



# Time for You

## **Stage 1 Report – Finding Hidden / Under Reached Family Carers**

**Date: 13<sup>th</sup> September 2010**

**Pilot area: Brandon**

**Organisation: Turning Point**

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# 1. Introduction

## About this report

In October 2009 Turning Point's Connected Care Team was commissioned by Suffolk County Council to become a partner in the Department of Health Carer Demonstrator Short Break Pilot Site programme (known in Suffolk as the Time for You project). The main purpose of this report is to share the findings from the research done as part of pilot.

The report takes the following format:

- **Section 1 and 2** provides an overview of the project
- **Section 3** introduces the community researchers who carried out the research in Brandon
- **Section 4** outlines how family carers were found to take part in the research and the diversity statistics of family carers involved in the project
- **Section 5** presents the findings from the research
- **Section 6** looks at the impact the project has had in Brandon
- **Section 7** makes some recommendations based on our learning from the Time for You Brandon Project

## 2. Project Overview

Turning Point's Connected Care team was invited to become a partner in the Time For You project by Suffolk County Council in March 2009. Turning Point was already working in Brandon on a Connected Care project<sup>1</sup> and Suffolk County Council was interested in using the Connected Care research methodology in relation to family carers.

The Connected Care research methodology involves recruiting local people and training them up, and supporting them to become community researchers. For the Time for You project, Suffolk County Council were interested in Turning Point recruiting up to 5 family carers from the Brandon area and training them to become researchers.

Once trained, these researchers would then go out and speak with up to 200 eligible family carers in Brandon about their caring role and the short breaks they would like to receive. In return for taking part in the research each family carer was offered a £100 award to spend on a short break of their choice. Family carers were eligible for the project if they:

- look after a family member, friend of neighbour who is over 18 years old
- are over eighteen
- can show they have not received the right type and amount of short break services in the last 12 months
- live in Brandon.

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<sup>1</sup>Connected Care is Turning Point's model of community led commissioning; one that integrates health, housing and social care. The model provides a means to achieving integrated services, through community-led commissioning. It narrows the gap between commissioner priorities and the needs of the local population through community engagement.

By delivering a joined-up, user led approach to health, housing and social care, greater efficiencies can be achieved when:

- Services are designed around people's needs so therefore are more likely to meet them
- By listening to local people, services will be located in areas where they are most needed

Turning Point was involved in the original bid to the Department of Health in March 2009. The bid was lead by Suffolk County Council and involved Turning Point, Ipswich Borough Council, Suffolk ACRE and Suffolk Family Carers as bidding partners. This resulted in Brandon, Ipswich and Peasenhall and Sibton being selected as the areas to carry out the project. The bid was successful and in Oct 2009 Suffolk became one of 12 national Department of Health Short Break Carer Demonstrator Sites.

## **2.1 The Brandon Time for You Area**

The Time For You project in Brandon focuses on the Brandon East and Brandon West Ward. The area of Weeting was also included in the research. Although technically in Norfolk, Weeting’s address and postcode is Brandon, Suffolk and people living in Weeting look to Brandon as their nearest town.

## **2.2 A pen portrait of Brandon**

Brandon is a small market town and civil parish in the English county of Suffolk. Surrounded by agriculture and Forestry Commission land it is considered a rural town, although there is an RAF air base on lease to USAF, Lakenheath, just a mile or so away. The wards of Brandon East and Brandon West include the town of Brandon and the villages of Wangford, and Elveden and the Centre Parcs holiday resort in Elveden.

The Time For You area consists of two wards – Brandon East and Brandon West. Both wards fall under Forest Heath District Council. The total population of Brandon is 10,455 (ONS Mid-year estimates, 2007). Brandon East has a population of 6,359 (ONS Mid-year estimates, 2007) and Brandon West has a population of 4,096 (ONS Mid-year estimates, 2007). There is an even gender spread across the two wards.

The majority of the population living in Brandon are from white backgrounds; 96 per cent of people, 1.6 per cent of people are from Black or Black British backgrounds, 0.3 per cent are from Asian or Asian British backgrounds and 0.8 per cent are from Chinese or other ethnic backgrounds (ONS Census, 2001).

Population estimates suggest that the population of Brandon is relatively older than much of Suffolk. 25 per cent of the population of Brandon is aged over 60. This is higher than the England average of 21 per cent (ONS Mid-year estimates, 2007).

In terms of family carers in Brandon, the census 2001 reports that 821 people living in Brandon classify themselves as providing unpaid care. The majority of family carers in Brandon provide less than 19 hours care a week, however there is a significant number that provide more than 50 hours care a week:

### **Brandon East Ward**

Provides 1 to 19 hours care a week (Persons) <sup>1</sup>	Count	334
Provides 20 to 49 hours care a week (Persons) <sup>1</sup>	Count	48
Provides 50 or more hours care a week (Persons) <sup>1</sup>	Count	129

### **Brandon West Ward**

Provides 1 to 19 hours care a week (Persons) <sup>1</sup>	Count	193
Provides 20 to 49 hours care a week (Persons) <sup>1</sup>	Count	35
Provides 50 or more hours care a week (Persons) <sup>1</sup>	Count	82

These figures suggested that the target of finding 200 family carers to involve in the Time For You project ought to be attainable.

### 2.3 Project targets

Turning Point's target was to recruit up to 5 family carers and train them to become community researchers. The other main target was to find 200 hidden family carers, who for a variety of reasons were unable to access or were unaware of current short breaks that were available to them, and involve them in the research.

### 2.4 Project Plan

In Brandon the original plan was to start the project in August 2009 and finish the project in May 2010. However the project was delayed and then the timescales were extended by Suffolk County Council and the project ran from October 2009 until Sept 2010. The activity plan for Time for You Brandon follows below:

Project Plan												
	Oct-09	Nov-09	Dec-09	Jan-10	Feb-10	Mar-10	Apr-10	May-10	Jun-10	Jul-10	Aug-10	Sep-10
1. Recruit 5 family carer CRs												
2. Train family carer CRs												
3. Design research questionnaire												
4. Release publicity/posters around £100 award												
5. Find 200 seldom served family carers and conduct research												
6. Analyse research findings												
7. Write 1st draft of report												13th Sept
8. Put 1st draft to SG for Comments												13 <sup>th</sup> Sept
9. Finalise report in light of any changes recommended by project SG												30th Sept

### 2.5 The £100 award

In exchange for taking part in the research the family carers were offered £100 to spend on a break of their choice. Family carers were able to spend the £100 on anything that they considered to be a break from their caring role. This could include for example:

- Having an allotment (with others) – such as the Community Garden
- Going to a group with other family carers / membership of clubs

- Sharing an evening out with friends
- Going on a shopping trip or a weekend retreat
- Seeing a West-end show or visiting a museum
- Having driving lessons / going to evening or day classes / English language classes
- Getting help with housework / laundry / gardening
- Purchasing equipment or adaptations to your home
- Purchasing a bus pass, a mobile phone, or IT equipment
- Paying a friend / neighbour to be with the person you care for
- Playing a sport / going to a fitness class / Gym membership
- Therapy in the home
- 'Befriender' for the cared for person to take the pressure of the family carer for a while. This will include taking them out for a while.
- Someone to go out with both the family carer / informal carer and person cared for

## **2.6 The Time For You questionnaire**

In order to receive the £100 award family carers needed to complete 3 parts of a questionnaire for the Time for You project:

**Part 1:** was a short questionnaire, comprising only eight questions to see if the family carer was eligible for the £100 award. This was normally conducted over the telephone with a member of the Turning Point Connected Care team.

**Part 2:** was a longer questionnaire and involved a pair of the community researchers going to meet the family carer at a time and place most convenient for the family carer. Typically this part of the questionnaire was carried out in the family carer's home. The questionnaire included questions about their caring role, their feelings around their caring role and the types of short breaks the carer would like to receive. Once this step was completed the £100 was paid into the family carers bank account by a bank transfer.

**Part 3:** was slightly shorter than part 2 and involved the community researchers speaking to the family carers in their home or over the telephone to find out about how the family carer spent the £100 award. They also asked the family carers about their caring role and their feelings about their caring role to see whether the £100 award and having a short break had any impact on their well being.

All of the research was carried out between January and September 2010.

### **3. Community Researchers**

A fundamental part of Turning Point's research methodology is to use community members to carry out research in the community that they live in. As members of their local community, community researchers are able to add local credibility to the project. They can access parts of the community which may otherwise have not been reached, whilst developing their own skills, understanding and confidence at the same time. This method of using local people to help address and solve local problems is known as action research.

Five family carer community researchers were recruited. Their background and experience of the community researchers involved in the Time for You project are captured in this section of the report. They were supported by four of the original Connected Care community researchers (also local people).

#### **3.1 Recruitment**

In October 2009 Turning Point started the recruitment process to find family carers who would like to become community researchers. A number of different methods were used to recruit the family carer community researchers.

