARING SINCE I AM ONLY 88 I ASSUME I AM NOT OLD ENOUGH TO QUALIFY. I EMPLOY A GARDENER FOR 1 HOUR A WEEK AND 2 LADIES FOR A COUPLE OF HOURS FORTNIGHTLY TO DO A LIMITED CLEAN. I GET 2 HOURS*
I HAVE VERY LITTLE SOCIAL LIFE AS I AM SELDOM WITHOUT MY HUSBAND.
I HAVEN'T HAD ANY EXPERIENCE OF THESE SERVICES JUST GET ON WITH THINGS MYSELF. GP IS EXCELLENT.
I WAS CARING FOR A TEENAGER WITH A MENTAL HEALTH PROBLEM. MEDICAL CARE FOR HER WOULD HAVE BEEN USEFUL AS WOULD EDUCATION SERVICES AND A DAY CENTRE.
IN THE EARLIER STAGES OF ILLNESS EG PARKINSON'S IT WOULD HAVE BEEN HELPFUL FOR CARER TO HAVE 2HRS FREE EG CARED-FOR TAKEN FOR A DRIVE & CUP OF COFFEE IN CAFE. (EXPENSES PAID BY NCARER.)
INTRODUCTION OF HOBBIES FOR CARER THAT COULD BE SHARED WITH THE PERSON BEING CARED FOR.
INVITE TO COUNCIL AND SUPPORT ORGANISATIONS MEETINGS WHEN CARER SUBJECTS ARE TO BE DISCUSSED - DECIDED UPON.
JUST SUPPORT! PEOPLE COME - OFFER A FEW WORDS OF HELP - THEN PERMANENTLY DISAPPEAR. NOT MUCH IS ACHIEVED.
MORE INFORMATION & ADVICE FAR EASIER TO ACCESS. ONCE CARERS HAVE BEEN IDENTIFIED/REGISTERED/WHATEVER, THEY SHOULD HAVE AN INFORMATION PACK (NOT TOO BIG!) WITH ALL THE CONTACTS THEY NEED, THEN REGULAR BULLETINS. PERHAPS AN ANNUAL VISIT (BY APPOINTMEN*
MORE SUPPORT FOR CARERS/SUPPORTERS OF SPECIAL NEEDS PEOPLE WHO RARELY ASK FOR

HELP
MY HUSBAND NEEDS OVER BED HOISTS ETC, & SO FINDING RESPITE CARE HAS BEEN DIFFICULT - I NEEDED A BREAK TOO - LAST HOLIDAY NOV 2004. I'VE ALSO BEEN DIAGNOSED WITH BREAST CANCER.
MY MOTHER LIVES IN THE KENNET AREA BUT I LIVE IN SWINDON SO I HAVE FOUND HELP FOR MY MOTHER BUT NO SUPPORT FOR ME GENERALLY.
MY WIFE AND I ARE BOTH DISABLED. WE CARE FOR 1 YEAR OLD MOTHER.
NOT EVERYONE KNOWS WHAT AN E-MAIL OR WEBSITE IS
PLAY SCHEMES DURING HOLIDAYS
PLEASE FORGIVE THE DON'T KNOW COLUMNS TICKED. THIS IS BECAUSE I HAVE ONLY JUST BECOME AN OFFICIAL 'CARER'. I DID NOT KNOW OF THESE WONDERFUL PEOPLE WHO HELP, UNTIL I LITERALLY THREW MY HUSBAND INTO ADCROFT SURGERY, CRYING FOR HELP, WHICH THEN WENT I*
PRACTICAL HELP - DOMESTIC AND GARDENING
PRESENT TRANSPORT "SERVICES" TOTALLY INADEQUATE
PROVISION OF RESPITE CARE.
RE-INSTATE THE MONDAY AFTERNOON MEETING FOR MENTAL HEALTH CARERS
RECOGNITION OF MY ROLE-CAMPAIGN FOR INCREASED NI STAMP & BETTER PAYMENTS I COULDN'T PAY SOMEONE THE AMOUNT I RECEIVE & EXPECT THEM TO GIVE THE 24/7 CARE I GIVE.
SOME CARER'S SOCIAL EVENTS ARE IN THE EVENING. I WOULD HAVE TO PAY SOMEONE TO SIT WITH MY HUSBAND SO I COULD GO OUT.
SOMEONE TO RECOGNISE CARERS ALSO NEED TO BE CARED FOR
SUPPORT AT POINT OF DIAGNOSIS - OFTEN CARERS JUST LEFT TO GET ON + FIND OUT EVERYTHING THEMSELVES
THE LOCAL CARERS GROUP PROVIDE EXCELLENT SUPPORT - WITHOUT THEM I WOULD HAVE GIVEN UP BY NOW.
TLC & FUN VITAL
TO DATE, MANAGE WITHOUT HELP FROM OTHERS
TRAINING FOR STAFF SO THEY CAN SPECIALIZE EG. S.E.N.
UNDERSTANDING 'WHO DOES WAHT' IN HEALTH/SOCIAL SERVICES
VITAL ROLE OF TLC
WE ARE NOT VERY ACTIVE AND MANAGE REASONABLY WELL, HELPED BY A SON.
WE CURRENTLY HAVING PROBLEMS WITH NEIGHBOURHOOD NOISE YET NOONE PREPARED TO HELP WITH ANY PRACTICAL SUGGESTIONS.
WITHOUT DOUBT, THE MOST USEFUL SUPPORT WOULD BE CARER BREAKS AND RESPITE CARE AND ANYTHING FINANCIAL OR PRACTICAL THAT WOULD ENABLE THESE.

4.2. Appendix B

Q2. Please select one of the following options below that describes your current work situation: Other.

'SELF - UNDER-EMPLOYED'
AGED 82 YEARS - DISABLED AND MY TIME IS DEVOTED TO FULL TIME CARING
ALTHOUGH WORK DEFINED/I CONTRIBUTE TO SEVERAL CHARITIES MANAGEMENT.
BEEN A HOUSEWIFE FOR 22 YEARS.
BEFORE I RETIRED I STARTED CHARITY WORK THIS I FIND IS TIME CONSUMING BUT IT EASES MY STRESS
BUT AN UNPAID VOLUNTEER WITH 2 ORGANISATIONS
CAN'T WORK, AS DISABLED MYSELF.

CANNOT WORK MORE BECAUSE OF LACK OF CHILDCARE.
CASUAL WORK. INVIGILATING & VOLUNTARY WORK CAB + 2 OTHER GROUP MEMBER WVCP & WWRU
CHARITY SHOP 2 MORNINGS
COULDN'T WORK BECAUSE DON'T HAVE THE TIME IN TOTAL CARING.
CURRENTLY VOLUNTEER
DISABLED CARER
DO VOLUNTARY DRIVING AND CARE FOR SOMEONE (NOT RELATIVES) FOR 4HRS A WEEK. NEED FLEXIBLE WORK.
DUE TO ILL-HEALTH
ELDERLY DISABLED MOTHER NOW MOVE INTO WARDEN CONTROLLED PLACE
FULL TIME CARER
FULL TIME DEGREE COURSE STARTING SEPT '08 - LA SECONDMENT
FULL TIME STUDENT
FULL-TIME STUDENT
I DO SOME VOLUNTARY WORK
I HAD MY ELDERLY MOTHER & MY HUSBAND TO LOOK AFTER.
I HAVE M.E.
I WAS APPROACHING RETIREMENT ANYWAY, BUT LEFT WORK BECAUSE OF MY CARING ROLE
I WAS THE SINGLE CARER FOR 2 FAMILY MEMBERS FOR 16 YEARS (ONLY 1 NOW)
I'M NOT THAT WELL OFF. I RECEIVE 88 POUNDS A WEEK TO LIVE ON WITH RENT PAID
ITS VERY FLIXIBLE WITH A GREAT BOSS WHO UNDERSTANDS THE IMPORTANCE OF MY CARERS ROLE.
LEFT WORK TO HAVE CHILDREN '4 HAVE NOT GONE BACK BECAUSE OF CARING ROLE.
MY DAUGHTER'S HEALTH WAS A FACTOR IN RETIRING EARLY.
MY WIFE DIED, PEACEFULLY AT HOME, IN FEB 2008.
NO CHANGE
NO CHANGE.
NO LONGER HIS CARER AS WE ARE DIVORCED
NOT IN WORK CURRENTLY, BUT IN THE PROCESS OF LOOKING FOR EMPLOYMENT
NOT WALKING
OAP
ON CAREER BREAK (2 YEARS) TO SUPPORT SON
PART TIME IN RESIDENTIAL HOME, ALSO SELF EMPLOYED WORK AT HOME
PREVIOUSLY AN ARTIST WORKING AT HOME, NOW VERY LITTLE TIME.
RETIRED AND STILL RETIRED
RETIRED IN 18
RETIRED.
RUNNINGS MY MOTHER'S HOME AS WELL AS MY OWN AND MY FAMILY.
SELF EMPLOYED

SELF EMPLOYED FAMILY PARTNER (WIFE) AND RUN B&B.
SELF-EMPLOYED
STUDYING
UNABLE TO WORK DUE TO CARERS RESPONSIBILITIES
VERY PART TIME & CASUAL
VOLUNTARY - SUE RYDER
VOLUNTARY WORK PART-TIME.
VOLUNTARY WORK.
WAS BEING MADE REDUNDANT TOOK JOB LESS HOURS AND PAY/GRADE
WORK AS VOLUNTEER
WORK VOLUNTARILY
WOULD LIKE FINANCIAL HELP TO RETRAIN - CARERS ALLOWANCE DOESN'T COUNT FOR REDUCED FEES AT COLLEGES.

4.3. Appendix C

Q3. Please tell us the impact that your financial situation has had on your caring role. Please tell us more:

24HR CARER, VERY TIRING, STRESSFUL + TIME CONSUMING
7
ABOUT THE SAME AS BEFORE.
AFFECTED MY ABILITY TO SAVE AT A CRUCIAL TIME IN MY LIFE AFTER MY CHILDREN BECAME SELF SUFFICIENT.
AM DISABLED MYSELF BUT STILL LOOK AFTER MY HUSBAND WITH DEMENTURE.
AS A PENSIONER WITH A TEACHERS PENSION IT HAS NOT AFFECTED ME.
AS I AM RETIRED I FALL IN BETWEEN
AS I HAVE 2 CHILDREN AT HOME THE WHOLE FAMILY IS ADVERSELY AFFECTED
AS WE ARE BOTH RETIREMENT AGE WE ARE NEITHER
BECAUSE OF POOR HEALTH MYSELF, MOST THINGS ARE RESTRICTED.
BENEFITS + PENSION DO NOT COME TO SAME AS PAID EMPLOYMENT
BOTH HUSBAND & MYSELF HAVE MENTAL HEALTH PROBLEMS PLUS I HAVE SOME PHYSICAL PROBLEMS.
BROKEN THREE VERTEBRAE'S IN SPINE.
CAN ONLY DO THINGS THAT CAN BE DONE BY WIFE IN WHEELCHAIR
CANNOT GET RESPITE BECAUSE SELF FUNDING
CARING HAS LIMITED WORK/CAREER CHOICES
CONCERNED ABOUT FUTURE FINANCIAL SITUATION
CONSTANT * WITH A DAUGHTER-IN-LAW HAS CAUSED GREAT DISTRESS

CONSTANT BATTLE WITH FINANCIAL SITUATION. HUSBAND HAS NO REAL CONCEPT OF MONEY/SAVING ETC.
CONSTANT WORRY ABOUT FINANCE HAS MADE ME MORE STRESSED, IRRITABLE, AFFECTING MY DIGESTION, SLEEP, ARTHRITUS. NOT ONLY IS MY INCOME GREATLY REDUCED, BUT GOINGS ARE GREATLY INCREASED AS WE CAN'T DO D.I.Y. JOBS ANYMORE OR THE GARDEN.
CONSTANT WORRY RE MY ELDERLY PARENTS
CONSTANTLY BEING 24 HRS CAREERING!
COPING OR AT PRESENT.
COST OF KEEPING HUSBAND WARM INCREASED AS HAS THE COST KEEPING MECH. AIDS CHARGED UP
DEPRESSION AND MIGRAINE
DEPRESSION, BLOOD PRESSURE
ECZEMA, ALWAYS TIRED.
EVERYTHING IS AFFECTED BY CARING, CARING COMES FIRST BEFORE GOING OUT, HOLIDAYS (WHATEVER THEY ARE) EVEN DR'S APPOINTMENTS FOR MYSELF!
FINANCE WAS NOT AN ISSUE, EXCEPT THAT IF WE HAD BEEN ABLE TO PAY FOR TREATMENT WE MIGHT HAVE GOT WHAT WE NEEDED.
FINANCIALLY NO WORSE OFF JUST THE EXTREME DIFFICULTY OF GETTING AROUND AND ABOUT WITH MOBILITY SCOOTER.
FINANCIALLY WOULD BE BETTER OFF CLAIMING BENEFITS BUT DO NOT WANT TO.
FOR 8 YEARS I NURSED MY WIFE, I BECAME ILL. SHE IS NOW IN A NURSING HOME AND NOW I HAVE FOUND A LIVE IN CARER FOR MYSELF.
HAS NOT AFFECTED ME IN ANY WAY
HAS NOT HELPED MY OWN DISABILITIES
HASN'T AFFECTED IT AS WASN'T WORKING BEFORE CARING ROLE BEGAN
HAVE TO WEIGH UP COST OF EVERYTHING IN MONEY AS OPPOSED TO WHOLE PICTURE
HEALTH HAS DETERIORATED, SPELL IN HOSPITAL
HOSPITAL RUNS / PARKING COSTS A LOT OF MONEY, STRESS + WORRY AFFECTS MY HEALTH
HUSBAND & I ARE BOTH 'PENSIONERS' STUCK AT HOME.
HUSBAND CANNOT HAVE POEPLE IN, AS HE FEELS THEY DO NOT UNDERSTAND US.
HUSBAND MADE REDUNDANT - I CANNOT WORK
I AM CARING MYSELF AND JUST GET BY ON MY PENSION
I AM CURRENTLY GOING BANKRUPT.
I AM HAPPY TO BE A CARER AND FIND IT FULFILLING
I AM HAVING TO USE UP MY CAPITAL & CAN NO LONGER SAVE.
I AM NOW ALSO DISABLED
I AM NOW UNABLE TO WALK FAR.
I AM TRAPPED
I AS A MUM/CARER TOO HAVE HEALTH PROBS