An advert was designed and placed in the local newspaper – the Brandon Life (please see the following page for a copy of the advert used). This paper is widely read in Brandon as it contains articles from local councillors and information on everything that is happening in Brandon. The paper is free and is delivered to every house in Brandon. The advert was also enlarged into an A3 poster and these posters were put up in various key locations in Brandon such as local shops and on notice boards through the town.

The Turning Point project lead for Brandon, Kate Jones also spoke to Suffolk Family Carers and West Suffolk Crossroads who kindly agreed to send out the advert to their contacts in the Brandon Time for You area.

Kate also attended other meetings which family carers may attend such as the Brandon Handicapped Club and the Mildenhall Alzheimer's society meeting to speak to the group about the project to see if any family carers may be interested in taking part in the project.

Five family carers expressed an interest in the project and each family carer was interviewed for the role. Two of the community researchers came via the advert sent to them by Suffolk Family Carers, one came through an advert sent by West Suffolk Crossroads, one came through the meeting at the Alzheimer's meeting and one came via a Connected Care contact at the Brandon Learning Disability Club – the CRU.

All five were appointed. The family carer community researchers came from a variety of different caring backgrounds, one cared for her husband, two cared for their children, one cared for her husband who had recently died and one cared for her elderly mother. This meant the group had a wide variety of caring experiences and the ability to empathise with other family carers when doing the research, because of all their caring experience.

The group comprises of five females. Unfortunately no male family carers expressed an interest in the role. However all the community researchers were committed to improving local services for family carers and broadening their own experience. None of the community researchers had done this type of work before.

In addition to the five family carer researchers, four of the experienced Connected Care community researchers expressed an interest in working on the Time for You project. They were employed to work on the project and their help was invaluable as they were able to act as mentors to the new family carer researchers. These Connected Care researchers help build the confidence and research skills of the carer community researchers and were also of great help as the capacity of some of the family carer community researchers was limited due to the demands of their caring roles.

### The Time for You Recruitment Advert:

**CONNECTED CARE  
TALKING COMMUNITIES,  
TRANSFORMING SERVICES**

**TURNING POINT**  
turning lives around

What's wrong with your services?

Voice your opinion

SPEAK UP

Speak out and be heard

tell it like it is

**DO YOU WANT TO MAKE A DIFFERENCE?**

Carers don't think of themselves as 'carers', but the caring they provide often changes people's lives. They help and support those, who, due to old age, illness or an addiction could not manage otherwise. Carers often do this for free, out of kindness and love.

We believe carers should be given as much support as possible. If you agree and are caring for someone, then we would love to hear from you. We are looking for up to 10 people who are carers who would like to get involved in a new project in Brandon.

**For more information please contact Kate Jones on:  
07768 317 188 or email on [kate.jones@turning-point.co.uk](mailto:kate.jones@turning-point.co.uk)**

**We offer you:**

- Payment of £7 an hour
- Full training and support
- Flexible hours (from 1 hour a month up to 6 hours a week)
- The chance to develop new skills and meet new people
- The chance to improve future employment prospects
- We can also provide a Crossroads Carer whilst you are working for us, so you need not worry about the person you are caring for.

**In return, we ask that you:**

- Be a carer
- Take part in our training course (training can be arranged at times that suit you)
- Carry out research in your local community

This project has been funded by Department of Health.  
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### **3.2 Training**

Following the recruitment process, the family carer community researchers completed the Turning Point Connected Care training programme, which has been quality assured by the Social Care Institute for Excellence. Their training consisted of three sessions, each three hours long, and covered:

- An introduction to Connected Care, Turning Point and the Time For You Project
- An introduction to community action research, safety and ethics in community research and the Connected Care audit
- An introduction to the design and delivery of research methods including sampling methods and conducting and designing interviews, focus groups, and questionnaires.

Once the training was completed the first of many 'next steps' sessions began in January. The 'next steps' sessions were held once every two weeks for two hours, usually on a Friday afternoon and they continued for the duration of the project.

The purpose of these sessions were to support the researchers and offer further training when needed. Examples of some of the sessions include:

- Piloting and refining the questionnaires so that the researchers had the opportunity to improve the questionnaire
- Practicing carrying out the questionnaires, including some role play exercises
- Representatives from the other Time for You Projects in Ipswich and Peasenhall and Sibton came to Brandon to meet the Brandon community researchers
- Representatives from Suffolk County Council's family carers team meeting and speaking to the group about benefits family carers are entitled to receive
- Discussions on how to find more family carers
- Organising times and dates for community researchers to visit family carers to carry out the research.

### **3.3 Carrying out the research**

Once fully trained the researchers went out into the community and carried out questionnaires with family carers. The majority of the research was carried out by pairs of community researchers. This was primarily for health and safety reasons as the research was most commonly carried out in family carer's homes. However, working in pairs also meant that one person could ask the questions and the other person could note take which increased the quality of the research.

To build their confidence, each family carer community researcher was paired up with an experienced Connected Care community researcher at the start and did the note taking during the questionnaires. Once they felt ready, the family carer community researchers started asking the questionnaires and were assisted by the Connected Care researchers. And only when fully confident were family carer community researchers paired up with other family carer researchers.

### **3.4 Case Studies of the Community Researchers**

Brief case studies and a photo of each of the community researchers are laid out below. The case studies are in the researchers own words and give a flavour of why they decided to get involved with the Time for You project, their caring role, how they found the training they received at the start of the project, how they found doing the research and some of the things they feel they have learnt through taking part in the project.

Unfortunately of the nine researchers originally recruited one of the family carer community researchers had to drop out of the project due to a change in their personal circumstances as did two of the Connected Care community researchers. Unfortunately one of the Connected Care researchers was diagnosed with cancer and the other moved away from the area. The researchers are however still in contact with the project though and will receive copies of the research report and are of course welcome to come back to the project if their circumstances change.

### Family carer community researcher case studies:



**Lisa:** I am in my late 30's and care for my daughter Bethany Shaw who is 6 years old. Bethany has severe developmental delay, severe microcephaly and is partially sighted. I got a flyer from Crossroads about the Time For You Project and thought the job sounded interesting and felt that this was something I could do with the little free time I have. I also thought that the project sounded like a good way to meet and hopefully help carers.

I have found doing the research thoroughly interesting and hope it will help carers in the future. But it has been hard not being able to help the carers I have spoken too even more, and also hard to see how difficult some carers have it. It is also been hard knowing that the project is coming to an end.

I have learnt that even a little money can help and that carers often don't want or need lots of money. It is often just some company and

people's understanding that they need. I have also learnt that every situation and carer's needs are different.

I have thoroughly enjoyed being part of this team. We are a great team with members having different points of view, but we all seem to work well together and have empathy for others and want to help. I hope that we can one day work together again. I hope that the research we have done will enable carers to get more help and also get the sort of help that they require.



**Jan:** I am in my early 60's but I am not too doddery! I cared for my husband who died 18 months ago. He suffered from Parkinson's, Lewy Body dementia, Emphysema and had a de-fib fitted due to Sudden Death Syndrome. The loss of my husband has been so very hard. We were inseparable so I had to find something to make me want to carry on alone. This project has done just that. It's given me the opportunity to channel my grief into helping carers and their loved one along with the camaraderie of my fellow researchers.

I loved the training sessions we took part in. I found it a bit confusing to begin with but it did all fit into place and the gentle guidance we got from our trainers was exceptional. Doing the research has been satisfying but at time also heartbreaking. I felt that I have made many carers feel a bit better by both the £100 and the chats we had. It has been hard leaving some of the carers and their cared for but it was great to be a friendly face that they could turn too. I have learnt a lot through this project – I know that there are people far worse than me out there, but also that there is help available once you are in the loop. I have also learnt that I can contribute.

I have also enjoyed working as a team. It has been great fun. I feel that if this project finished now most of us would still be friends or stay in touch.

The Time for You project has given me the opportunity to feel wanted and useful once again.



**Julia:** I am 51 years old and help my father care for my 94 year old mother who has severe Alzheimer's. I wanted to get involved in the Time for You project as I have seen for the past ten years how dementia has affected my entire family and how carers have to cope with ever increasing problems and difficulties. I have really loved being part of this project. I found the training very enjoyable and informative and I especially enjoyed the visits from other organisations to Brandon.

I have found doing the research incredibly interesting but I have found it hard to speak to carers who were caring for people in the early stages of Alzheimer's. Having seen my mother go rapidly downhill I know how much harder their lives will get. I have learnt how incredibly humble many of these carers are, some don't even think of themselves as carers. Some of the people we have spoken to have made me realise that although my mother is so poorly, there are many people in far worse situations.

It has been really enjoyable working as a team on the Time for You project. We have all worked really well together and everyone had something important to contribute to the project.

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**Trisha** I am in my mid 70's and I care for my husband Norman, who has motor neurone disease, arthritis and bi polar. I was interested in this project as my husband is severely disabled and needs a lot of help in every aspect of his life. I think it is important to have contact with other people so I decided to take part in the Time for You project.