I CARE FOR MY SONE 24/7
I DO NOT HAVE A PROBLEM HERE.
I DO NOT MIND. HE IS MY HUSBAND AND I LOVE HIM
I DON'T FIND OUR FINANCIAL SIUTATION HAS INFLUENCED THESE EITHER WAY.
I DON'T HAVE ANYTHING SPECIFIC TO ANSWER ON THIS QUESTION.
I DON'T HAVE THAT MUCH TIME BUT I LOVE CARING FOR MY MUM
I HAD TO RETIRE AT 50 TO CARE FOR MY HUSBAND & DAUGHTER WITH MANIC DEPRESSION.
I HAVE HEART TROUBLE, HAVE BEEN IN HOSPITAL TIWCE RECENTLY.
I HAVE LOST MY RESTBITE DUE TO DEATH OF GRAN
I HAVE MORE TIME TO EXERCISE BUT LESS SOCIAL INTERACTION
I HAVE NOW BEEN DIAGNOSED WITH ANGINA
I HAVE NOW DEVELOPED ANGINA
I HAVE OSTEOARTHRITIS
I HAVE TAKEN ON THE CARE OF MY DECEASED DAUGHTERS SON AT 6 YEARS OLD.
I INCUR A LOT OF EXPENSIVE LOSSES DUE TO VIOLENCE ETC. AND EVEN THOUGH DLA IS GIVEN THERE NEVER SEEMS TO BE ENOUGH FOR LUXURIES
I MANAGE ONE EVENING ON MY OWN PER 2 MONTHS
I NO LONGER GO OUT TO SOCIAL FUNCTIONS.
I NO LONGER GO OUT TO SPEND MONEY THEREFORE BANK BALANCE INCREASES ALL THE TIME
I WOULD SAY A BIT OF BOTH, IT'S DIFFICULT TO ANSWER
I'M ON 300MG A DAY ANTIDEPRESSANT
I'VE HAD ONE OR TWO PROBLEMS WHICH COULD BE DUE TO STRESS.
IBS THROUGH STRESS, NO CARERS ALLOWANCE (DIDN'T QUALIFY!) TOO LATE NOW!
IN AN I.V.A. SITUATION
IN WORK I GOT TWICE THE INCOME, OPPORTUNITY TO USE SPARKS FACILITIES AND FRIENDS AT WORK.
INSURANCE PAYMENT MEANS I CAN TAKE RESPITE BREAKS REGULARLY.
IT HAS AFFECTED OUR FINANCIAL SIUTATION
IT HAS GIVEN ME HIGH BLOOD PRESSURE
IT HAS GREATLY ADDED TO MY STRESS LEVELS - OCCASIONALLY I HAVE HAD TO REFUSE B&B BOOKINGS TO MEET MY CARERS ROLE.
IT IMPACTS ON EVERYTHING.
IT IS VERY HARD AND A GREAT WORRY AT TIMES; WHEN YOU HAVE P OF A
JUST FELT WORN OUT FOR A FEW YEARS
LACK OF FINANCE AFFECTS EVERY ASPECT OF LIFE.
LIFTING GETS MORE DIFFICULT DAILY
LOSS OF INDEPENDENCE THE GREATEST FACTOR.
LOST MOST OF MY FRIENDS, DO NOT SEE MUCH OF MY FAMILY, HAVE BEEN IN HOSPITAL WITH ULCER. HAVE HAD TO SELL HOUSE TO MOVE SMALLER + INDEPENDENT NOW HAVE TO SELL

SMALLER HOUSE
MAINLY LACK OF SLEEP!
MONEY WORRIES AFFECT MY MENTAL HEALTH
MORE TIRED OTHERWISE NO CHANGE.
MY FINANCIAL SITUATION HAS BEEN UNAFFECTED.
MY FINANCIAL SITUATION IS 'BETTER' THAN BEFORE
MY FINANCIAL SITUATION IS FINE
MY HAIR HAS BEEN THINNING, I DON'T SLEEP WELL AND DON'T RELAX WELL.
MY HEALTH HAS BEEN WORSENED BY A CARING ROLE (BUT THIS IS A SEPERATE ISSUE FROM MY FINANCIAL SITUATION).
MY HEALTH IS BETTER NOW THAT I AM NOT HAVING TO TRY TO WORK AND CARE AT THE SAME TIME
MY HUSBAND HAD TO RETURN WITH ILL-HEALTH (POLIO FOR 80 YEARS) AND MY DAUGHTER IS BI-POLAR FOR 27 YEARS, I HAVE PARKINSONS & A RECENT DIAGNOSIS OF BREAST CANCER AND I AM TIRED.
MY HUSBAND IS A DOUBLE AMPUTEE WITH ABHASIA. EVERYTHING HAS TO BE ARRANGED AROUND HIM, NOTHING CAN BE DONE ON THE SPUR OF THE MOMENT.
MY HUSBAND IS IN CARE, WINGFIELD - SO MORE FREE TIME
MY HUSBAND IS NOW ILL AND I HAVE TO COPE.
MY HUSBANDS MS DETERIORATION HAS CAUSED ME TO HAVE REACTIVE DEPRESSION
MY LIFE IS IN TWO PLACES. WORK AND HOME.
MY SON IS BECOMING MENTALLY + FINANCIALLY BETTER AT THE MOMENT
MY SON IS IN SUPPORTED LIVING BUT I WILL NEVER AHIEVE A MUCH BETTER FINANCIAL SITUATION
MY WIFE HAS OXYGEN 24 HRS MAKING TRAVELLING DIFFICULT AT TIMES
N/A
NEITHER FOR ALL ABOVE.
NO 'FINANCIAL' RECOGNITION OF MY EXTENSIVE CARING ROLE
NO CHANGE
NO CHANGE IN LIFESTYLE.
NO CHANGE.
NO EFFECT
NO FREEDOM - OFTEN WORRY WHEN OUT FOR THE DAY - ONLY TAKE SHORT HOLIDAYS - UNABLE ALWAYS TO GO WITH MY FRIEND.
NO INFORMATION AT ALL ON THE PROBLEM IN WHICH I AM TRYING TO COPE WITH HAVE BEEN LEFT ON MY OWN'ER.
NO PROBLEM.
NO SOCIAL LIFE - NO HOLIDAY SINCE AUG 2006
NO-ONE TO LOOK AFTER ME WHEN ILL, NO TIME TO SEEK MEDICAL ADVICE.
NONE
NOT AFFECTED US FINANCIALLY
NOT ENOUGH FINANCIAL HELP FOR CARERS' LOOKING AFTER PEOPLE WITH SEVERE DISABLITIES

AND WE ARE FORCED TO WORK.
NOT ENOUGH MONEY FOR FULL-TIME CARERS.
NOT ENOUGH MONEY, HEALTH ISSUES DUE TO HITTING ETC.
NOT MUCH DIFFERENT.
NOT REALLY FINANCIAL. THE WORRY/STRESS AFFECTED ALL 3 ITEMS.
NOT SO MUCH FINANCIAL BUT TIED AT HOME
NOT SURE!
NOW SUFFER DEPRESSION ANXIETY
ON MEDICATION FOR DEPRESSION. ALSO REGULAR BACK PAIN, POOR SLEEP ETC.
RESTRICTIONS ON MY ART GROUP MEETS/WORKSHOPS AND BOWLING.
ROUTINE FOR PATIENT CAN GET MONOTONOUS
SAME.
STAYED THE SAME.
STRESS & HAVE SUFFERED A STROKE MYSELF
STRESS + DEPRESSION CAUSED BY THE CHANGES THAT HAD TO BE MADE
STRESS, DEPRESSION, NO PARITY WITH USER GROUP EXPENSES.
STRESS, DEPRESSION, SLEEP APNEA
STRESS; TENSION; WORRYING ABOUT MONEY
STRESSED ALL THE TIME. NO TIME TO MYSELF, ALWAYS ON EDGE FOR CAREE.
SYSTEMIC LUPUS IS AN UNPREDICTABLE ILLNESS AND PLANNING ANYTHING IS DIFFICULT
TAKES ENERGY I DO NOT HAVE
TAKING AGENCIES TO COURT. PAYING INDUSTRIUL SPECIALIST AS STATUTORY REFUSE TO ASSESS
THE COST OF PAYING FOR CARE COMES FIRST BEFORE ANYTHING ELSE.
THE EXPENSE OF SS PAYMENTS AND TAXI USE HURTS US FINANCIALLY
THE STRESS HAS AFFECTED MY HEALTH. ONLY FOOD SHOPPING, NO PLEASURE TRIPS. ONE WEEK OFF A YEAR.
THINGS ARE MUCH BETTER SINCE FATHER MOVED TO HIS OWN ACCOMODATION AGAIN.
THOUGHT I WAS OK BUT HAVE BEEN TO I HAVE HIGH BLOOD PRESSURE DUE TO STRESS. I HAVE ALSO DONE A K TEST FOOD INTOLERANCE TEST AND THAT COMES UP WITH STRESS WHICH MAY AFFECT BODY FUNCTION ESPECIALLY RISK OF GALL STONES.
TRIPS LIMITED BY OUR DISABILITY, NOT FINANCIAL SITUATION
UNABLE TO GO OUT SO GETTING DEPRESSED.
UNABLE TO SECURE FULL TIME EMPLOYMENT WHICH IMPACTS ON FINANCES YET NOT ABLE TO CLAIM CARERS ALLOWANCE
VERY STRESSFUL.
WAS BEING MADE REDUNDANT TOOK JOB AT LOWER GRADE AND LOWER RATE OF PAY, LOWER HOURS - WORSE OFF
WAS FULL-TIME, NOW CARING NEED TO BE PART-TIME
WE MANAGE WITH WHAT WE HAVE

WHEN I WAS CARING AT HOME IT CAUSED ME STRESS, DEBT AND MADE ME ILL
WHEN MY HUSBAND BECAME DISABLED BY HIS PARKINSON'S DISEASE WE MADE THE DECISION TO CONCENTRATE ON OUR HOBBY/LEISURE ACTIVITY, WHICH IS SINGING AND TRAVELLING UP AND DOWN THE COUNTRY TO MUSIC EVENTS, WHILE HE WAS STILL ABLE TO DO SO. THIS HAS NECESSI*
WHILST I WELCOME THE OPPORTUNITY TO SPEND TIME WITH MY SON, IT HAS AFFECTED MY RELATIONSHIP WITH MY DAUGHTERS.
WIFE NOW IN SELF-FUNDING NURSING HOME
YOU NEED AN EXTRA BOX HERE FOR TRUTHFUL ANSWERS.

4.4. Appendix D

Q4. Please explain the arrangements you have in place to look after the person you care for whilst you are out. Other:

1 1
A SCOOTER REALLY HELPS MY HUSBAND GET OUT.
AT 86 I AM A FULLTIME CARER FOR MY 84 HUSBAND WHO IS DIABLED - NO HELP OFFERED
AT THIS TIME WE MANAGE BETWEEN US
BUT I HAVE TO BE ABLE TO ATTEND TO MY SON AS SCHOOL, DECLARE IT NECASSARILY. AT TIMES, IT SEEMS THEY ARE UNWILLING TO HELP HIM BECOME MORE INDEPENDENT.
CAN'T GO OUT TO WORK.
DAUGHTERS TAKE OVER.
DEPENDENT ON IMMEDIATE FAMILY TO PROVIDE SUPPORT - SIBLINGS
DO NOT WORK
DO NOT WORK, WELL PAST RETIRING AGE
DO NOT WORK.
FULL TIME CARER
GAVE UP WORK
HAVE OTHER CARERS AVAIABLE WHEN NEEDED
I AM NOT IN EMPLOYMENT - ABOVE DOES NOT APPLY
I AM ON THE END OF A PHONE, ONLY TROUBLE IS THE OPENING OF THE FRONT DOOR. I CANT AFFORD AN ELECTRICAL DOOR RELEASE OR VIEWER TO LET A CARER IN.
I AM PARENT CARER MY SON GOES TO COLLEGE.
I AM RETIRED AND LOOK AFTER MY HUSBAND TOTALLY, HE DOES NOT WANT PEOPLE IN.
I DID START TO USE LEONARD CHESHIRE AS A SITTING SERVICE BUT YOU HAVE NOW CHANGED THE SYSTEM REF 1/10/2008 AND I AM NOT SURE WHAT TO DO NOW.
I DO NOT WORK
I DON'T LIVE WITH MY MOTHER BUT 8 MILES AWAY IN SWINDON.
I GO SHOOTING AND HOPE FOR THE BEST BY THE TIME I RETURN
I HAVE TWO CHILDREN THAT HELP WHEN THEY ARE IN FROM WORK.
I KEEP IN TOUCH BY MOBILE PHONE
I LOOK AFTER MY HUSBAND 24 HRS A DAY 7 DAYS A WEEK
I ONLY WORK 'FROM HOME' GIVEN UP WORK REQUIRING TRAVEL
I TICKED 2X BOXES AS I'M THE MAIN CARER BUT SHE HAS A FRIEND WHO WILL POP IN AND GET BREAKFAST AND THEN SHE COPES.
I USE DIRECT PAYMENTS