The training was very helpful and we were able to make friends with the other members of the group and it has become quite a sociable occasion to come to the meetings. Doing the research was very interesting and to find out about other people in similar circumstances was very important. It has been difficult trying to contact carers to interview and some of the questions we had to ask were a bit confusing. I was surprised to learn how many disabled people there are in Brandon and Weeting, I have very much enjoyed working on this project and being a member of the Time for You team.

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#### **Connected Care community researchers:**

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**Lisa**

I'm a Suffolk County Council Home First Carer in my 40's and I work for social services. I got involved in the Time For You project through the work I did on the Connected Care project. I found doing the research very interesting and informative, as I spoke to lots of different people in many different situations. It was hard listening to some very sad stories and to find people who need lots of help and support which they obviously were not receiving. I have learnt that many carers get "missed out" on lots of information and services. It has been a really good team to work with and has been a great working environment.

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**David:** I am 38 years old and live with my parents who are semi retired. I wanted to get involved in the Time for You project as I am interested in how individuals cope when life changes mean someone close to them needs looking after. It has been very special being allowed into people homes and hearing how a small amount of money can make a big change to how they feel.

I have really enjoyed doing the research. Working in a pair has been a great help and supporting each other during visits to people homes has been great. I believe it was a great help to those being interviewed with two people – with one person asking the questions and the other writing down the answers this meant that the person asking the questions was able to give their full attention to the family carer. I have really enjoyed working as part of a team on this project and I have really enjoyed this experience.

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**Group photo of a Brandon next step team meeting in Brandon Country Park:**



## 4. Finding Family Carers

### 4.1 Finding hidden family carers

The target number of family carers we aimed to involve in Part one of the Brandon Time for you project was 200. In total we found 112 family carers. 17 of these family carers were not eligible for the project. In total we found 95 hidden eligible family carers.

Finding hidden family carers proved far harder than was anticipated by all of the Time for You team, particularly in light of the fact we were able to offer £100 as an incentive to take part in the research. It is important to note that the other Time for You projects in Ipswich and Peasenhall and Sibton also struggled to find hidden family carers. The Ipswich project managed to locate 150 eligible family carers out of their target of 300, and Peasenhall and Sibton located 4 eligible family carers out of their target of 50.

Although the target was not reached, we were very pleased to find so many hidden family carers in such a small population. Brandon's total Time for You project population is 8,785 whereas as Ipswich's area's population was 117,069 and Peasenhall and Sibton's population of 2,048. Seeing as the Ipswich project struggled to find hidden family carers in such a large population, finding 95 hidden family carers in Brandon was a definite success.

The Brandon Time For You team worked very hard to find hidden family carers throughout the duration of the project. The main actions taken to find family carers included:

- 4 full page advertisements in the local free paper 'The Brandon Life'
- Putting circa 15 posters advertising the project in key locations in Brandon
- Getting 2 articles on the project in local newspapers
- Holding 2 market stalls in the town square on market day
- Door knocking in area where older people live in Brandon
- Leafleting houses (around 350 leaflets were posted in Brandon)
- Attending local group meetings such as the Visually Impaired Club, the Brandon Handicapped Club and the Brandon Alzheimer's Club meetings to speak to the group about the project and see if any carers who were attending the meetings were willing to get involved in the project.
- Community researchers using their own contacts and knowledge of Brandon to find family carers and involve them in the project
- Although not an action taken, word of mouth was a very effective method of finding family carers.

These different methods of finding family carers to involve in the project met with varying success. Family carers were very slow to come forward at the start of the project, but as the project continued more momentum built up and more carers began to come forward in larger numbers.

The majority of family carers involved in the project came through the advertisements placed in the Brandon Life. We were also lucky to get one of the local well known District Councillors to put some information in his regular column about the project. This article also helped encourage family carers to get involved as a trusted community figure was affectively endorsing the project.

As the community researchers themselves lived in Brandon we began the research by asking them to speak to people they knew to be carers and asking them to get involved in the research. This was particularly useful for the community researchers as they were able to carry out the questionnaires for the first time with people they knew and so felt more comfortable.

Word of mouth was also a very effective method of finding family carers. Family carers who took part in the project encouraged friends and neighbours who are family carers to get involved in the project. Whilst family carers may have seen the advertisements in the paper and the posters advertising the project around Brandon, having a friend recommend the project and reassuring them that this project was legitimate and enjoyable to take part in, really encouraged other family carers to get involved.

The market stall events also proved to be quite successful and helped raise the profile of the project in Brandon, although they were heavily dependent on having good weather. At the first market stall event, nine eligible family carers were located. At the second stall one family carer was identified then the weather turned too bad to continue and the third market stall had to be cancelled due to adverse weather conditions.

Around 10 family carers were found through door knocking. Door knocking as a method of finding family carers met with mixed success. The community researchers were at first reluctant to go door knocking but with support from the Connected Care staff team a number of them went out door knocking in Brandon. Areas with large numbers of older people were targeted for door knocking and around 20 streets in Brandon were covered.

The majority of family carers found through door knocking had heard about the Time for You project and were not sure if they wanted to get involved in the project. Meeting a project representative face to face encouraged them to take part and also allowed them to ask any questions they had about taking part in the project.

The least successful method was the use of posters put up around Brandon and leaflets posted through people's doors. Only one family carer came in contact with the project via the poster campaign and 3 family carers came through the leaflets posted. The lack of success of the posters could be due to the fact that the size of font used on the posters, which was designed in house by the Suffolk County Council, was very small and therefore quite difficult to read. However whilst not successful in encouraging family carers to directly approach the project the posters, leafleting and articles in local newspapers may well have raised the profile of the project in Brandon.

#### **4.2 Marketing and Publicity**

Turning Point approached a couple of the local newspapers that cover Brandon at the start of the research to raise awareness of the project in Brandon. One local paper wrote an article on the project which was published in both the Eastern Daily Press and the Thetford and Brandon Times along with a photo of some of the community researchers:

##### **Eastern Daily Press Article** **Suffolk carers get extra support**

[REBECCA GOUGH](#)

Last updated: 05/03/2010 06:22:00

Hundreds of family carers will be given a break from their roles thanks to a new project designed to develop support in Suffolk.

The Time for You project aims to identify 200 carers from the Brandon area who do not use short break services, to take part in a research project.

Initially, five people, including family carers, have come forward to become what are known as "community researchers".

Those five will be tasked with visiting the first 200 eligible family carers who come forward and who will then be asked to complete a short survey.

As an added incentive, there is £100 on offer for each of the 200 carers, to be spent on what they consider to be a break from their role. This could be anything from time away from the cared for person, to a mobile phone which would enable them to spend time outside of the house.

Each person will then be visited after a month to determine how and if the money has helped them, with a view to establishing long-term support in the town.

Lisa Baker, 38, from Princes Close in Brandon is one of the first five people to liaise with other carers. She is a full time carer to her six-year-old daughter Bethany who has a condition called microcephaly which causes its sufferers to develop a smaller than usual head, and therefore brain. Ms Baker also has a four-year-old son, George.

"If you're a carer there's still a stigma attached to it," she said. "It's really rewarding but everything is a fight and everybody in that situation needs help.

"It can be very isolating for carers and there's not enough help for anybody anywhere."

Funded by the Department of Health (DOH), and led by Suffolk County Council, the project will run until March 2011.

Throughout this period, family carers in each area will be consulted about which support services they would most like to see developed, plus contribute to a website containing a wealth of information about short breaks.

Tricia Ball, 75, from St Benedicts Road in Brandon, looks after her husband of more than 50 years, Norman, who has the degenerative condition motor neurone disease.

"Your whole life changes because the person you're looking after is totally dependent," she said. "You end up being confined to your home and you feel you're not getting enough help."

More than £1m was secured from the DOH by Suffolk County Council, and is only one of 12 areas in the country to be selected as a "short break demonstrator" pilot project.

The county council has commissioned social care specialists Turning Point, Suffolk ACRE, and Ipswich Borough Council to carry out research and identify and support family carers within their local communities, starting with Brandon, Ipswich, Peasenhall and Sibton .

Project leader for Turning Point, Kate Jones, said according to the 2001 census there were 800 family carers in Brandon.

Short break coordinator at Suffolk County Council, Clare Hammerton, added that throughout Suffolk 90pc of carers were unknown. "The aim is to understand the impact a break has on the carer and their caring role," she said. "On a Suffolk basis we'll be using the information to see what services are really effective and it will lead onto the future commissioning of services. We're looking for the hidden carers."

Variations on the advert for the project below were placed in the local free paper the Brandon Life, 4 times throughout the duration of the project:

## The 'Time for You' project



- **Do you live in Brandon or Weeting?**
- **Do you look after a relative, friend or neighbour, perhaps because they are ill, frail or have a disability?**
- **Would you like £100 to spend on a break from your caring role?**

Turning Point, a national charity that is working in Brandon, is trying to find out what sort of breaks carers need. We are offering 200 family carers in Brandon a gift of £100 to spend on a break. From sharing an evening out with friends, to visiting a show, the money is to help you have a break from your caring role.