I WORK AT HOME.
I WORK FROM HOME FOR 3/4 OF WORKING TIME
IF I AM OUT MY SONS RING AND I RING LOTS OF TIMES TO MAKE SURE EVERYTHING IS OK, I WOULD ONLY BE OUT FOR A SHORT TIME.
IF I HAVE A MORNING OUT WITH A FRIEND - HE CAN MANAGE
MOBILE PHONE AND LIFE LINE. I AM ONLY 1 MILE AWAY
MY DAUGHTER NOW LIVES IN A RESIDENTIAL HOME AND COMES HOME EVERY 3RD WEEKEND
MY HUSBAND IS NOW IN A NURSING HOME.
MY MOTHER IS STILL IN HER OWN HOME AND CAN STILL MANAGE AT NIGHT ON HER OWN - PAID CARERS AND DAY FACILITIES KEEP HER GOING DURING THE DAY.
MY SON ATTENDS PRIVATE A.S.D. SCHOOL
MY WIFE COPES WITH O.C.D. AT HOME AS IT IS HER 'SAFE PLACE'.
MY WIFE DOES NOT GO OUT OF HOUSE WHEN I AM NOT THERE AS SHE HAS OCD + PANIC ATTACKS + BIPOLAR DEPRESSION
MY WIFE WORKS FULL TIME AND HAS HOME CARE, ACCESS TO WORK FOR PA SUPPORT.
N/A
NEIGHBOURS HAVE OFFERED, BUT MY HUSBAND SAYS HE'LL MANAGE. VERY INDEPENDENT.
NO APPLICABLE
NO HELP OR SUPPORT FROM ANYONE.
NO LONGER A CARER AT HOME, DO THIS AS A FULL TIME JOB AND HAVE DONE FOR 25 YEARS
NO LONGER WORKING DECIDED TO RETIRE
NOT APPLICABLE
NOT IN WORK
NOT RELEVANT.
OAP
OTHERWISE MY PARTNER TAKES OVER OR I USE PAID CARE (ILLNESS, SCHOOL HOLIDAYS ETC).
OUR SON IS IN FULL TIME BOARDING COLLEGE TERM TIME
PAID CHILDCARE.
PAID WORKERS COME IN WHILE I AM NOT THERE.
REGISTERED CHILD CARE 3 MORNINGS.
RETIRED
RETIRED DAUGHTER HELPS TWO DAYS PER WEEK
RETIRED FROM WORK BUT HAVE PAID WORKER IN IF I GO OUT.
RETIRED.
SHOWER 3 TIMES PER WEEK
SITTING SERVICE
SON AND DAUGHTER IN LAW DONT LIVE FAR FROM US / POP AROUND FREQUENTLY TO SEE IF WE'RE OK
SON IS SUPPORTED LIVING OUT OF COUNTY - COMES HOME OFTEN - WE WORK ROUND MY HUSBAND'S SHIFTS
THERE IS NO ONE ELSE BUT ME.
TRY NOT TO WORK DURING SCHOOL HOLIDAYS.
UNABLE TO WORK DUE TO CARING ROLE AND OWN HEALTH
VERY DIFFICULT TO FIND SITTERS!
VOLUNTARY WORK, P/T
WE ARE BOTH RETIRED
WE WORK TOGETHER - SELF-EMPLOYED FROM HOME
WISH I COULD WORK, NO JOBS SUIT.

WORK AT HOME.

4.5. Appendix E

Q7. What information would you find useful? Other:

ABOUT THE FUNDING FOR THIS AREA & HOW MANY CARERS RECEIVE SERVICES DIRECTLY.
ACTIVITIES THE LESS MOBILE
ADULT EDUCATION FOR MY SON
ALL ADULTS
ALL CHILDREN GROWN UP + MARRIED
AS A CARER YOU TEND TO FEEL YOU ARE A STATISTIC AND FEEL UTTERLY ISOLATED
BADMINTON
BENEFITS
BENEFITS AND RETRAINING FOR WORK.
CLUBS ETC FOR WHEELCHAIR USERS, NONE IN MY AREA
DIDN'T KNOW THE LIBRARY HAD ALL THIS INFORMATION
FOR THE DISABLED PERSON SERVICES FOR WHOLE FAMILIES OF CARERS
FOR THE ELDERLY AND THEIR CARERS, ENTITLEMENT TO BENEFITS/SUPPORT.
FRENCH CONVERSATION, CLASSICAL MUSIC.
GATEWAY, LITTLE JOBS WITH MONEY
GP REFERRAL TO OUR GYM HAS BEEN A GODSEND.
GYMS ETC FOR LOSING WEIGHT
HAVE TICKED ALL - IF YOU DON'T HAVE ACCESS TO INTERNET - LIBRARY IS BEST
HELP WITH REDUCTION SPORTS CENTRE/SWIMMING.
HOLIDAY BREAKS FOR DISABLED
HOLIDAY'S FOR SEVERELY DISABLED
HOSPICE + DAY CARE FACILITIES
HOW TO GET FUNDING
HOW TO GET HELP WITH EDUCATION
I COULD ONLY VISIT A LIBRARY WHILE SOMEONE WAS WITH MY HUSBAND.
I DON'T USE LIBRARIES
I HAVE BEEN ASKED TO CONTACT "SOCIAL INCLUSION" BUT HAVE NEVER HEARD OF IT UNTIL NOW.
I ONLY USE THE MOBILE LIBRARY, WHICH HAS LIMITED SPACE.
I THINK THIS INFORMATION IS BEST DELIVERED ON A ONE TO ONE BASIS OR IN A SMALL GROUP WHERE QUESTIONS CAN BE ASKED.
I WOULD LIKE TO LEARN TO USE A COMPUTOR.
INFO RE RESPITE OPTIONS/AVAILABILITY.
INFORMATION REGARDING FINANCIAL HELP TOWARDS EQUIPMENT/HOLIDAYS
INTERESTED IN ART LESSONS + WRITING
KEEP FIT.
LEAFLETS ARE NEVER VERY HELPFUL.
LINE DANCING; WALKING
LOCAL GYMS.
LOCAL.
MANY OF US CARE FOR ADULTS AND NEW GUIDANCE ON OUR RIGHTS AND THE RIGHTS OF THE

PERSON WE CARE FOR
MORE LOCAL GROUPS
MY PARTNER IS A BI-LATERAL AMPUTEE, 81 YEARS OLD - WHAT WOULD BE AVAILABLE - HE IS SOCIABLE
N/A
NO LEISURE ACTIVITIES IN THIS AREA.
NONE
PLAYSCHEMES SPECIFICALLY FOR SEN CHILDREN
RELEVANT ACTIVITIES.
RESPITE
RESPITE CARE - AVAILABILITY.
SERVICE USER RIGHTS AND RELEVANT REPRESENTATIVES.
SOMETHING FOR ELDERLY TO TAKE PART IN
SPECIFICALLY, WHICH MENTAL HEALTH FORM DEALS WITH WHAT AND WHEN AND WHERE.
SUBSCRIPTIONS TO ONLINE HEALTH INFORMATION DATABASES WOULD ENABLE PROPER RESEARCH
SWIMMING, BOWLS PHOTOGRAPHY COURSES.
THE INFORMATION THAT THERE ARE NO SERVICES LOCALLY ISN'T MUCH HELP.
THE INTERNET IS MORE SUITABLE
THINGS EXPLAINED MORE EASILY
THINGS THAT RUN DURING THE DAY, ESPECIALLY LEISURE ACTIVITIES FOR DISABLED PEOPLE/CHILDREN
WITH WHAT TIME AND MONEY?

4.6. Appendix F

Q8. How do you generally prefer to access information? Other:

AS A MEMBER OF LOCAL GROUP
ATTENDING WORKSHOPS.
CARER'S SUPPORT.
CARERS GROUP MEETING
CARERS INFO
CARERS SUPPORT GROUP
FOUND THE COURSE IN TIDBURY VERY HELPFUL.
FROM CARING STAFF
G.P'S SURGERY
GP
I HAVE OTHER SOURCES WHICH MEET MY NEEDS
IF YOU DON'T ASK YOU DON'T GET. INFORMATION IS NO T VOLUNTEERED TILL YOU ASK
INFORMATION SERVICES
INTERNET
LETTERS
MAIL
NEWSLETTERS.
OTHER CARERS.
PHONE
PHONE CALL

PHONE.
POST
PROVIDER POLICY & PROCEDURE
SUBJECT SPECIAL MEETINGS
TALKING TO “name of care worker” (MY CARER SUPPORT).
TELEPHONE
TELEPHONE EG CARE HELP DESK
THROUGH A GP
THROUGH GP FOR MY MOTHER, ALZHEIMER'S SUPPORT, MARLBOROUGH.
THROUGH OTHER CARERS.
VERBAL VIA K.C.ASSM.
WEB
WHENEVER AVAILABLE
WORD OF MOUTH
WORD OF MOUTH FROM OTHER CARERS.
WRITTEN DOWN SO I CAN UNDERSTAND

4.7. Appendix G

Q11. Books in Alternative formats, e.g. listening books. Please specify:

AUDIO
AUDIO BOOKS FOR CHILDREN
AUDIO BOOKS.
AUDIO TAPES.
C.D'S
CD
CDS
CHILDREN'S.
DON'T HAVE TIME FOR READING.
E-BOOKS
FILMS, CD'S, TAPES
FOR THE BLIND?
GREAT FOR CAR JOURNEYS.
I HAVE MY OWN LIBRARY AND I BUY BOOKS ONLINE
I HAVE NO DESIRE TO USE THE LIBRARY
LARGE PRINT
LARGE PRINT.
LISTENING
LISTENING BOOK
LISTENING BOOKS
LISTENING BOOKS.
MORE BOOKS ON ARTIST/ART & RELAXATION
POETRY, STORIES, MUSIC APPRECIATION.
PROVIDE LARGE PRINT BOOKS FOR THE RELATIVE I CARE FOR.
READ A WIDE VARIETY OF BOOKS
SPOKEN WORD
TALKING BOOKS/PAPERS
TAPED BOOKS.

4.8. Appendix H

Q11. How could the library make reading more enjoyable for you? Other:

A CARER CANNOT GO TO GROUPS - A CARER IS HOUSEBOUND
ALLOW THE USE OF WISECARDS ON ANY DAY OF THE WEEK.
BETTER SELECTION OF MORE FICTION BOOKS AND REFERENCE BOOKS
CARERS WRITE REVIEWS ON CARER RELATED LITERATURE
CHARITY SHOPS ARE A WONDERFUL SOURCE OF FINDING THE BOOK YOU ALWAYS WANTED
DELIVER A SMALL BUNDLE OF BOOKS TO MY DOOR MONTHLY AND UPLIFT THE LAST LOT.
DIFFICULT TO ANSWER BECAUSE MY CARING ROLE IS 24-7/
DIMINISHING EYESIGHT DISCOURAGES ME
ELECTRONIC BOOKS.
EXTENDED BORROWING PERIOD, LITERATURE QUIZZES.
GROUP READING (FICTION AND POETRY)
HAVE THE LIBRARY OPEN MORE OFTEN
I ALREADY FIND READING VERY ENJOYABLE.
I ALREADY USE LIBRARY EXTENSIVELY
I AM A BOOK WORM
I AM A FULLY COMMITTED READER + DO NOT NEED ANY OF ABOVE
I BUY BOOKS FROM CHARITY SHOPS
I BUY THE BOOKS I WANT TO READ THEREFORE HAVEN'T USED THE LIBRARY
I CAN'T READ LONGER THAN 15 MINS, EYE PROBLEM
I DO NOT HAVE TIME FOR READING OR GOING TO A LIBRARY.
I DO NOT NEED THESE SERVICES BUT MY SON DOES.
I DON'T GET MUCH TIME FOR READING - SO BORROW FRIENDS BOOKS
I DON'T GO THE LIBRARIES
I DON'T READ BOOKS.
I ENJOY READING WHEN TIME ALLOWS.
I FRIND READING INTERESTING AND READ WHEREVER POSSIBLE.
I HAVE NO TIME TO GO TO THE LIBRARY AND THE CHILD I CARE FOR HAS NO INTEREST. (TEND TO BUY BOOKS ONLINE - IT'S EASIER).
I HAVE TIME TO READ AT HOME AND LIBRARY.
I LOSE ATTENTION AND FEEL DROWSY. NEED TO GET UP AND DO SOMETHING.
I NEVER USE THE LIBRARY
I ONLY READ WHEN MY WIFE IS IN BED.
I READ ALL THE TIME, MY HUSBAND DOES NOT BECAUSE OF BAD SIGHT
I READ BUT MY SOLE INTEREST INFIELD OF ELECTRONICS/ELECTRICAL ENGINEER. I AM A RETIRED SENIOR ENGINEER IN BOTR FIELDS, NO REF. SUBJECTS IN LIBRARY
I READ BUT NO TIME TO GO TO LIBRARY
I READ LIBRARY BOOKS ALL THE TIME.
I READ MOST NIGHTS AND HAVE 30-50 BOOKS FOR FUTURE READING.
I READ MOSTLY FOR INFORMATION THEREFORE I BUY BOOKS MORE THAN I BORROW.
I READ MY OWN CHOICE OF BOOKS FROM SHOPS.
I READ, BUT WOULDN'T WANT TO DO ANY OF THE ABOVE
I SELDOM GO OUT WITHOUT MY HUSBAND, WHO HAS NO INTEREST IN READING.
I THINK THE LOCAL LIBRARY IS VERY HELPFUL GIVEN THE CHANCE
I WOULD READ EVERYTHING I CAN PUT MY HANDS ON
I'VE ALWAYS BEEN AN AVID READER AND VISIT LIBRARY AT LEAST 3 X PER WEEK
IF I HAD ANY MORE BOOKS, HE WILL GO MAD AS I READ A LOT IN SPARE TIME

IS THERE A LOCAL POETRY GROUP?
JUST TO BE ABLE TO GET TO THE LIBRARY BY MYSELF
KEEPING STOCK UP-TO-DATE WITH AUTHORS LATEST WORKS
LARGE PRINT BOOKS, MORE OF
LATE NIGHT OPENING ONCE A WEEK
LEAFLETS ABOUT NEW BOOKS ETC.
LISTING LITERACY ITEMS ABOUT CARING & DISTRIBUTING IT & A LISTING OF ALL THE CARERS VOICE QUESTIONNAIRE RESULTS.
LITTLE TIME TO READ - I HAVE PARKINSONS NOW & TIME IS TAKEN UP AT THESE MEETINGS & JUST CARING.
LITTLE, BUT WOULD LOVE TO DO MORE!
MORE & BETTER LIBRARY STOCK DISPLAYED ON PROPER SHELVES.
MORE EVENING WEEKEND OPENINGS AS I WORK.
MORE SELECTION OF LARGER PRINT BOOKS.
MORE UP TO DATE BOOKS
MOSTLY, I READ THE DAILY TELEGRAPH AND SUNDAY TIMES NEWSPAPERS.
MY CARING ROLE HAS NO IMPACT ON ACCESSING BOOKS/READING
MY SIGHT DOES NOT PERMIT THIS
MY WIFE HAS DIFFICULTY IN FOCUSING - MAGNIFICATION WOULD HELP.
MY WIFE RECEIVES RNIB TALKING BOOKS!
N/A
NEED TO RENEW BOOK TOO OFTEN BEFORE I GET TO THE END OF IT!
NEWSPAPER, SPORTS BOOKS
NEWSPAPERS, MAGAZINES
NO PROBLEMS IN THIS AREA.
NOT A LOVER OF READING
NOT APPLICABLE AT THE MOMENT
NOT HAVING TO PAY TO ORDER BOOKS
OFTEN TOO TIRED TO READ.
ON THE BLIND REGISTER, GET DISCS.
ON-LINE LIBRARY CATALOGUE & BOOK ORDERING CONNECTED TO '10' ABOVE.
OPENING HOURS IN THE EVENING
PERFECTLY HAPPY WITH MOBILE SERVICE PROVIDED.
SPECIFIC INTEREST WEEKS/SESSIONS
SUPPORT ON F.O.C. BOOK EXCHANGE
TRUE BUT WOULD LIKE TO BE ENCOURAGED TO READ MORE.
WE BOTH READ A LOT & I BELONG TO A READING GROUP.
WIDER VARIETY OF BOOKS (CHILDRENS) WITH POSITIVE IMAGES OF DISABLED PEOPLE.

4.9. Appendix I

Q12. Please rank the options below in terms of helping you to use the library.
Other:

1
A PHOTOCOPYING SERVICE FOC
AS 11 ABOVE
AS ABOVE
BEING OPEN MORE HOURS, MORE DAYS

CARING LEAVES ME NO TIME TO READ
DO NOT USE THE LIBRARY.
DON'T NEED THIS SERVICE - SHARE WITH FRIENDS.
DON'T READ
DON'T USE LIBRARY AS I USED TO AS I HAVE LITTLE TIME FOR READING.
DON'T USE LIBRARY.
HAVEN'T USED THIS SYSTEM.
I AM PARTIALLY SIGHTED.
I DO NOT USE THE LIBRARY
I HAVE NO DESIRE TO USE THE LIBRARY
I NEVER USE THE LIBRARY
I THINK EXISTING ARRANGEMENTS ARE ADEQUATE.
IE. TOO DISABLED
LARGER PRINT + OVERLAYS FOR DISLEXIA SUFFERERS
LATER OPENING HOURS.
MY CARING ROLE HAS NO IMPACT ON ACCESSING BOOKS/READING
N/A
NO INTEREST.
NO PROBLEMS
NO PROBLEMS - REGULAR LIBRARY USER.
NOT APPLICABLE
NOT INTERESTED
NOT USED
OFFER NEW CARER RELATED PUBLICATIONS AS THEY ORIGINATE
ONLINE BOOK IN STOCK ACCESS
ONLINE RESERVATIONS - SO WE DON'T MAKE A WASTED JOURNEY.
ORDERING OF NEW BOOKS - NO PAYMENT.
OTHERS "FAMILY" CAN COLLECT FOR ME.
PERSONALLY I DON'T NEED ANY OF THE ABOVE.
REMAINDER VIA PHONE THAT BOOKS ARE DUE BACK.
TRANSPORT/ESCORT TO COLLECT READERS (SPECIFIC BUS SERVICE)
USE OF WISECARDS FOR REDUCED LOAN CHARGES ON ANY DAY OF THE WEEK.

4.10. Appendix J

Q13. Libraries can offer or host additional service and events of benefit to Carers. Would any of the following be of interest to you? Other:

A BETTER ORGANISED LIBRARY SIGN POSTED FOR ALL USES - EG CARERS, POLICE ETC WOULD ENCOURAGE MORE PEOPLE TO USE THE LIBRARY
BENEFITS ADVICE ON ONE TO ONE
BOOKS & LEAFLETS ARE SO IMPERSONAL - FACE TO FACE ADVICE IS THE ONLY THING WHICH REALLY HELPS.
CARER/CARED FOR SESSIONS WITH DEDICATED LIBRARY STAFF SUPPORT SESSIONS
ENABLING OF FORMATION OF VOLUNTEER GROUPS & TO PUBLICISE MORE FOCUSED QUESTIONNAIRES & SURVEYS THEY DEVELOP.
FAMILY DAYS IN THE LIBRARY.

HELP WITH COMPUTER TRAINING.
I AM NOT FREE TO GO OUT VERY OFTEN
I CANNOT ACCESS ANYTHING OUTSIDE OF HOME, I ONLY HAVE 2 HOURS TO SHOP, PENSION, HAIRCUT A WEEK
I CANNOT VISIT THE LIBRARY.
I DON'T HAVE ANY FREE TIME.
I NEVER USE THE LIBRARY
I REALLY WOULD LIKE TO GO OUT WITH MY HUSBAND NOT ON MY OWN FOR A BREAK.
I WOULD PREFER OUTINGS ETC WHICH INCLUDED PATIENT.
LACK OF PRIVACY WOULD BE SERIOUS FACTOR IN OUR TINY LIBRARY (ONLY 1 ROOM)
MY DIFFICULTY IN HAVING ENOUGH 'TIME OFF' TO USE THE LIBRARY.
NOT ALL CARERS CAN GET OUT!!
QUESTION AND ANSWER SESSIONS WITH FUNDERS OF SERVICES.
STANDARD OPENING TIMES
STRESS MANAGEMENT COURSE - ONE DAY ONLY
USE OF WISECARDS ON ANY DAY OF WEEK.

4.11. Appendix K

Q15. Please tell us if you agree or disagree with the following statements about Carer's Assessments: "I am put off from completing an Assessment". "If you have agreed with this statement, please tell us why":

A SOCIAL WORKER ASSESSMENT ONLY.
ASSESSMENTS ARE ALWAYS USEFUL I WOULD THINK.
AVAILABLE TIME TO DO IT
BECAUSE I HAVE NOT HAD A PROPER ASSESSMENT
BECAUSE I WOULD LIKE TO ANSWER QUESTION MYSELF AND NOT TICK BOXES.
BECAUSE I WOULD NOT FEEL I WOULD COMPLETE IT PROPERLY - WHAT IS ASKED FOR?
BECAUSE LIKE SOCIAL SERVICES ASSESSMENT, I WOULD NEED TO BE ON THE VERGE OF A NERVOUS BREAKDOWN TO QUALIFY FOR ANY SUPPORT.
BECAUSE THE SOCIAL WORKER HARDLY SEE'S US.
BECAUSE THEY SAY I DON'T MEET THE CRITERIA TO GET ANY SUPPORT.
BECAUSE YOU MAY NEED A SERVICE BUT IT MAY NOT BE AVAILABLE.
CAN'T SEE THE POINT
CAUSE I GET INFO WHEN NEEDED.
CONFIDENT WITH CURRENT SUPPORT
DIDN'T KNOW THEY EXISTED
DIDN'T REALLY UNDERSTAND WHAT IT WAS SEEN AS JUDGEMENT ON MY CARING.
DO NOT FEEL COMPETENT TO MAKE ONE
DO NOT KNOW WHAT IS INVOLVED
DO NOT KNOW WHAT IT ENTAILS OR EVEN IF WE ARE ELIGIBLE
DOES IT MAKE ANY DIFFERENCE.
DON'T ALWAYS UNDERSTAND FORMS.
DON'T LIKE FILLING OUT FORMS
FEEL I MIGHT MISS SOME ENTITLEMENT.
FEEL I NEED ADVICE
FEEL UNCOMFORTABLE ASKING FOR HELP
FORMAT IS CONFUSING (AS IS LANGUAGE AND 'LEADING' QUESTIONS) NO OPTIONS FOR

ALTERNATIVE ANSWERS.
FORMS ARE COMPLICATED.
HOW I AM FEELING VARIES FROM DAY TO DAY SO OWULD BE DIFFICULT TO ANSWER - ALSO, UNDER PLAY WHAT I ACTUALLY DO AS A CARER
I ALWAYS THINK THAT HELP IS NOT NEEDS LEAD ONLY MONEY LEAD
I AM A RETIRED WARD SISTER / HEALTH VISITOR
I AM NOT ABLE TO CLAIM FOR EVEN THE TINY CARERS ALLOWANCE SO WHAT IS THE POINT OF FURTHER FORMS ETC.
I DIDN'T KNOW A SELF-ASSESSMENT WAS POSSIBLE.
I DIDN'T KNOW WHAT HELP I COULD GET
I DO NOT THINK THIS WOULD HELP MY SITUATION.
I DON'T HAVE ALL THE INFORMATION.
I DON'T REMEMBER BEING TOLD ABOUT "SELF" ASSESSMENT
I DON'T THINK IT WOULD REFLECT MY TRUE STATUS
I FEEL NOTHING IS EVER DONE TO ALLEVIATE PROBLEMS HIGHLIGHTED
I KNOW I JUST HAVE TO COPE ON MY OWN.
I WANT AN OBJECTIVE ASSESSMENT.
I'M STILL IN DENIAL OF BEING MY HUSBANDS CARER
IN MY VIEW FAR TOO MUCH PAPER WORK WITH NEGATIVE RESULTS.
INSUFFICIENT KNOWLEDGE
IT DOESN'T SEEM TO MAKE MUCH DIFFERENCE.
IT MAKES NO DIFFERENCE
IT NEEDS TO BE COMPLETED BY A PROFESSIONAL.
LACK OF TIME AND I DON'T THINK I WILL GET MORE HELP AS A RESULT.
LACK OF TIME.
MUDDLED
MY EXPERIENCE SO FAR WITH SOCIAL SERVICES HAVE BEEN NEGATIVE & THEY HAVE NEVER OFFERED ANY HELP.
NO ASSESSMENT NEEDED - I AM RETIRED S.R.H.
NO KNOWLEDGE OF SCHEME
NO ONE CAN HELP ME AT PRESENT
NO WISH FOR ASSESSMENT.
NOT REALLY SURE WHAT IS ENTAILED
NOT SURE IF FILLED IN CORRECTLY
NOT SURE IF I QUALIFY AS I DO NOT DO AS MUCH CARING AS MANY OTHERS.
NOT SURE IF I'D HAD ONE OR NOT.
NOT SURE WHAT IS INVOLVED.
NOT SURE WHAT IT WOULD ACHIEVE
NOTHING HAPPENS!!
NOTHING SEEMS TO HAPPEN AFTER COMPLETION
NOTHING SEEMS TO HAPPEN AFTERWARDS
OFTEN HAVE TO REPEAT QUESTIONS, THE NEXT PAGE IS ASKING THE SAME THING
OTHER PEOPLE'S BAD EXPERIENCES.
POINTLESS EXCERCISE - JUST FOR STATISTICS!
POORLY DESIGNED AND INAPPROPRIATE QUESTIONS ON THE FORMS AND I DID NOT KNOW WHAT OUTCOMES COULD BE EXPECTED.
PROBLEM IS GETTING ASSESSMENT.
PROFESSIONAL HELP IS NEEDED, THEY KNOW WHAT SERVICES TO OFFER AND NEEDED.
PROFESSIONALS ASK QUESTIONS WHICH HIGHLIGHT POINT I MAY NOT HAVE THOUGHT IT.
SADLY NO CARER NEEDED
SHOULD HAVE ONE TO ONE HELP

SO EASY TO MISUNDERSTAND QUESTIONS.
SOCIAL SERVICES
TAKES TOO LONG
THE CARING ROLE CAN BE SO DEMANDING, OVERWHELMING & TIRING THAT YOU PUT OFF EVERYTHING ECXEPT THE MOST IMMEDIATE THINGS.
THEY ARE OPPRESSIVE, INTRUSIVE FOR LITTLE BENEFIT
THEY CAN BE INTRUSIVE AND TIME CONSUMING AND NO GAIN BECAUSE OF MEANS TESTING.
TIME SCALE ON COMPLETING ASSESSMENT
TIME TAKEN OUT OF MY DAY TO DO IT!
TIME TAKEN.
TOO MANY FORMS
TOO MUCH FORM FILLING
TOO MUCH INTRUSION.
TOO MUCH OFFICIAL JARGEN.
UNSURE
UNSURE AS TO THE VALUE END RESULT.
WASTE OF TIME - REASON - MEANS TESTED!
WE JUST NEED TO ACCESS THE SERVICE IF CHANGES OCCUR.
WHEN YOU ARE AN EXHAUSTED CARER AT THE END OF YOUR TETHER IT IS VERY DIFFICULT TO GET MOTIVATED TO HELP YOURSELF.
WHO DOES ANYTHING TO HELP?
A SOCIAL WORKER ASSESSMENT ONLY.
ASSESSMENTS ARE ALWAYS USEFUL I WOULD THINK.
AVAILABLE TIME TO DO IT
BECAUSE I HAVE NOT HAD A PROPER ASSESSMENT
BECAUSE I WOULD LIKE TO ANSWER QUESTION MYSELF AND NOT TICK BOXES.
BECAUSE I WOULD NOT FEEL I WOULD COMPLETE IT PROPERLY - WHAT IS ASKED FOR?
BECAUSE LIKE SOCIAL SERVICES ASSESSMENT, I WOULD NEED TO BE ON THE VERGE OF A NERVOUS BREAKDOWN TO QUALIFY FOR ANY SUPPORT.
BECAUSE THE SOCIAL WORKER HARDLY SEE'S US.
BECAUSE THEY SAY I DON'T MEET THE CRITERIA TO GET ANY SUPPORT.
BECAUSE YOU MAY NEED A SERVICE BUT IT MAY NOT BE AVAILABLE.