In return for the £100 we would like to speak with you to find out about your caring role, your feelings around it and most importantly about the kind of breaks that would help you. The information you give us will be entirely confidential and will be used to improve breaks that are provided for carers in Suffolk.

Contact us now, and start planning your break! This could be: Going on a shopping trip or a weekend retreat (with or without the person you care for), having driving lessons, going to evening or day class, getting help with housework, laundry or gardening, buying equipment or adaptations to your home or paying a friend or neighbour to help you look after the person you care for.

We have already spoken to 70 carers in Brandon. Many of these carers have enjoyed the experience of taking part in the Time for You project and have already spent their £100 for example:

Mrs Porter of The Rookery, Brandon said 'Don't be embarrassed. This money is here to help you. If you are struggling with your caring role grab this opportunity with both hands. I have enjoyed being part of the Time for You project'

**This project ends in September 2010 so please get in contact with us A.S.A.P if you would like to take part.**

To find out if you are eligible for the £100 please contact:

**Claire Turnbull on 07983 246003**

Or email Claire at [claire.turnbull@turning-point.co.uk](mailto:claire.turnbull@turning-point.co.uk)

**This project has been funded by the Department of Health. Turning Point is a registered charity 234887 [www.turning-point.co.uk](http://www.turning-point.co.uk)**

### ***4.3 Numbers of family carers involved in the Time for You Brandon project***

In total 112 family carers contacted the project. Of these 112, 95 were eligible to take part in the project and 17 were not eligible for the project.

Of these 17 who were not eligible, 13 carers were not eligible as they reported that they did not feel in need of a short break or at all stressed by their caring role in Part 1 of the questionnaire. One family carer was not eligible as they were caring for children under the age of 18, one carer who contacted us did not live in Brandon and one did not want to take part in a research project. The outstanding ineligible family carer's daughter contacted the project to find out more about the project for her father, who cares for her mother. However, although it sounded as though the carer would be eligible for the project, he did not want to take part.

Of these 112, only one family carer did not complete Part 1 of the questionnaire. This was because when it was explained to them that they would need to take part in some research, they did not feel comfortable taking part in a research project and did not want to discuss their caring role with anyone else.

All of the 95 eligible family carers accepted the £100 award and completed Part 2 of the questionnaire. To date 74 of the family carers have completed part 3 of the questionnaire. Another 21 Part 3's are outstanding for a number of different reasons. Unfortunately a number of family carers could not be contacted, a couple of family carers had lost the person they cared for and did not want to take part in the final part of the questionnaire. Some family carers had also not spent the £100 as yet and could not complete the Part 3. These questionnaires will be completed where possible by the community researchers although the result will not feed into this report.

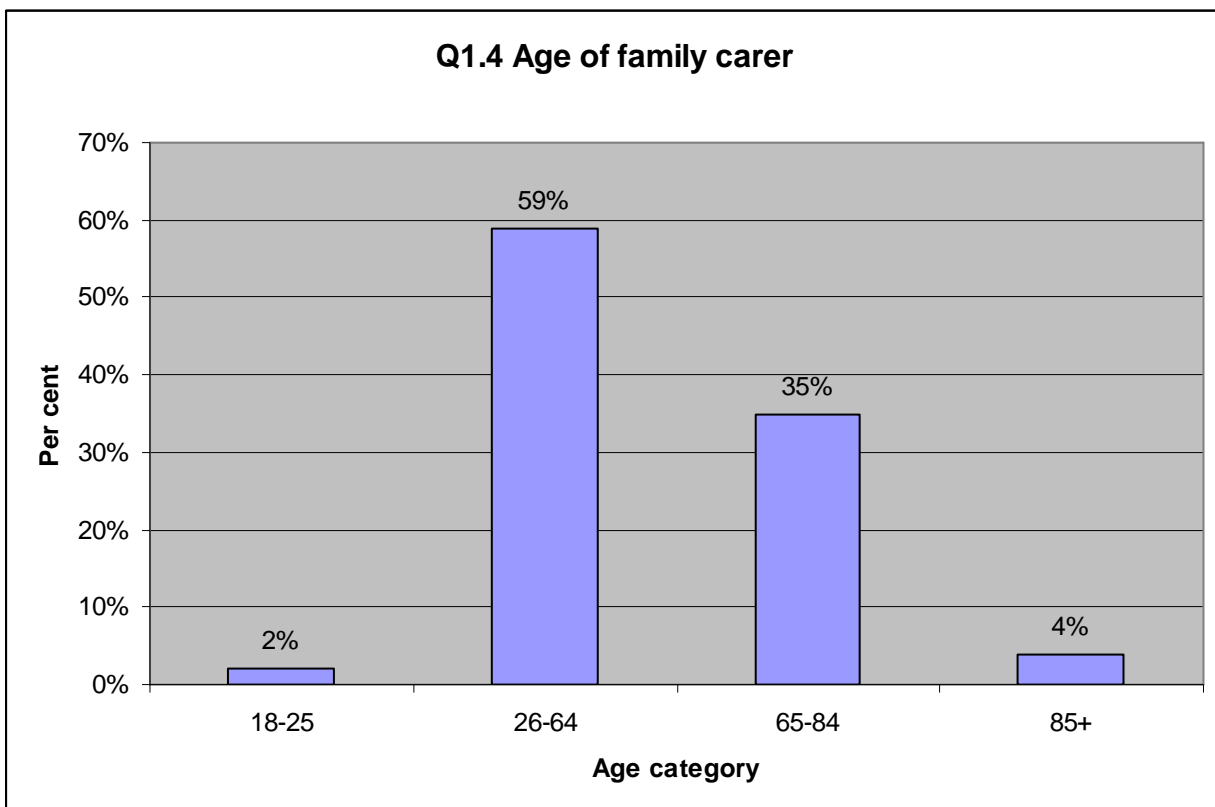
#### 4.4 Diversity of family carers

The following section outlines the age, gender, ethnicity, health, sexual orientation and employment status of the family carers who completed the questionnaire in Brandon against the proposed diversity targets set by Suffolk County Council at the beginning of the project.

The diversity targets set by Suffolk County Council come from a comparison with the population in Brandon and or for sexual orientation and gender identity, national statistics. As we are working with such a small sample size there are limitations with the targets set when compared to national statistics. As we are also working with a population of 'hidden family carers' we do not know if the targets are appropriately for Brandon as little is known about the profile of hidden family carers.

#### Age

The average age of family carers involved in the Time for You Project in Brandon was 59. The proposed diversity target was to involve 14 male carers under the age of 25 and 18 females under the age of 25. Unfortunately only 3 family carers under the age of 25 chose to get involved in the Time for You Brandon project.



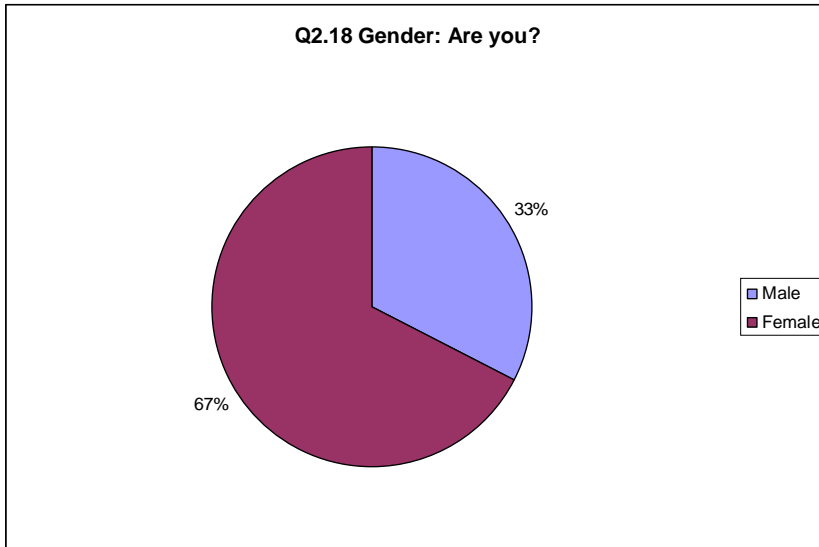
#### Ethnicity

Of the 95 family carers involved in the Time for You project 97 per cent of them were from White British backgrounds, one per cent were from a White Irish background and one per cent was from a Black Caribbean background. One per cent of the result was missing as the family carer did not want to answer the question.

The diversity target was to include 13 family carers from backgrounds other than White British. In total 2 family carers from backgrounds other than White British were included in the research.

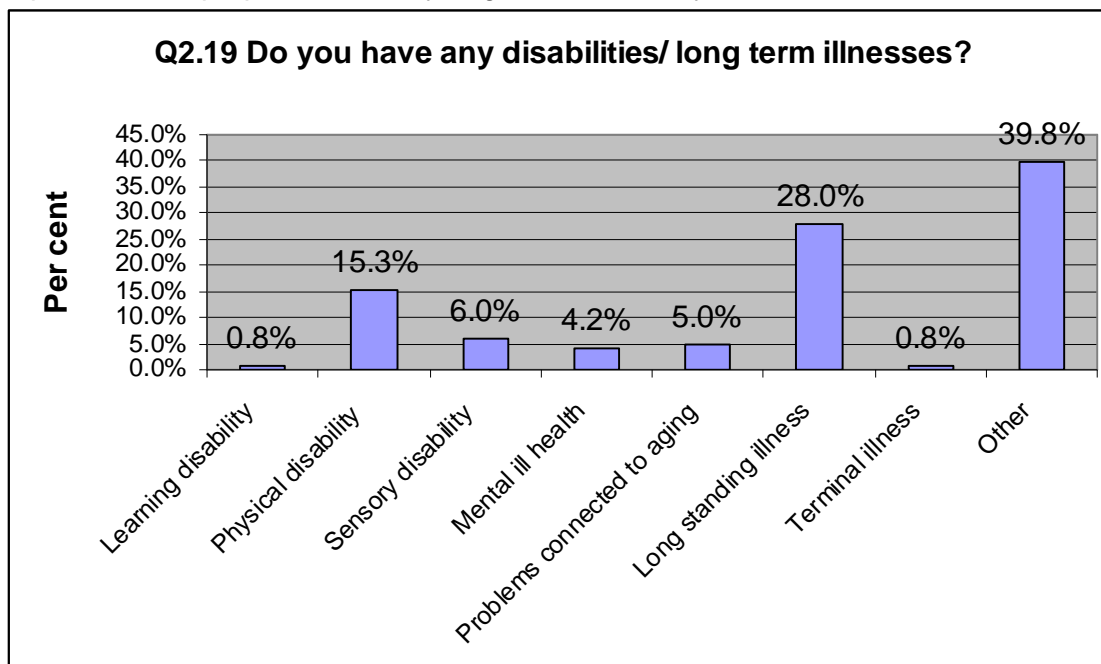
**Gender**

Of the 95 family carers involved in the Brandon Time for You project, 33 per cent of carers were male and 67 per cent were female. None of the carers spoken to were transgender. There was therefore an overrepresentation of female family carers involved in the Time for You project. The proposed diversity target was to involve 88 (44 per cent) male family carers and 112 (56 per cent) female family carers, and two transgendered. However, as females live longer than men it is more likely that there are going to be more women caring for men in any population.



**Disability**

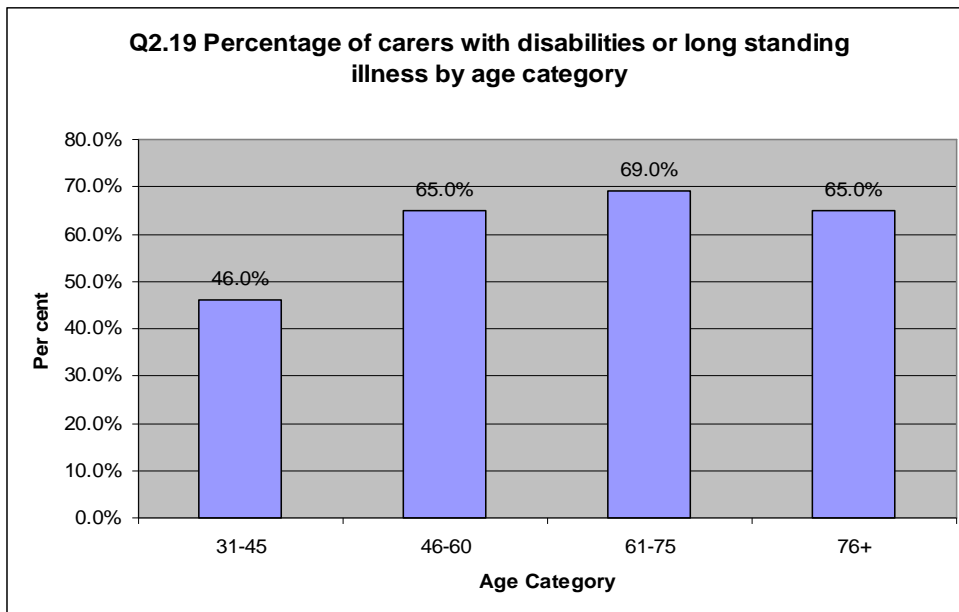
Interestingly out of the 95 family carers involved in the Time for You project in Brandon 60 per cent said that they had a disability or a long term illness. This was a far higher number than we expected. The proposed diversity target was 20 family carers.



'Other' reported illnesses included:

Type 2 diabetes.
Left and right hip replacements.
Arthritis - hands and back. NSAIDS taken.
Total knee replacement wasn't successful needs another op.
Gout.
High blood pressure, thyroid problems.
Asthma and IBS at times.
General aches and pains not being helped by caring role.
Spinal problem - arthritis.
Osteoarthritis
Diabetes, arthritis in my spine.
Right hand had an accident, losing my middle finger.
Osteoarthritis.
Heart disease.
But hopefully I have recovered from my breast cancer.
Illness mainly related to diverticulitis suffers slight mental health problems.
Arthritis/spine.
Treating for depression, have cyst on foot.
Knee problems.
knees and problem with head and blood clots meant he lost his balance.
Arthritis and diabetes.
Depression and spinal disease.
MS medication.
Tendon problems, awaiting an operation.
Registered disabled, she has Lupus - Fibromyalgia. Arthritis in hip and spine. (this couple are both in their 40's)
Deformed discs lower back, thyroids
Arthritis (80% of her body) Psoriasis, hearing aid.
Blood pressure - high.
Reynard's.
Arthritis in hips and knees.
Diabetic.
Diabetes - controlled by diet, high blood pressure.
Under active thyroid and arthritis in her leg and hip.
Tinnitus, menuirs and hiatus hernia.
Osteoporosis.
Spine problems, arthritis in neck.
Epilepsy, heart problems, partial sight in one eye.
Arthritis in shoulder and skin ulcers.
Diabetes Type 2 , occupational arthritis.

Interestingly the rates of reported disabilities and long term illnesses does not correlate to the fact that a lot of older family carers participated in the research. The graph above demonstrates that 65% of family carers in the age range 46-60 had a disability or long standing illness as do 65% of family carers in the age range 76+.



### Religion or Belief

Of the 95 family carers involved in the Brandon Time for You project 77 per cent of family carers were Christians, 5 per cent were of no religion, 17 per cent were of other religions and 1 per cent preferred not to answer. The 'other' religion category included a pagan and two spiritualists. This meant the proposed diversity target of involving 1 family carer with beliefs other than Christian, no Religion and Religion not stated was achieved.

### Sexual Orientation

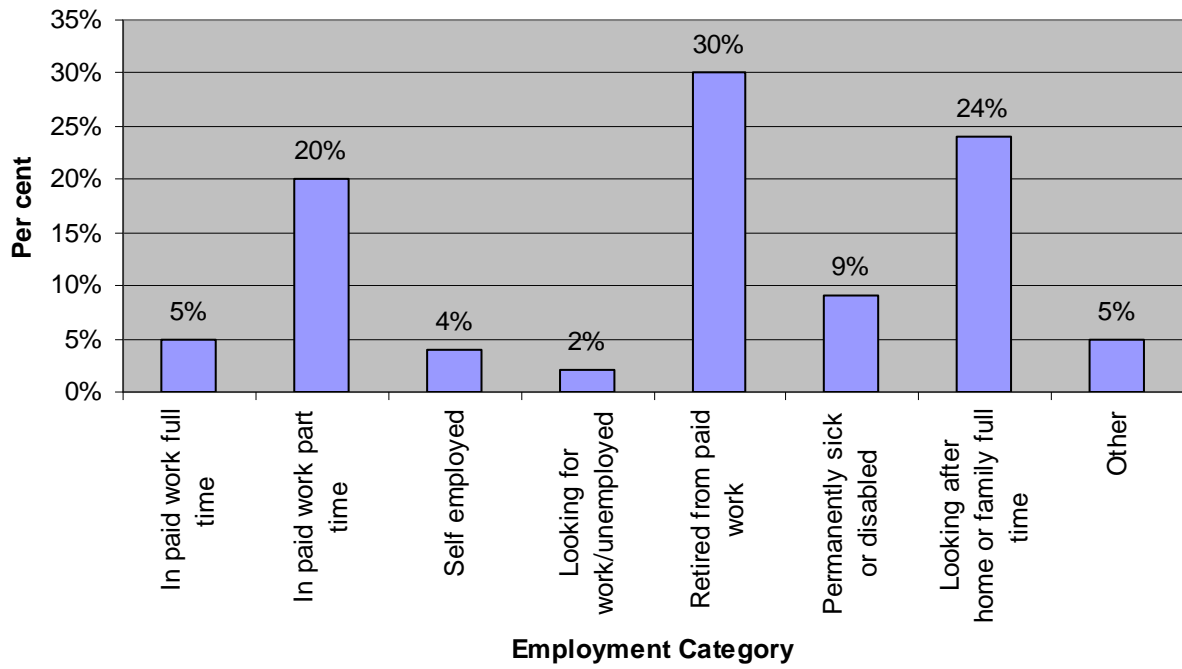
Of the 95 family carer involved in the Time for You Brandon project 93 (98 per cent) identified themselves as being heterosexual/ straight, one person (1 per cent) identified themselves as bisexual and one person (1 per cent) preferred not to answer. The proposed diversity target was 10 family carers from LGB background.