4.12. Appendix L

Q16. Please let us know what you would like out of a Carer's Assessment:

'WHOLE FAMILY' APPROACH TO ASSESSMENT, AS A FAMILY WE SHARE THE CARE/SUPPORT AND PRACTICAL ASSISTANCE. "name of son" (27) NEEDS TO LIVE INDEPENDENTLY.
1. AN UNDERSTANDING AND APPRECIATION OF MY CIRCUMSTANCES AND NEEDS. 2. PRACTICAL HELP, SUPPORT AND ADVICE RELEVANT TO MY NEEDS. 3. A LINK TO ONE EASILY ACCESSIBLE HEALTH WORKER OR SOCIAL WORKER WHO IS KNOWLEDGEABLE ABOUT THE RANGE OF ALL SERVICES AVAILABLE AND WHO CAN CO-ORDINATE BETWEEN DIFFERENT BRANCHES OF CARE. 4. FOLLOW UP AND ON GOING SUPPORT - NOT JUST AT TIMES OF CRISIS.
A AGREED/MUTUAL RECOGNITION OF AREAS OF DIAGNOSIS, TREATMENT AND SUPPORT NEEDED FOR ME TO BE KNOWLEDGABLE OF WHAT IS REQUIRED OF ME AND HOW I CAN BE CONFIDENT IN MY ROLE.
A BIT MORE SUPPORT AND MORE SOCIAL OUTINGS WITH ENTERTAINMENT, WHERE WE CAN BRING THE FAMILY WE LOOK AFTER.
A BREAK FROM MY WIFE FOR A DAY OR TWO WHERE I DO NOT HAVE TO WORRY ALL THE TIME. P.S. WHAT IS THE INTERNET? AND A WEBSITE?
A BREAK FROM THE FEELING OF ISOLATION. THE ONLY REAL POSITIVE HELP I GET IS FROM THE

ALZHEIMERS SOCIETY. I CARE FOR A WIFE WITH PARKINSONS, LEARY BODY DEMENTIA, SELENTDERMA AND OSTEOPOROSIS
A CARE WORKER WHOM MY SON KNEW (MAYBE FROM OAK HOUSE) WHO COULD OCCASIONALLY 'BABYSIT' HIM SO MY HUSBAND AND I COULD GO OUT TOGETHER ONCE IN A WHILE - IN REALITY THIS PROBABLY MEANS A MAGIC WAND!!
A HOLISTIC APPROACH TO YOUR CARING NEEDS, IE VIEWING THE SITUATION AS A WHOLE. HELPING YOU TO MAKE THE MOST OF YOUR LIFE WHILST BEING A CARER AND PREPARING YOU FOR THE TIME WHEN THAT MIGHT CHANGE AND YOU HAVE TO STOP CARING OR TAKE ON MORE CARING RESPONSIBILITY. ALSO IDENTIFYING ISSUES THAT MAY COME UP IN THE FUTURE WELL IN ADVANCE AND PREPARING YOU FOR THEM.
A LISTING OF THE TYPE OF SERVICES THAT MAY BENEFIT BOTH ME & THE PERSON I CARE FOR AND A LIST OF THOSE SERVICES AVAILABLE LOCALLY THAT WOULD MEET THOSE RECOMMENDED TOGETHER WITH INFORMATION ON THE COSTS TO ME OR ALTERNATIVE FUNDING OPPORTUNITIES.
A SENSE THAT SUPPORT IS THERE IN A CRISIS. I HAVE HAD WONDERFUL SUPPORT FROM SOCIAL SERVICES WHEN I HAD CANCERN/
A STRAIGHTFORWARD AND EASY TO UNDERSTAND PACKAGE FOR OUR FUTURE
A TRUE ASSESSMENT OF NEEDS + FUNDING AVAIABLE TO MEET NOT AN ASSESSMENT THAT MEETS THE FUNDS AVAILABLE, W-C-C HAVE NO IDEA!
A TRUE ASSESSMENT OF THE SITUATION - BEING WATCHFUL OF THE PERSON BEING CARED FOR. IT IS NOT ALWAYS EASY TO APPRECIATE HOW A CARER AUTOMATICALLY CARES DAY TO DAY, SOME TIMES EVEN WE CARERS DO NOT REALISE WHAT WE DO!
ACCESS TO ALL HELP AND SERVICES THAT A CARER IS ENTITLED TO.
ACTION
ACTION - IT IS NOT AN IDLE PIECE OF PAPER, POINTS LISTED NEED TO BE ACTIONED NOT FILED AWAY AND FORGOTTEN.
ACTION OF SUPPORT, IT SEEMS THE FORMS ARE FILLED OUT, FILED + FORGOTTEN
ACTION PLAN - WITH TIMINGS BASED ON ASSESSED NEEDS. NAMED INDIVIDUAL WHO WILL PROVIDE UPDATES AND PROGRESS REPORT ON ACTION PLAN. (WITHOUT PROGRESS ON THE ABOVE, THE TIME SPENT BY THE PROFESSIONAL AND THE CARER IS WASTED - AND COST/BENEFIT INEFFECTIVE).
ACTION POST ASSESSMENT
ADVICE AND ANY HELP NEEDED.
AFTER COMPLETING CARERS ASSESSMENT I HAD HOPED MY EXPERIENCE OF BEING A CARER WITH MENTAL HEALTH CONCERNING MY SON WOULD BE LISTENED TO, I FIND THAT IS NOT SO
AGREED ACTION PLAN/S WHEN A CRISIS OCCURS. AGREED AIMS/OUTCOMES TO MEET MY NEEDS EG I CHECK OUT THE LIBRARY.
ALL ABOVE.
ALL MY NEEDS MET
AM I DOING MY JOB PROPERLY?
AN ASSESSMENT WAS CARRIED OUT WHEN MY HUSBAND WAS RECENTLY ADMITTED TO MENTAL HOSPITAL. IT WAS CARRIED OUT ON THE EVENING HE WAS ADMITTED. I HAD NO TIME TO THINK ABOUT IT, THE NURSE WHO ADMINISTERED IT WAS VERY BUSY; I WASN'T GIVEN A COPY AND I DON'T KNOW WHO HAS ACCESS TO THE INFORMATION OR WHAT IT IS USED FOR. IT WAS AN UPSETTING EXPERIENCE.
AN EMERGECY PLAN FOR I HAVE NONE AND WORRY WHAT WILL HAPPEN IF I GET SICK, I ASKED FOR ONE BUT IT WAS NOT FORTHCOMING.
AN EVALUATION OF ALL MY PROBLEMS AND ALLEVIATION OF AT LEAST SOME OF THEM!
AN OPPORTUNITY FOR THE STATING OF FACTS. AN OPPORTUNITY FOR BEING LISTENED TO RE THE EMOTIONAL & PHYSICAL DEMANDS OF CARING. AN OPPORTUNITY TO IDENTIFY NEEDS AND SERVICES/RESOURCES TO HELP.
AN UNDERSTANDING THAT NOT ALL CARERS FIT INTO YOUR SEEMINGLY PRE-DEFINED BOX AND A GREATER WILLINGNESS TO UNDERSTAND PROBLEMS, SUGGEST AND SUPPORT SOLUTIONS AND BE AVAILABLE EQUALLY TO ALL DISABLED AND THEIR SUPPORTERS. THERE IS ALSO A NEED FOR LONG TERM PLANNING WHERE CARERS MAY DIE BEFORE THOSE THEY CARE FOR
APART FROM THE PROBLEM OF IDENTIFYING CARERS AND OFFERING THE ASSESSMENT - I WOULD LIKE THE ASSESSMENT TO ASK QUESTIONS THAT GET BEHIND THE 'CHEERFUL' FACADE THAT CARERS CAN PUT UP. FOR THE ASSESSMENT/ASSESSOR TO SAY WHAT

SERVICES/SUPPORT IS AVAILABLE, AS THE CARER WILL NOT KNOW, BUT THEY WILL KNOW WHETHER SUCH SUPPORT WOULD BE HELPFUL.
APPROPRIATE HELP
ARE THEY EVER WILLING TO ACCEPT THE SERVICES WE ARE OFFERING, THE ROUND THE CLOCK AVAILABILITY, THE FACT THAT A CARER ENDS WORSE THAN THE ONE HE/SHE CARES????
AS A RESULT OF A RECENT ASSESSMENT I DID RECEIVE SOME EXTRA HELP BUT THE BIGGEST PLUS POINT WAS JUST HAVING SOMEONE TO LISTEN TO ME AND MAKE ME FEEL I WAS NOT ALONE.
AS ABOVE
AS ABOVE, FEEDBACK & WHAT SERVICES THIS EQUATES TO IN AN INDIVIDUAL CASE.
ASSURANCE BOTH I (THE CARER) AND MY MOTHER (FOR WHOM I CARE) ARE GETTING THE MOST/BEST ADVICE, HELP (INFORMATION ETC.), SUPPORT VIA FACILITIES (CLUBS, DAY CENTRES, HOSPITAL IF NEED BE) AND FINANCIAL INFORMATION AND PAYMENTS THAT WE ARE ENTITLED TO.
AT LEAST A LITTLE AWARENESS THAT 'I AM A CARER'. AT LEAST A LITTLE KNOWING THAT 'THE SYSTEM' IS NOT TOTALLY IGNORING 'US'. ANY - EMOTIONAL, PRACTICAL & FINANCIAL SUPPORT THAT MIGHT BE SUITABLE/AVAILABLE.
AT MOMENT PEACE AND TRANQUILLITY WHILST WE HAVE A VICIOUS DAUGHTER IN LAW NO CHANCE WAS MARRIED TO OUR SON DIVORCED LEADING HIM A VISCIOUS LIFE STOLLEN FROM HIM CHEATED ON HIM STOLE HIS MONEY AND NO MARRIED TO HIS BROTHER THE CRIMINAL IN FAMILY DISOWNED BY ALL FAMILY. JUST LIKE SOMEONE TO COME AND TALK TO US SOMETIME SOMEONE WE TRUST AND NOT BLAST OUR AFFAIRS AROUND AND THEY KEEP OUR AFFIARS TO THEMSLEF AND WHAT AUTHORITY HE OR SHE WORKS UNDER. THANKYOU
AT THE MOMENT I'M QUITE HAPPY WITH THINGS AS THEY ARE, AS THE PERSON THAT I LOOK AFTER FEELS QUITE WELL, BUT WHEN THINGS GET WORSE I SHALL PROBABLY BE IN TOUCH FOR A SELF ASSESSMENT
AT THE MOMENT MY CARERS ROLE IS FAIRLY EASY. MY HUSBAND 80 IS STILL REASONABLY ACTIVE AND ALERT, SO MANY OF THE QUESITONS HERE DO NOT APPLY TO ME AT THE MOMENT!
BECAUSE THE PERSON YOU CARE FOR HEALTH AND WELL-BEING CHANGE ALL THE TIME I THINK ASSESSMENTS SHOULD BE CARRIED OUT EVERY 3 MONTHS. BECAUSE SO MANY THINGS CHANGE SO QUICKLY.
BETTER HELP FOR MY MUM. AS I CAN ONLY DO SO MUCH FOR HER
BETTER TARGETTING OF ASSISTANCE
CAN'T COMMENT I DO NOT UNDERSTAND IMPLICATIONS.
CARER NEEDS TO FEEL THEY CAN TURN TO SOMEONE FOR MORAL AND FINANCIAL ADVICE - IT IS HARD WORK, TIME CONSUMING AND OFTEN LONELY LOOKING AFTER SOMEONE WHO IS ILL AND OFTEN THE CARER, LIKE MYSELF IS CARING FOR MORE THAN ONE PERSON.
CARERS ASSESSMENT WOULD IDEALLY CHECK TO MAKE SURE THE CARER IS GETTING ALL THE HELP THEY ARE ELEGIBLE FOR AND NEED + IF THIS IS NOT THE CASE HELP THEM ACCESS IT QUICKLY + EASILY
CLEAR STATEMENT OF ENTITLEMENTS AND LIST OF THINGS I WOULD BENEFIT FROM AND HOW TO ACCESS THEM MYSELF. AUTOMATIC REFERRAL FOR SERVICES TO WHICH I AM ENTITLED.
CLEAR, CONCISE INFORMATION HIGHLIGHTING MY NEEDS AS A CARER
CLEARLY IDENTIFIED NEEDS AS A CARER WITH GUARANTEED HELP WHEN REQUIRED. A CONTRACT WITH W.C.C. TO PROVIDE NECESSARY RESPITE AND ACTIVITIES
CONDENSED TO THE ESSENTIALS, BACKED UP BY CARE PROFESSIONAL WHO KNOWS MY SITUATION
CONFIDENCE THAT I AM RECEIVING ALL THE HELP AND BENEFITS POSSIBLE FOR MY SITUATION, AND THAT MY HUSBAND IS RECEIVING ALL THE HELP AND CORRECT TREATMENT HE NEEDS FOR HIS SITUATION.
CONFIDENCE THAT MY NEEDS ARE BEING ADDRESSED
CONSTANT UPDATES ARE ESSENTIAL TO NOTE CHANGES IN FAMILY AND DIRECT CIRCUMSTANCES.
DIFFICULT TO ANSWER AS ALL CARERS HAVE DIFFERENT STRENGTHS AND THEREFORE DIFFERENT NEEDS. AFTER 10 YEARS CARING FOR A TETRAPLEGIC I HAVE MOSTLY 'SORTED OUT' MY SUPPORT. MOST CARERS NEED TO BE ENABLED AND GIVEN CONFIDENCE. PRACTICAL SUPPORT BY OCCUPATIONAL & PHYSIOTHERAPISTS ON A ONE TO ONE BASIS IS OF MORE USE THAN WRTTEN MATERIAL.