### Employment Situation

Of the 95 family carers involved in the Brandon Time for You project the most common employment situation was 'retired'. This is not surprising seeing as the average age of respondent was 59.

A surprising low percentage (25 per cent) of the family carers we spoke to were in employment in Brandon. This could be because many family carers who are in employment may not have wanted to have taken the £100 as they are coping finically or did not have the time to take part in the project.

### Q2.22 Employment Situation



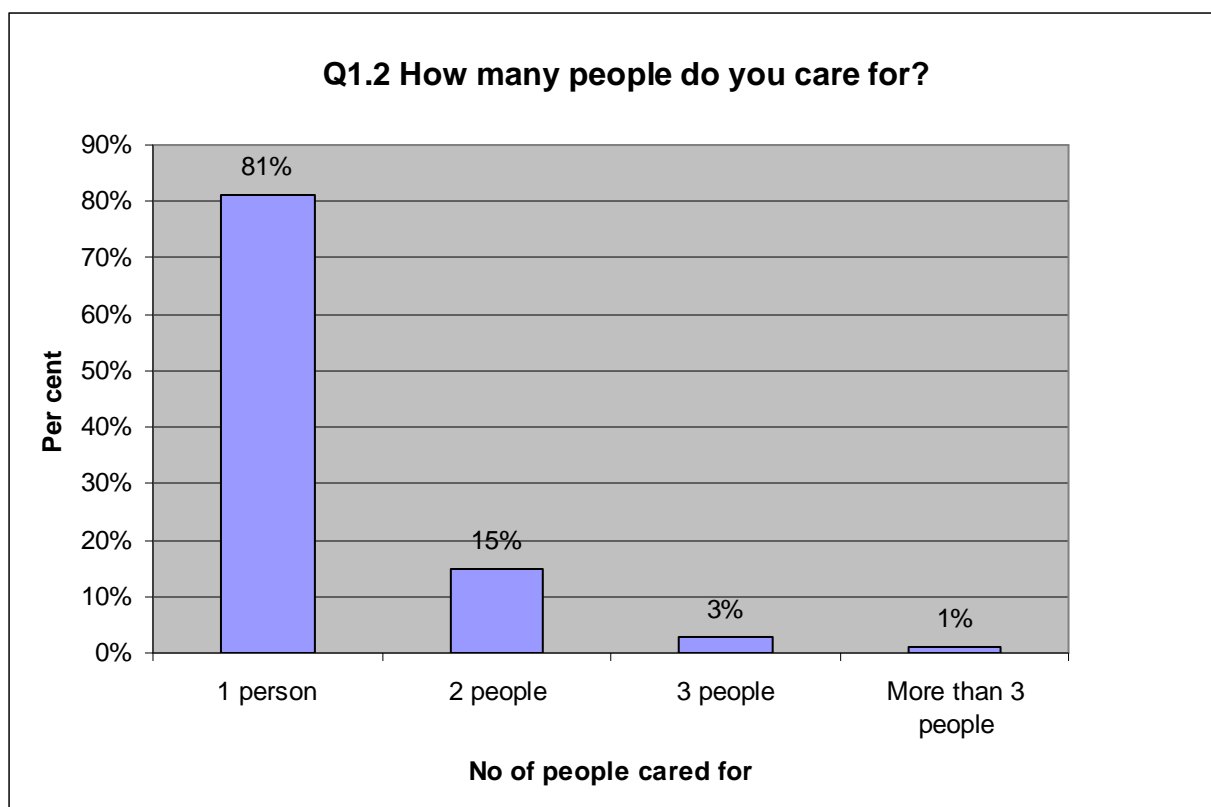
## 5. Questionnaire results

The next section of the report outlines the results from the questionnaires. Where possible questions are compared with similar questions asked in Part 3 of the questionnaire. This enables us to see if having £100 to spend on a break of their choice has helped improved the family carer's situation. However, it is very difficult to prove that there is a relationship between the family carer receiving the £100 award and any improvement/ worsening of their health or feelings. This is because the £100 award is just one small variable that may affect their feelings or health.

### Statistic Results

#### Q1.2 – How many people do you care for?

As the graph below demonstrates, the majority of family carers (81 per cent) we spoke to care for one person. 15 per cent cared for two people, 3 per cent of family carers cared for 3 people and one per cent cared for more than 3 people. People who were caring for 3+ people were normally caring for neighbours.



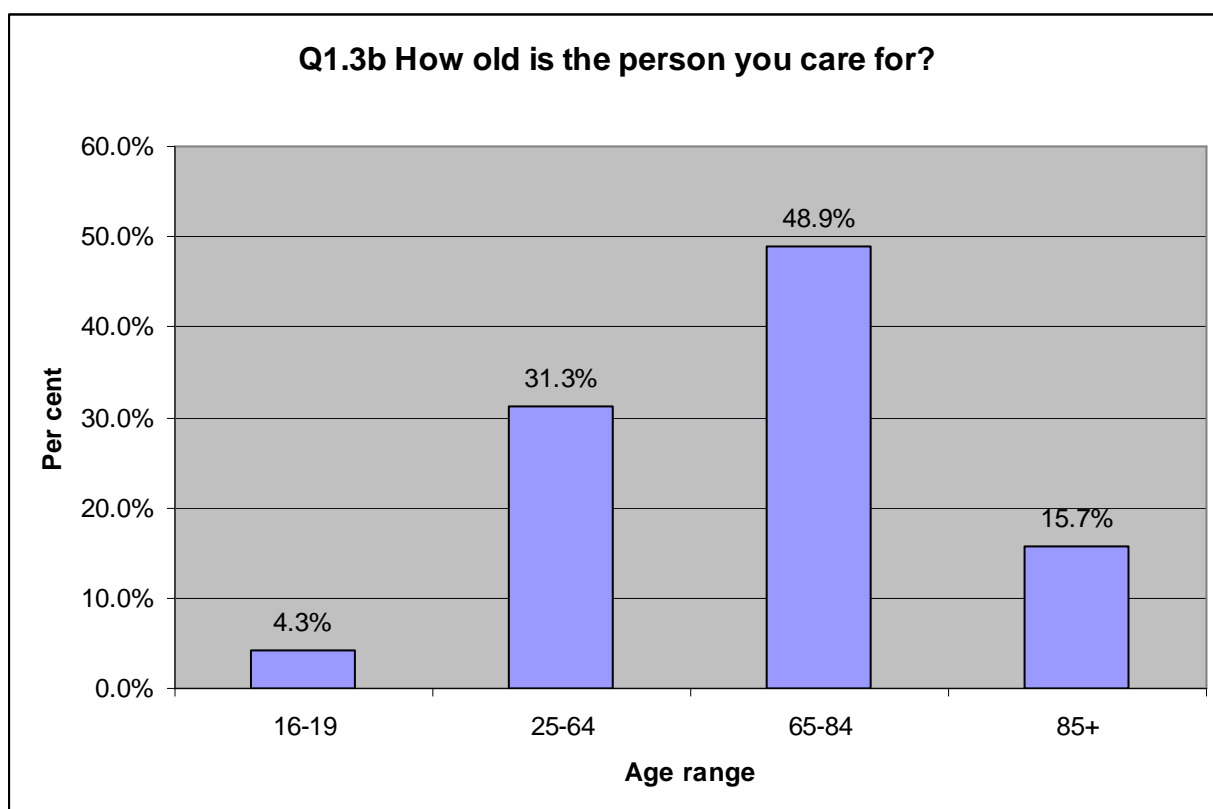
### Q1.3 a – Is the person (s) you care for aged over 18?

All of the family carers involved in the researcher were caring for someone aged over the age of 18. Only one person who contacted the project was caring for children under the age of 18.

### Q1.3b How old is the person you care for?

The table and graph below show the age of all the people, involved in the Time for You project, who are cared for in Brandon. Interestingly there were a higher number of people aged 25-64 who are being cared for than maybe expected given that Brandon has such a high percentage of older people in the population.

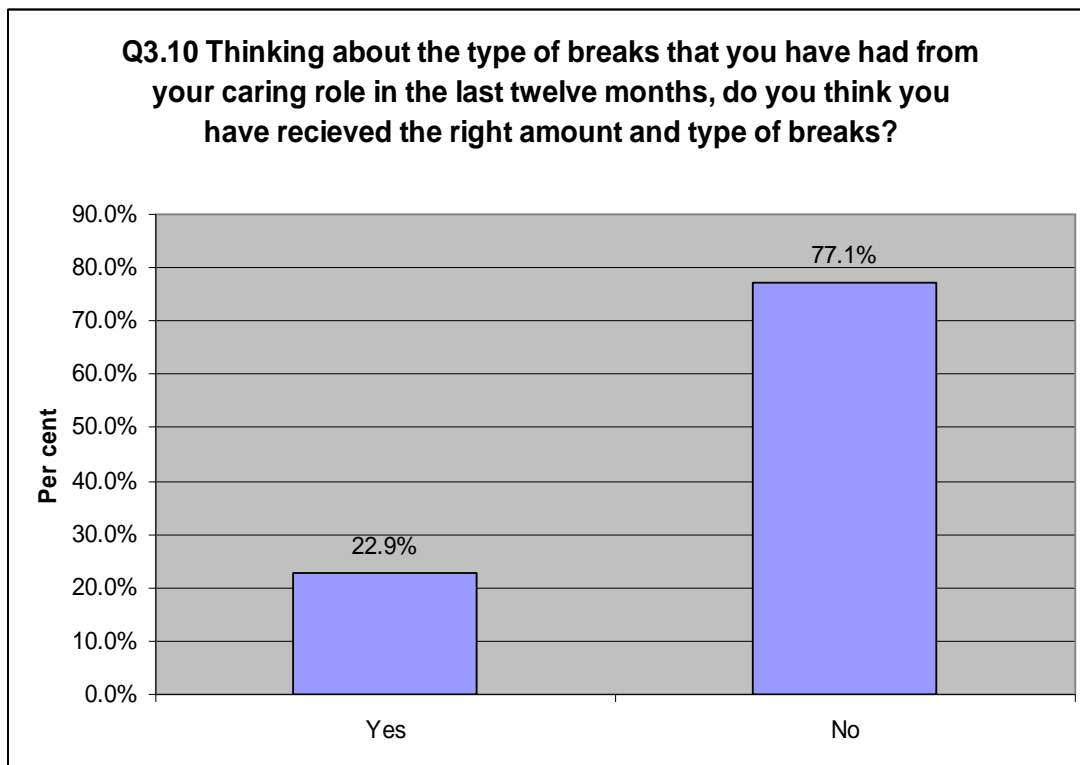
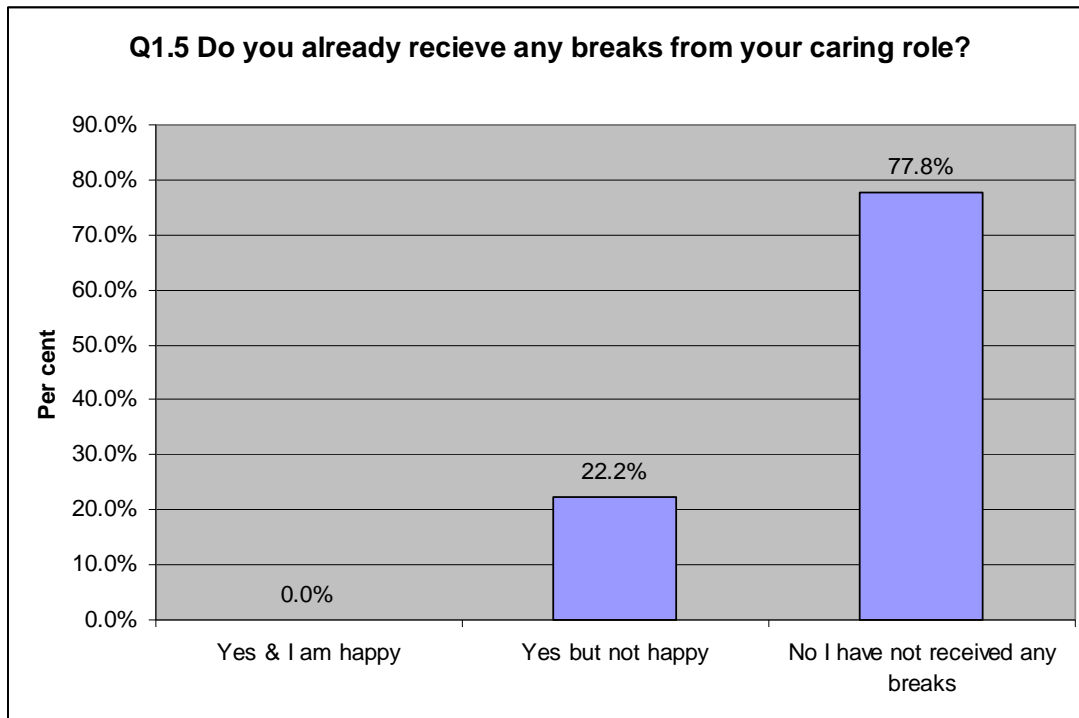
	1st person Cared For	2nd Person Cared For	3rd Person cared for	Total	Percent
<b>16-19</b>	4	1	0	5	4.3%
<b>25-64</b>	27	8	1	36	31.3%
<b>65-84</b>	49	6	1	56	48.9%
<b>85+</b>	15	2	1	18	15.7%
<b>Total</b>	95	17	3	115	100.2



**Q1.5 Do you already receive any breaks from your caring role? (compared to Q3.10 )**

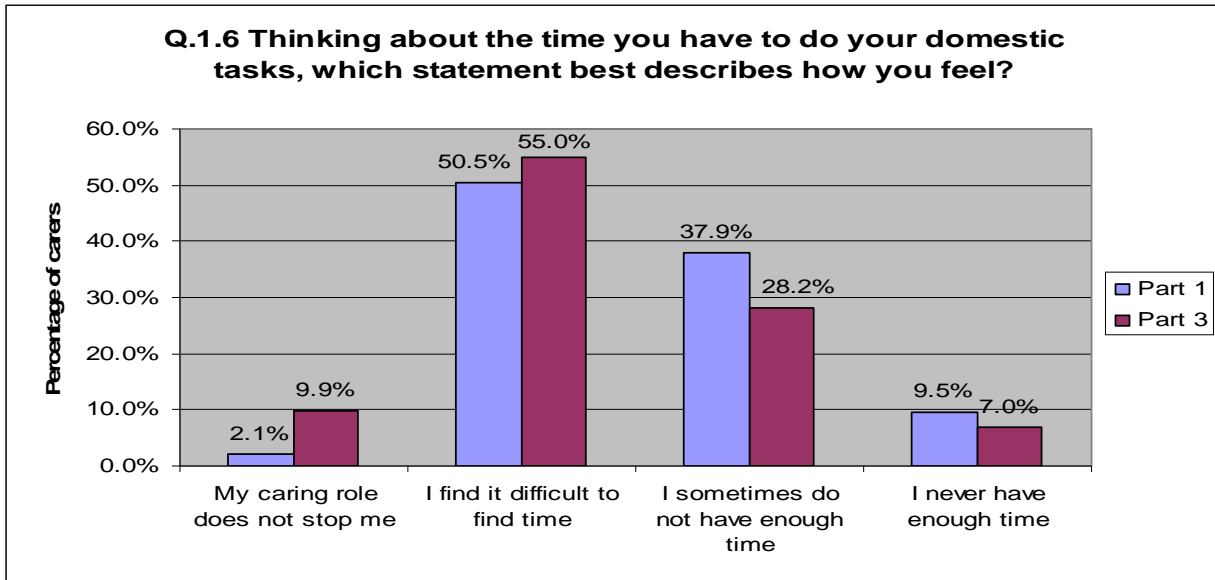
(Note questions are not directly comparable as questions differed in part 1 and part 3)

The graph below shows that the majority of family carers who took part in the Time for You project do not feel that they have received the right type and amount of breaks from their caring role. Interestingly the figures changed only by 0.7 per cent after the family carers received a £100 to spend on a break of their choice.



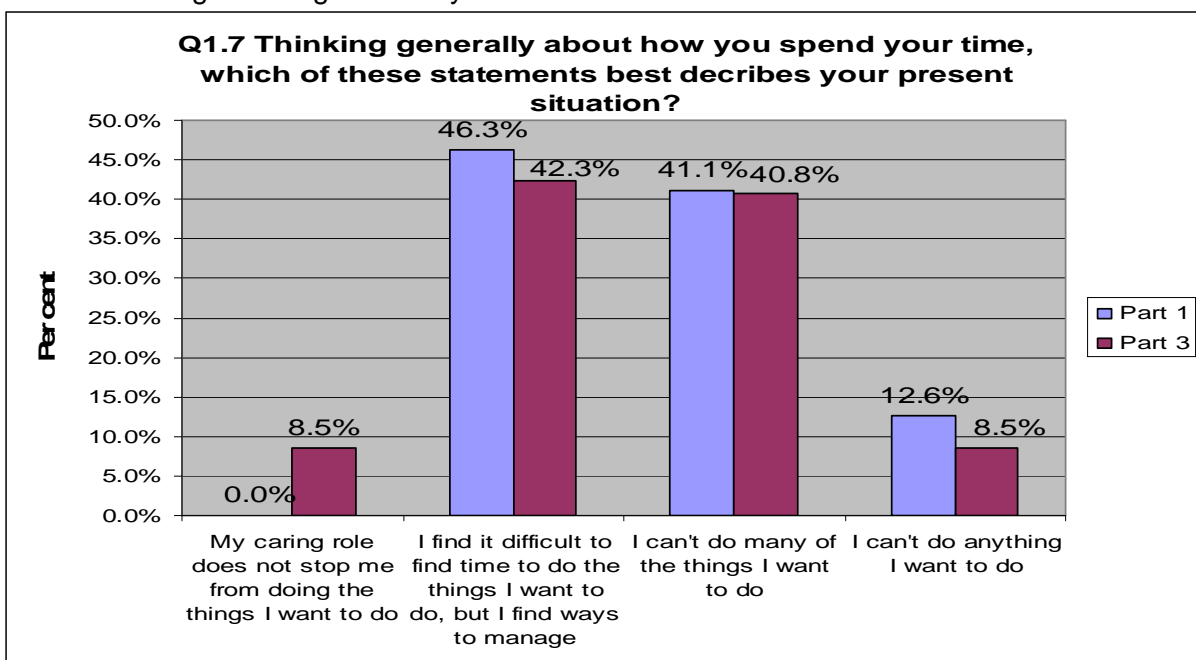
**Q1.6 Thinking about the time you have to do your domestic tasks (such as looking after your house and family members) which statement best describes how you feel? (compared to Q3.11)**