DO AWAY WITH MEANS TESTED ASSESSMENT
DO NOT KNOW WHAT THE POSSIBILITIES ARE SO CAN'T COMMENT
DON'T KNOW.
DURING THE LAST ASSESSMENT (2 YEARS AGO) I WAS ASTONISHED TO BE INFORMED BY THE SOCIAL WORKER THAT ASSESSMENTS ARE A COMPLETE WASTE OF TIME AND THEY ARE POINTLESS AS THERE IS NO MONEY TO MAKE CHANGES ANYWAY! SHE WAS ONLY TELLING ME WHAT I'D ALREADY SUSPECTED FOR A LONG TIME.
FELT SATISFIED WHAT I WAS DOING WAS GOOD FOR US BOTH!
FLEXIBILITY - EG FOR RESPITE, MEETING OTHER NEEDS. FUNDING EG TO BE ENABLED TO DO A COLLEGE COURSE/STUDY/RETRAIN.
FOR THE PERSON TO BE MORE THOROUGH IN THE ASSESSMENT.
FULL INFORMATION ON WHAT BENEFITS ARE AVAILABLE TO BOTH THE CARER AND THE PATIENT (ESPECIALLY IF FAMILY). MORE DETAILED LISTING OF ALL OFFICES OF CONTACT FOR BOTH BENEFITS & EQUIPMENT. QUICKER AVAILABILITY OF WHEELCHAIRS WHERE NEEDED. A BETTER AND NOT AUTOMATED TELEPHONE ACCESS TO ALL DEPARTMENTS.
FULL RECOGNITION OF THE PHYSICAL, MENTAL & EMOTIONAL ASPECTS OF YOUR CARING ROLE (EVEN IF THERE ARE NO CURRENT SERVICES TO AMELIORATE SUCH NEEDS.) THIS INFORMATION IS VITAL FOR FUTURE PLANNING OF SERVICES. IDEALLY THE PROVISION OF INFORMATION OR SERVICES (BOTH FOR YOURSELF AND THE PERSON CARED FOR) TO MAKE YOUR CARING ROLE EASIER, IF YOU OR THE PERSON CARED FOR AGREE THIS WOULD BE BENEFICIAL AND CONSENT TO THIS.
GENERAL INFORMATION + BACK UP WHEN NEEDED
GENERALLY, ASSESSMENT OF MY PHYSICAL ABILITY TO CARRY OUT THE NECESSARY ACTIVITIES IN THE HOME
GETTING ONE COMPLETED.
GUARANTEE THAT SERVICES NEEDED WILL BE IMPLEMENTED AND NOT JUST A BOX TICKED ON A STATISTICS SHEET. GUARANTEE THAT ANY SERVICES ONCE IN PLACE CANNOT BE WITHDRAWN.
GUIDANCE TO EFFECTIVE CARING BOTH PHYSICAL PROBLEMS THAT MIGHT OCCUR AS WELL AS MENTAL. INFORMATION REGARDING SYMPATHETIC GUIDELINES.
HAVE JUST HAD ME
HAVE NEVER HAD ONE, BECAUSE AT PRESENT I FEEL ABLE TO MANAGE WITHOUT SUPPORT, HOWEVER, THIS MAY CHANGE AND I HOPE I WOULD HAVE ACCESS TO PROPER MEDICAL FACILITIES AND EQUIPMENT TO HELP ME TO CARE MORE EASILY FOR MY HUSBAND.
HEALTH CHECK, BENEFIT CHECK, SERVICES RECEIVED CHECK
HELP AND UNDERSTANDING.
HELP AS I DON'T READ BOOK ENGLISH I AM ITALIAN.
HELP IN ALL AREAS.
HELP!! NOT WORDS.
HELPING AND INCREASING SELF CONFIDENCE.
HIGHLIGHT MY NEEDS AND PROBLEMS AND WHAT HELP THERE IS AVAILABLE.
HIGHLIGHTS ONE'S PHYSICAL, MENTAL AND ENVIRONMENTAL WELLBEING AND SEES THE WAY FORWARD IF THERE ARE PROBLEMS.
HOPE.
HOW CAN I BEST CARE FOR MY WIFE AS HER CONDITION SLOWLY DETERIORATES?
HOW DO I GET ONE? MORE INFO / PUBLICITY TO CARERS ABOUT CARER'S ASSESSMENTS
I AM A CARER FOR MY HUSBAND BUT I AM ALSO ILL MYSELF WITH OSTEO-ARTHRITIS & FMS. FILLING IN FORMS LIKE THIS IS VERY DIFFICULT. HOPE I HAVE ANSWERED ALRIGHT.
I AM A HEALTH CARE WORKER + CARER FOR MY HUSBAND I COMPLETED A SELF ASSESSMENT WITH A SOCIAL WORKER WHEN I ASKED WHAT THE POINT WAS OF FILLING IN THIS FORM, I WAS TOLD "TO IDENTIFY MY NEEDS". I HAVE NEVER HAD ANY FEEDBACK AS TO MY IDENTIFIED NEEDS. SO TO RETURN TO THE ORIGINAL QUESTION - WHAT WAS THE POINT.
I AM FAIRLY NEW TO THE AREA AND TO BEING A CARER SO AM UNABLE TO GIVE AN OPINION ON ALL SUBJECTS
I AM QUITE HAPPY WITH MY PRESENT SITUATION
I AM VERY GRATEFUL TO HAVE YOUR CARERS' MAGAZINE AND FEEL THAT WITH THAT I KNOW I CAN CONTACT YOU AT ANY TIME SHOULD I NEED HELP. THANK YOU. “name of Carer”.

I DO NOT HAVE TIME FOR THIS. I AM BUSY CONSTANTLY WITH MY HUSBAND, MY HOME + CURRENT ACTIVITIES.
I DO NOT KNOW MUCH ABOUT CARERS, ALL I CAN SAY HE IS MY HUSBAND AND I WILL FOREVER DO MY BEST AS LONG AS I CAN.
I DON'T KNOW WHAT IT IS, SO NOT SURE WHAT SHOULD GET OUT OF IT.
I DON'T KNOW WHAT IT IS.
I DON'T WISH TO HAVE ONE
I FEEL SELF ASSESSMENT IS TOTALLY POINTLESS. THE WHOLE POINT OF A PROPER ASSESSMENT IS TO DISCUSS ONE'S SITUATION & GET PROBLEMS IN PERSPECTIVE. SELF ASSESSMENT IS LIKELY TO BE TOTALLY UNREALISTIC & SHOULD NOT EVEN BE CONSIDERED.
I FEEL THAT SIBLINGS - YOUNG CARERS NEED SUPPORT. ALSO INFO ABOUT WHAT WE ARE LEGALLY ENTITLED TO SO THERE IS A LONGTERM STRATEGY IN PLACE NOT REACTIVE SERVICES ONLY.
I HAVE BEEN GIVEN THE INFORMATION ABOUT WHAT I COULD APPLY FOR. I AM NOT READY TO ACCESS THESE AT THE MOMENT BUT I AM AWARE OF HOW TO CONTACT SOCIAL SERVICES IN THE FUTURE.
I HAVE FOUND MY CARER'S ASSESSMENT (REVIEW) MOST HELPFUL + IT WAS ACTED UPON VERY QUICKLY - NO COMPLAINTS!
I HAVE NEVER RECEIVED ANY FORMAL IDENTIFICATION THAT I AM A CARER, AS IF YOU RECEIEVE STATE PENSION, YOU DO NOT QUALIFY FOR CARERS ALLOWANCE IF YOUR INCOME IS ABOVE A CERTAIN AMOUNT.
I HAVE ONLY RECENTLY BECOME A CARER. I HAVE HAD SOME VERY NICE PEOPLE VISIT ME AND MY WIFE, WHO IS DISABLED. THEY HAVE ALL BEEN VERY NICE AND VERY HELPFUL BUT I HAVE FOUND THE WHOLE PROCEDURE VERY CONFUSING AND HAVE TO THINK VERY CAREFULLY BACK TO CHECK WHO CAME TO SEE ME FOR WHAT REASON. I CANNOT STATE FOR CERTAIN IF I HAVE HAD AN ASSESSMENT AS SUCH, BUT I BELIEVE IT WAS THE LAST LADY WHO VISITED. I NOW WOULD HAVE LIKED THE FIRST VISITOR TO GIVE ME A LIST OF AVAILABLE OPTIONS WHICH I COULD HAVE TICKED OFF AS I WENT ALONG AND FILLED IN PHONE NUMBERS AND NAMES.
I HAVE ONLY RECENTLY JOINED THE CARERS SUPPORT AS I HAVE BEEN CARING IN A MUCH GREATER CAPACITY FOR THE LAST FOUR MONTHS. BEFORE THAT IT WAS PRACTICAL CARING AS MY HUSBAND THEN COULD DO MORE FOR HIMSELF.
I HAVE TRIED TO HAVE A CARERS ASSESSMENT ONLY TO BE PUSHED FROM ONE TEAM TO ANOTHER, SO IN THE END YOU GIVE UP.
I JUST DON'T KNOW
I JUST LIKE GETTING THE NEWS LETTER AND KNOWING THAT IF NEED BE THERE IS SOMEBODY OUT THERE THAT CAN HELP ME. THANK-YOU.
I REALLY DON'T KNOW. MAYBE MORE HELP.
I REALLY PREFER A ONE TO ONE TO DISCUSS EVERYTHING AS YOU CAN'T PUT DOWN ON PAPER ALL WHAT YOU'D LIKE TO SAY.
I SUFFER WITH PARKINSON'S AND GETTING VERY FORGETFUL, AND FINDING IT HARDER TO DO THINGS FOR MYSELF, LET ALONE FOR MY HUSBAND.
I THINK SOME OF THE QUESTIONS, I THOUGHT I DIDN'T LIKE. EXAMPLE, HOW LONG CAN YOU CARRY ON CARING? I WILL CARRY ON AS LONG AS MY MUM'S ALIVE. DIDN'T LIKE THE QUESTIONS.
I WAS ASSESSED IN SWINDON WHEN MY MOTHER WAS INITIALLY DIAGNOSED WITH ALZHEIMER'S DISEASE IN 2007. HOWEVER, MY MOTHER LIVES IN KENNET AREA AND SO WE FALL BETWEEN TWO AREAS. KENNET HAVE BEEN FAR MORE HELPFUL THAN SWINDON.
I WOULD HOPE THAT MY MANY PROBLEMS COULD BE SORTED OUT MORE QUICKLY. I WOULD NOT FEEL SO ALONE.
I WOULD LIKE MY NEEDS TO BE MET!
I WOULD LIKE THE ASSESSMENT TO BE FOLLOWED UP WITH APPROPRIATE HELP AND SUPPORT, I WAS GIVEN THE IMPRESSION FOLLOWING MY CARER'S ASSESS THAT I WAS TOO MIDDLE CLASS, KNOWLEDGABLE & AFFLUENT TO QUALIFY FOR HELP, DESPITE BEING AT BREAKING POINT WITH MY CHILD WHO HAS ASD.
I WOULD LIKE THE SERVICES TO ACTUALLY FOLLOW UP AND CARRY OUT THE CARER'S NEEDS AS STATED ON THE ASSESSMENT INSTEAD OF JUST PUTTING IT TO ONE SIDE.
I WOULD LIKE TO BE ABLE TO ACCESS SERVICES MUCH QUICKER, AS BEING ON A WAITING LIST IS VERY SOUL DESTROYING AS CARERS LIKE MYSELF NEED SERVICES AVAILABLE 24/7.
I WOULD LIKE TO FIND OUT MORE ABOUT CARER'S BREAKS AND POSSIBLE HELP WITH

FINANCING.
I WOULD LIKE TO KNOW IF IT IS WORTH APPLYING FOR CARERS ALLOWANCE. I WAS ADVISED NOT TO WHEN I FIRST APPLIED TO CARERS SUPPORT.
I WOULD LIKE TO KNOW THAT ADVICE AND SUPPORT WERE AVAILABLE WHEN I NEED THEM.
I WOULD LIKE TO KNOW THAT SOMEBODY IS LISTENING AND UNDERSTANDING THE PRESSURE OF BEING A CARER, THE COST OF LOOSING FRIENDS, FAMILY, HEALTH, CONFIDENCE, HAPPINESS, ALSO DEPRESSION, DESPERATION AND RELATIONSHIPS. I THANK CARERS SUPPORT WHO WITHOUT THEIR HELP I AM SURE I WOULD BE IN A LOT WORSE POSITION.
I WOULD LIKE TO KNOW THAT WHEN I NEED A BREAK, I CAN BE SURE MY MUM IS CARED FOR AND IT WON'T COST THE EARTH.
I WOULD LIKE TO KNOW WHAT SUPPORT IS AVAILABLE GENERALLY AND PARTICULARLY IF I AM TAKEN ILL (EG MEALS ETC)
I WOULD LIKE TO KNOW WHY A CARER'S ALLOWANCE IS NOT THERE FOR ME WHEN I ONLY HAVE A SMALL PENSION. WE HAVE TO RUN OUR OWN CAR & SCOOTER AS MOBILITY ALLOWANCE IS AGE RESTRICTED - WHY?
I WOULD LIKE TO MAKE SURE I HAVE GOT ALL THE EQUIPMENT AND HELP THAT MAKES MY HUSBAND'S LIFE AS COMFORTABLE AS POSSIBLE
I WOULD SOMEONE TO APPRAISE MYSELF AND MY SITUATION WITHOUT MY FEELING GUILTY ABOUT WANTING THINGS FOR MYSELF WHICH LOOK LIKE ME NOT CARING FOR MY HUSBAND (THE CARED FOR). I NEED SOME PEACE, SOME FUN, SOME SENSIBLE CONVERSATION AND A CHANCE TO BE ME ONCE AGAIN.
I'D LIKE TO KNOW WHAT EXACTLY DOES A CARERS' ASSESSMENT DO? AND THE PURPOSE OF IT?
IDENTIFY ANY SERVICE WHICH WOULD HELP ME TO CONTINUE TO COPE. ALERT ME TO ANY HELP I CAN GET WITH MY ROLE AS A CARER. TALKING TO SOMEONE WHO UNDERSTANDS HOW I FEEL.
IMPOSSILBE TO SAY WHAT YOU WOULD LIKE WHEN YOU DO NOT KNOW WHAT THE ASSESMENT IS ABOUT. I WAS NOT AWARE THERE WAS SUCH A SERVICE.
IN THE CASE OF ALZHEIMERS AND SIMILAR ILLNESSES THERE IS DIFFICULTY IN GETTING INFORMATION AND ASSESSMENTS AND BUCK IS PASSED BETWEEN WILTSHIRE SOCIAL SERVICES AND WILTSHIRE MENTAL HEALTH.
INFORMATION ABOUT APPROPRIATE SERVICES AND BENEFITS.
INFORMATION ABOUT BENEFITS
INFORMATION ABOUT HOW THEY HAVE PERCEIVED I AM COPING WITH MY SITUATION AND ONGOING PRACTICAL SUPPORT FROM THE MENTAL HEALTH TEAM. (RECENTLY ALL MY SUPPORT TEAM WERE AWAY FROM THE OFFICE OVER THE SAME 2 WEEKS AND NO DUPLICATES IN PLACE).
INFORMATION ON GOOD PRACTICE TOWARDS CARERS FROM WITHIN COUNCILS AND SUPPOT AGENCIES THROUGHOUT THE BRITISH ISLES. TO BE TOLD OF THE FUNDING TOTAL LOCALLY AND HOW THE MONEY IS SPENT IN GREAT DETAIL.
INFORMATION ON WHAT CAN HELP ME SPECIFICALLY.
INFORMATION R.E. FINANCE AND DOMESTIC HELP.
INFORMATION R.E. RESOURCES AND SENSE OF BEING VALUED FOR WHAT WE DO. WE NEED HOLIDAY SCHEMES FOR WORKING PARENTS WITH CHILDREN WITH ASD.
INFORMATION, HELP + ADVICE ON CARING. LIST OF EMERGENCY / HELPFUL LOCAL TELEPHONE NUMBERS.
INPUT FROM THE PATIENT AS WELL AS THE CARER. I FIND MYSELF IN A DIFFICULT POSITION AS I CARE FOR MY MOTHER, WHO BELIEVES EVERYONE ELSE BUT ME, AND WILL NOT BE HELPED BY ME OR MY ADVICE.
IT IS GOOD TO KNOW THAT SOMEONE COMES WITH A PROFESSIONAL OUTSIDE VIEW ON MY SITUATION. I GET SO USED TO JUST CARING ABOUT MY HUSBAND'S HEALTH THAT MY SITUATION IS VERY SECONDARY TO EVERYTHING.
IT IS VERY IMPORTANT THAT THE CARER'S NEEDS ARE LISTENED TO, UNDERSTOOD AND RECORDED. ACTION AND FEEDBACK IS THEN THE KEY TO AN EFFECTIVE ASSESSMENT, WHICH SHOULD THEN BE REVIEWED EVERY 6-9 MONTHS.
IT WOULD BE HELPFUL IF OUT OF AN ASSESSMENT, I MIGHT BE AWARDED SOME RESPITE AND PERHAPS A LITTLE MORE RELIEF. THE PROBLEM IS THAT MY WIFE IS TOTALLY DISABLED AND HAS ALTZIEMERS, SHE IS OFTEN INCONTINENT UNLESS WATCHED AND I DO NOT KNOW OF ANY TRUSTWORTHY CARE HOME ABLE TO TAKE UNLESS SHE CAN BE ACCEPTED IN WESTMINSTER HOSPITAL SHAFTESBURY FOR A WEEK.
IT WOULD BE NICE TO KNOW CARERS THAT ARE IN YOUR AREA I.E. JUST IN PEWSEY, SO

PERHAPS CARERS AND THOSE THEY CARE FOR COULD PERHAPS MEET, IF ABLE, FOR A CUP OF TEA IN ONE CARERS HOUSE. SOMETIMES I FEEL VERY ISOLATED.
JUST CONFIRMATION THAT I AM DOING THE BEST I CAN AS A CARER.
JUST FOR THE CARER'S ASSESSMENT TO HIGHLIGHT MY NEEDS AS A CARER
JUST TO HIGHLIGHT MY NEEDS AS A CARER
KNOWING IF I NEED HELP OF CHANGE IN CIRCUMSTANCES, I AM ABLE TO CONTACT A SOCIAL WORKER TO UPDATE HIM/HER ABOUT CHANGES IN MY LIFE.
KNOWLEDGE OF WHAT CAN BE CLAIMED FOR AND HOW TO USE DIRECT PAYMENTS. NEEDS CHANGE AND I'M NOT SURE HOW TO GET HELP. NEED TO KNOW ABOUT SERVICES AND LENGTH OF INTERVENTIONS - E.G. HOW LONG DOES GP REFERRAL LAST ETC.
KNOWLEDGE THAT WHEN A NEED IS IDENTIFIED IT IS ACTED UPON
KNOWLEDGEABLE HELP FROM SOMEONE AND FOR IT TO BE CONDUCTED THOROUGHLY.
LACK OF KNOWLEDGE OF S. WORKER, MY WHOLE EXP HAS BEEN A NIGHTMARE. ISNOW GOING TO COURT ITS APPALLING.
MADE AWARE OF FACILITIES AVAILABLE TO ME AS CARER. THE BENEFITS THESE WOULD HAVE FOR CARER + CARED FOR PERSON. MADE AWARE HOW EASY TO ACCESS THESE FACILITIES.
MAINLY TO KNOW THAT IT IS NOT FILED AWAY FOR 2 YEARS BEFORE YOU RECEIVE A COPY AND THEN BE TOLD BY A SOCIAL WORKER AFTER 3 YEARS PERHAPS IT SHOULD BE UPDATED, ESPECIALLY AS THERE ARE 3 PEOPLE IN THE FAMILY NEEDING CARE.
MAKING SURE MY HEALTH WAS GOOD
MAYBE MORE SUPPORT AND INTEREST IN EACH PERSONAL SITUATION.
MONITORING ONE'S HEALTH IF THERE IS A PROBLEM - IE BLOOD PRESSURE, CHOLESTROL, EMOTIONAL AND MENTAL HEALTH PROBLEMS, COPING WITH STRESS AND ANGER COURSE ETC.
MORE FEEDBACK, AND ACTIVELY BEING CARRIED OUT WITH RECOMMENDATIONS OFFERED. ASSESSMENTS HAVE BEEN VERY RANDOM OVER THE YEARS AND MISSED OUT.
MORE GUIDANCE TO PROBLEMS THAN I HAVE HAD IN THE PAST THIS IS JUST NOT THERE FROM SOCIAL SERVICES OR LOCAL CARERS MANAGEMENTS. I HAVE BEEN ON MY OWN'ER AS A CARER FOR OVER FIVE YEARS AND I AM STILL STRUGGLING ON, AND LIKELY TO BE IN THE FUTURE.
MORE HELP FOR THE PERSON CARED FOR.
MORE HELP!
MORE INFO IF NEEDED AND HELP.
MORE INFORMATION AS TO DAY CARE, EDUCATION & RESPITE OPTIONS.
MORE INFORMATION TO HELP ME COPE WITH MY WIFES ILLNESS ALSO HELP WITH MY DAY TO DAY CHORES WITH COOKING GETTING IN THE RIGHT FOODS FOR HER.
MORE MONEY, MORE QUESTIONS ABOUT THE PERSON I CARE FOR.
MORE RESPITE
MY DAUGHTER IS NOW LARGELY RECOVERED, BUT WE REPEATEDLY WENT TO SOCIAL SERVICES ETC ONLY TO BE TOLD THAT WE DIDN'T QUALIFY FOR HELP. THEY WEREN'T INTERESTED IN MY DAUGHTER, WHO WAS VERY ILL, THEY CERTAINLY DIDN'T WANT TO KNOW ABOUT ME.
MY HUSBAND DIED LAST WEEK, BUT I WAS NEVER OFFERED A CLAIM FOR CARERS ALLOWANCE OVER THE 10 YEARS AND AFTER I MOVED TO “name of Wiltshire town” NOV 2006 FROM “name of Wiltshire town” I HAD TO PAY ALL MY OWN CARERS FEES IN SALISBURY I HAD SOME HELP.
MY HUSBAND WAS FORCED TO RETIRE EARLY & HAS A MUCH REDUCED TEACHERS PENSION. I ALSO HAD TO END TEACHING EARLY SO NOW I HAVE PARKINSON'S I HAD A LOT MORE HELP AT HOME & CARE FOR MY HUSBAND. THIS IS VERY COSTLY & I WORRY ABOUTY IT SOMETIMES. MY DAUGHTER HAS GONE INTO RESIDENTIAL CARE SINCE LAST NOV, BUT SHE'S STILL AN ANXIETY FOR US LONG DISTANCE.
MY NEEDS ARE CENTRED AROUND HAVING SOME HELP TO GIVE ME TIME OFF ONCE OR TWICE A WEEK. IF THE ASSESSMENT COULD HELP IN THIS PROCESS IT WILL BE WORTHWHILE. I HAVE PLENTY OF INTERESTS TO FOLLOW IF ONLY TIME WERE AVAILABLE.
MY OWN HEALTH NEEDS AS WELL AS THOSE OF MY HUSBAND MAKE A REGULAR CARERS ASSESSMENT VERY IMPORTANT, HIS NEEDS ARE COMPLEX - CANNOT FEED PROPERLY CANNOT TOILET HIMSELF AND DO TEETH OR WASH AND DRESS HIM AM AND PM IS GETTING HARDER AS MY BALANCE IS DANGEROUSLY POOR. I GET HELP IN THE MORNING BUT PUT HIM TO BED MYSELF WHEN I AM VERY TIRED. HE SUFFERS MEMORY LOSS TOO. I NEED A BREAK.
MY PERSONAL FEELING REGARDING THE ABOVE IS NOT I AM AFRAID TO SAY VERY POSITIVE. I WOULD LOVE TO HAVE SOME FORM OF POSITIVE FOLLOW UP AS AN "ON GOING FOLLOWING

CARE" IE ADVICE - CHANGES IN PROCEDURE - NEW DIRECTIVES - ETC. CARING IS A LEARNING CURVE AND IT GETS EVER LONGER - WHAT IS NEXT ON THE HORIZON???
MY SON DOES NOT LIVE WITH ME SO ASSESSMENT N/A.
MY SON IS IMPROVING + SO MY WORK FOR HIM IS GETTING MUCH EASIER BUT I FEEL HE NEEDS MORE HELP WITH HIS SOCIAL LIFE. MY DUTIES ARE DECREASING.
MY WIFE DIED “date”. THANK YOU
MYSELF AND MY HUSBAND ARE BOTH ON THE BLIND REGISTER AND WE LOOK AFTER EACH OTHER. WE ARE BOTH OVER 80.
NEEDS HIGHLIGHTED, FOLLOW UP (AFTER CARING), POINTERS TO SELF HELP AND SUPPORT FACILITIES.
NEVER BEEN OFFERED ONE SO WOULDN'T KNOW WHAT THE OPTION ARE.
NO
NO LONGER APPLICABLE AS MY DAUGHTER NO LONGER LIVES WITH ME ALL THE TIME - SHE COMES HOME EVERY 3RD WEEKEND
NO LONGER REQUIRED AS NO LONGER A CARER AT HOME SO NOT ABLE TO ANSWER AT PRESENT
NOT HAVING TO WAIT FOR ASSESSMENT. SOMEONE TO LISTEN - TAKE ACTION AND IMPROVE MY SITUATION AS A CARER TO PREVENT ME BECOMING ILL TO BE REVIEWED FREQUENTLY.
NOT JUST A PAPER EXERCISE - BUT WHERE SOMETHING POSITIVE HAPPENS AFTER THE ASSESSMENT
NOT RELEVANT IN VIEW OF ABOVE NOT WITHSTANDING ANY OF MY ANSWERS, MAY I ASSURE YOU THAT I MUCH APPRECIATE EVERYTHING THAT IS DONE FOR US.
NOTHING SPECIFIC
ONCE AN ASSESSMENT HAS BEEN CARRIED OUT AND PROBLEM AREAS HAVE BEEN HIGHLIGHTED, ACTION IS TAKEN TO SOLVE THE PROBLEMS, SOONER RATHER THAN LATER.
PLEASE NOTE - CHANGE OF ADDRESS.
PRACTICAL SERVICES THAT ARE AS A RESULT OF A WHOLE FAMILY ASSESSMENT WHICH WOULD IMPROVE QUALITY OF LIFE FOR THE WHOLE FAMILY
PROMPT FEEDBACK (ACTION ON MATTERS IDENTIFIED)
REAL HELP FOR USER AS WELL AS CARER AS BOTH ARE AFFECTED BY AN ASSESSMENT OF CARERS NEEDS E.G. JOINT RESTBITE?
RECOGNITION FOR THE TOUGH JOB WE DO AND APPROPRIATE HELP AND SUPPORT FOR EMOTIONAL AND PHYSICAL NEEDS.
RECOGNITION FROM THE GOVERNMENT OF THE TRUE VALUE THAT CARERS GIVE TO THIS COUNTRY
RECOGNITION OF THE STRESSES & DEMANDS OF CARING & SOME PRACTICAL HELP TO RELIEVE IT. NOT JUST DIRECT PAYMENTS WHICH RELY ON THE CARER DOING THE ADMINISTRATION.
RECOGNITION THAT I AM DOING A GOOD JOB (OR AT LEAST THE BEST I CAN) BUT THAT I NEED SUPPORT - FINANCIAL, PRACTICAL AND EMOTIONAL.
REGULAR ASSESSMENTS AS SITUATIONS AND NEEDS CHANGE FREQUENTLY. FEEDBACK AND DETAILS OF WHAT HELP WE COULD BE GIVEN AND WHY HELP FOR US IS OFTEN REFUSED.
SADLY MY WIFE DIED ON “date”. GRATEFUL, THANKS FOR ALL YOUR HELP IN THE PAST 2 YEARS. VERY MUCH APPRECIATED. “name of Carer”.
SOME ACTION AND HELP: SO FAR IT HAS BEEN A WASTE OF PRECIOUS TIME. AS A FULL TIME CARER I WOULD LIKE HELP SO FAR THE ASSESSMENTS HAVE RESULTED IN NONHING.
SOME FEEDBACK ON WHAT I CAN DO TO IMPROVE MY QUALITY OF LIFE
SOME FORM OF PHYSICAL HELP.
SOME FORM OF SOLID HELP THAT DOESN'T COST AN ARM AND A LEG AS A RESULT OF A CARERS ASSESSMENT
SOME INFORMATION ABOUT FINANCIAL HELP AS I PAY MYSELF FOR A GARDENER AND DOMESTIC HELP. WHICH IS WHY ONLY SOME OF THE QUESTIONS ARE APPLICABLE.
SOME MORE INFO GIVES CONFIDENCE THAT I AM DOING THE RIGHT THING
SOME SUPPORT FOR WHEN THINGS ARE GETTING TOO MUCH SOMEONE TO BOUNCE OFF OF. ACTIVITIES FOR MY CHILD WITH SPECIAL NEEDS, IT IS NOT EASY TO FIND ANY CLUBS FOR HIM TO ENJOY AND BE A PART OF.
SOMEONE TO LISTEN TO ALL OF MY PROBLEMS. TO KNOW THAT THERE ARE OTHER CARERS LIKE

ME. TO TALK AND UNLOAD ALL OF THE STRESS OF BEING A CARER. TO PROTECT ME. TO ASK ME ABOUT MYSELF AND NOT JUST ABOUT THE PERSON I CARE FOR. TO BE ABLE TO SAY THANK YOU FOR CARERS SUPPORT.
SOMEONE WHO HAS FULL KNOWLEDGE OF YOUR SITUATION (A FULL HISTORY OF THE PERSON YOU CARE FOR) WHO LISTENS - SEES WHERE YOU REALLY NEED HELP BE IT FINANCIAL OR PRACTICAL. I WAS LUCKY I MET THE RIGHT PEOPLE - THERE ARE STILL PEOPLE WHO DO NOT KNOW THE HELP THEY CAN GET! MOST ARE FRIGHTENED BY FORMS AND OFFICIALS.
SORRY CAN NOT CARRY ON AS SUFFERED A SEVERE HEART ATTACK, AND RECENT CAR ACCIDENT, CHECK WITH SALISBURY HOSPITAL WHERE I WAS IN TERMINAL CARE
STATUTORY REQUIREMENT TO SUPPLY SERVICES REQUIRED TO MEET NEEDS IDENTIFIED
SUPPORT
SUPPORT + INFO
SUPPORT AND ADVICE.
SWIFTER PROCESSING.
THAT I HAVE THE RIGHT EQUIPMENT FOR MY NEED, SUPPORT AND KNOWLEDGE. THAT IT IS DONE AS A COUPLE AND NOT JUST ONE INDIVIDUAL (EG THE ONE BEING CARED FOR) THE CARER NEEDS TO KNOW THEY ARE NOT FORGOTTEN EVEN THOUGH THEY ARE REALLY THERE FOR THE ONE CARED FOR! ALSO NOT HAVE A PERSON EACH, HAVE SAME PERSON FOR BOTH OF YOU.
THE APPROPRIATE HELP BEING ORGANISED FOR THE PERSON I CARE FOR.
THE ASSESSOR TO BE A CONSISTENT ONE. WHO WOULD BE ABLE TO PICK UP ON CHANGES I MAY HAVE OVERLOOKED. I WOULD WANT TO KNOW THEY WERE INTERESTED IN MY LIFE TO WANT TO SUPPORT MY "LEGAL" NEEDS. I NEED THE ASSESSOR TO SHOW GENUINE INTEREST IN MY NEEDS NOT WASTING MY TIME. NO CONSISTENCY FROM CARER PROVISIONS. I AM CONSTANTLY HAVING TO TRAIN NEW CARERS THIS IS VERY WEARING AND TIRESOME. MAIN CARERS ARE PUT ON OTHER JOBS. THIS MAKES ME THINK I AND MY HUSBAND ARE OF NO CONSEQUENCE
THE HELP SOCIAL SERVICES OFFER A CARER IS VERY LIMITED. THE HELP IF OUR CASE FOR THE ONE BEING CARED FOR IS LIMITED. ACCESS TO INFORMATION AND CONTACTS, FOR SUCH THINGS AS SUITABLE HOUSING, TRANSPORT, PHYSIO, LEISURE ACTIVITIES ETC. A LACK OF HELP IN THESE FIELDS AND OTHER DOES NOT HELP EITHER CARER OR CARED FOR.
THE KNOWLEDGE THAT IT WAS NOT A WASTE OF TIME TO DO THIS AND THAT IT WOULD NOT THEN BE BURIED IN A FILE SOMEWHERE
THE MAIN THING IS TO MAKE SURE THERE IS SUFFICIENT CARE IN AN EMERGENCY.
THE MENTAL PROBLEM OF BEING A CARER OFTEN LEAVES ME AT MY WIT'S END. WHO DO I TALK TO? DOCTORS DO NOT HAVE THE TIME.
THE NEED TO UNDERSTAND THE 'CARING' FOR A PERSON AT HOME ALL THE TIME (EVEN THOUGH THE PERSON BEING CARED FOR SEEMS VERY ABLE WHEN OUT OF THE HOME OR TALKING TO A STRANGER).
THE PERSON WHOM I CARE FOR, “name of person cared for”, HAS NOW DIED AND I AM NO LONGER CARER. HIS OTHER BROTHER, “name”, IS ABLE TO CARE FOR HIMSELF.
THE REASSURANCE OF KNOWING HELP IS AVAILABLE
THE RIGHT SUPPORT INFORMATION AND SERVICES MADE AVAILABLE TO THE CARER. ALSO, ALL OPTIONS TO BE SHARED/DISCUSSED WITH THE CARER NOT JUST WHAT THE SOCIAL WORKER THINKS BEST!. THANKS.
THE SOCIAL WORKER ALLOCATED SHOULD BE AWARE WHETHER WE (PARENTS) ARE ALIVE OR DEAD SO THAT OUR SON'S NEEDS (EMOTIONALLY) WILL BE FULFILLED. OUR CONCERN IS WHO IS GOING TO CARE WHEN WE ARE DEAD.
THE WHOLE PICTURE LOOKED AT APPROPRIATE HELP FOR THE PERSON BEING CARED FOR AND THE CARER. REGULAR REVIEWS.
THERE IS ONLY ME TO PROVIDE CARE AND HELP TO MY FRAIL ELDERLY PARENTS. WE DO NOT QUALIFY FOR ANY FINANCIAL HELP OTHER THAN NON-MEANS-TESTED BENEFITS. I MUST JUST SOLDIER ON FOR THE NEXT TEN YEARS OR SO!!
THINK THIS FORM IS EXACTLY THE SAME AS THE LAST ONE I FILLED IN
THIS IS NO LONGER RELEVANT AS I AM NO LONGER A CARER AS MY WIFE IS IN PERMANENT CARE BUT I DO APPRECIATE THE HELP AND ADVICE I OBTAINED FROM THE GREEN LANE HOSPITAL, DEVIZES, PARTICULARLY BY “name of staff member”
THIS QUESTIONNAIRE SHOULD HAVE BEEN ADDRESSED TO ME “name of Carer” AS SOLE CARER OF MY HUSBAND “name of person cared for” AND NOT TO HIM. PLEASE AMEND YOUR RECORDS ACCORDINGLY. THANKYOU

TO BE ABLE TO ACCESS ANY HELP THAT I NEED, ALTHOUGH I TRY TO BE INDEPENDANT, I NOW KNOW THAT I NEED SOME HELP.
TO BE GIVEN INFORMATION ON SERVICES AND SUPPORT I CAN ACCESS, AS WELL AS LOCAL GROUPS MY DAUGHTER CAN JOIN, AS WELL AS INFORMATION ON SOCIAL INCLUSION. IT SEEMS A BIT 'MISS & HIT' WHERE USEFUL INFORMATION IS FOUND.
TO FEEL OUR FAMILY NEEDS HAD BEEN FULLY UNDERSTOOD AND THAT AS A RESULT WE WOULE RECEIVE NECESSARY HELP PARTICULARLY AS OUT SON WILL SOON LEAVE SCHOOL WHICH WILL GREATLY CHANGE CIRCUMSTANCES FOR ALL OF US.
TO FOLLOW THROUGH ON THE RESULT.
TO HAVE A NAMED INDIVIDUAL (NOT NECESSARILY A SOCIAL WORKER) WHO I CAN MAKE CONTACT WITH
TO KNOW IF I'M COPING AND GETTING THINGS RIGHT, WHY I SOMETIMES FEEL FRUSTRATED AND ANGRY, WHEN I AM NOT THE PATIENT. AND THEN ALTERNATIVELY LOSE INTEREST.
TO KNOW MORE ABOUT RESPITE CARE FOR A FEW DAYS.
TO KNOW THAT ALL MY NEEDS AND THAT OF MY CHILD ARE BEING CATERED.
TO KNOW THAT I AM DOING ALL THAT IS POSSIBLE TO GIVE MY MUM ALL SHE NEEDS TO ENJOY HER LIFE AS BEST AS POSSIBLE
TO KNOW THAT NEEDS HIGHLIGHTED BY THE ASSESSMENT WILL BE MET - OTHERWISE IT IS DRPESSING AND POINTLESS
TO KNOW WHAT SERVICES ARE AVAILABLE TO ME.
TO MAKE SURE I'M DOING EVERYTHING POSSIBLE FOR MY MUM'S WELL BEING.
TO MAKE SURE THAT ALL BENEFITS THAT ARE AVAILABLE ARE CLAIMED FOR BOTH CARER AND CARED PERSON. ANY CHANGE IN RULES FOR CLAIMING BENEFIT ARE UPDATED AND REVIEWED TO CARER/CARED
TO RECOGNISE ALL ASPECTS IN MY ROLE AS A CARER AND NEEDS OF INDIVIDUAL MEMBERS OF MY FAMILY WHICH ARE OR CAN BE AFFECTED BY MY ROLE AS A CARER.
TO RECOGNISE THE IMPACT ON THE CARER'S MENTAL HEALTH, PHYSICAL HEALTH AND ISOLATION.
TO SHOW ANY SERVICES OR HELP THAT I MAY BE ENTITLED TO THAT I HAVE NOT BEEN ABLE TO FIND OUT ABOUR MYSELF.
TO TALK FACE TO FACE WITH A PERSON.
VERY OFTEN THE ASSESSMENTS AND ASSESSORS FAIL TO READ BETWEEN THE LINES THEREFORE FAIL TO REALLY PINPOINT THE REAL AREAS FOR ESSENTIAL HELP. EXAMPLE - THE STRAIN ON PARTNERS RELATIONSHIP ETC ETC.
WE ARE VERY HAPPY WITH THE HELP WE GET FROM “name of social worker” OUR SON'S SOCIAL WORKER
WHAT IS A CARER'S ASSESSMENT?
WHAT IS AVAIABLE LOCALLY FOR CHILDS NEEDS
WHAT IS IT?
WHILST I HAVE EMPATHY FOR PEOPLE DOING 24/7 CARING AS I KNOW HOW THAT FEELS - I'VE DONE IT. BUT MY SON IS NOW IN SUPPORTED LIVING AND I'M IN MY MID FIFTIES AND WOULD LIKE HELP AND SUPPORT TO IMPROVE MY LIFE NOW. SORRY IF THAT SOUNDS SELFISH BUT IT'S HOW I FEEL.
WHY DOES THIS CARERS VOICE FOCUS SO HEAVILY ON THE LIBRARY SYSTEM? 9 QUESTIONS ON THE LIBRARY SERICE IS EXCESSIVE.
WOULD LIKE TO BETTER UNDERSTAND WHAT IT WAS. DIDN'T KNOW IT WAS FOR ME AS A CARER. JUST ME. SOCIAL WORKER NOT VERY HELPFUL AND SAID THE DRIVING LESSONS WOULD HAVE TO BE FUNDED BY A CHARITY LIKE ROUNDTREE. SO NO OUTCOME AND GAVE UP ON FILLING OUT FORM.
WOULD LIKE TO DISCUSS WHAT COULD BE DONE TO HELP MAKE THINGS BETTER
WOULD REALLY NEED TO HAVE A SOCIAL WORKER IN THE HOME FOR 24 HOURS TO REALLY ASSESS A CARERS WORK, AN HOUR OR TWO DOES NOT GIVE A TRUE PICTURE.