The graph below shows that the majority of family carers involved in the Time for You project struggle to find the time to carry out their domestic tasks, alongside their caring role. However after receiving a break of their choice, family carers reported feeling somewhat more likely to have the time to do their domestic tasks.



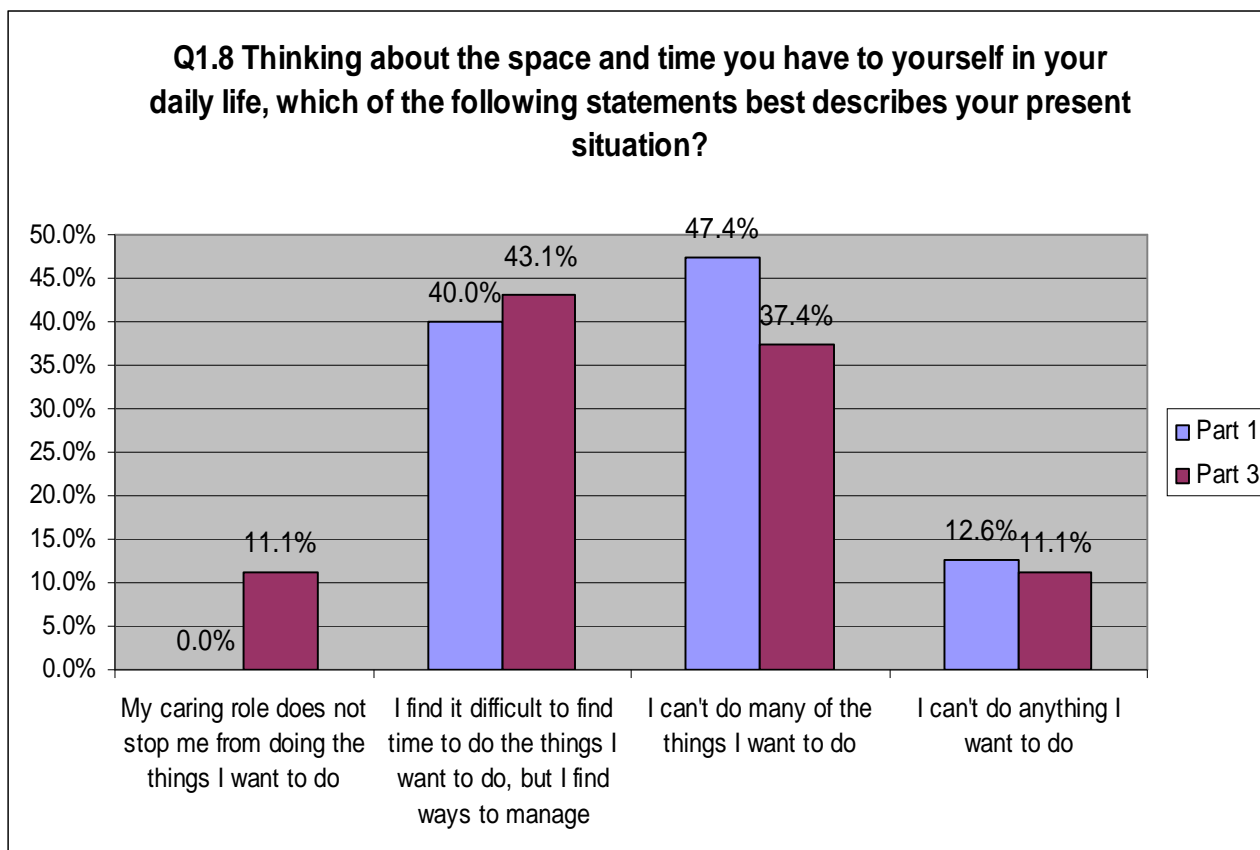
**Q1.7 Thinking generally about how you spend your time, which of these statements best describes your present situation? (compared to Q3.12)**

The graph below shows that the majority of family carers involved in the Time for You project struggle to find the time to do the things that they want to do, such as leisure, community activities, employment education and doing things for others, because of their caring role. However since the family carers received the £100 award more carers reported that their caring role does not stop them from doing the things that they want to do.



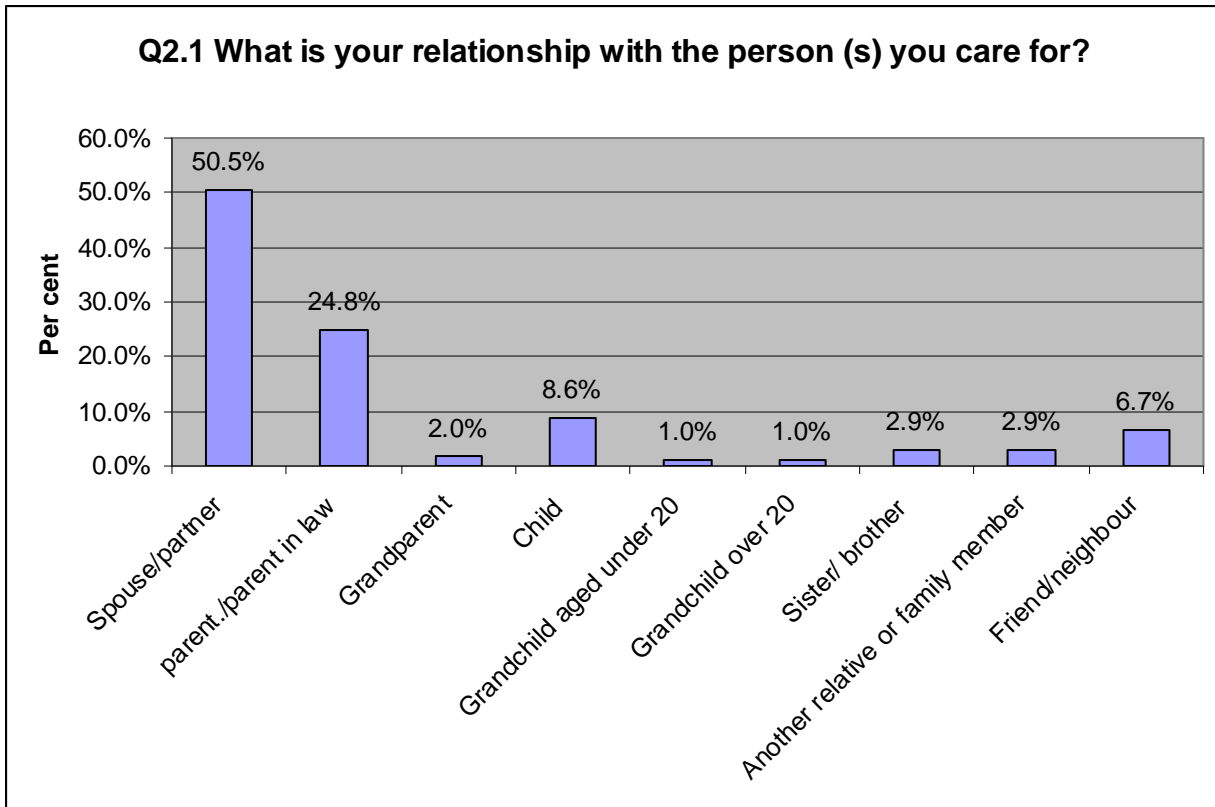
**Q1.8 Thinking about the space and time you have to yourself in your daily life, which of the following statements best describes your present situation? (compared to Q3.13)**

The graph below shows that the majority of family carers involved in the Time for You project struggle to find the time enough space and time for themselves in their daily life. A significant number of family carers said they can not do many of the things they want to do because of their caring role. However after they had received a break of their choice, more family carers reported that they have more space and time to do the things that they want to do.



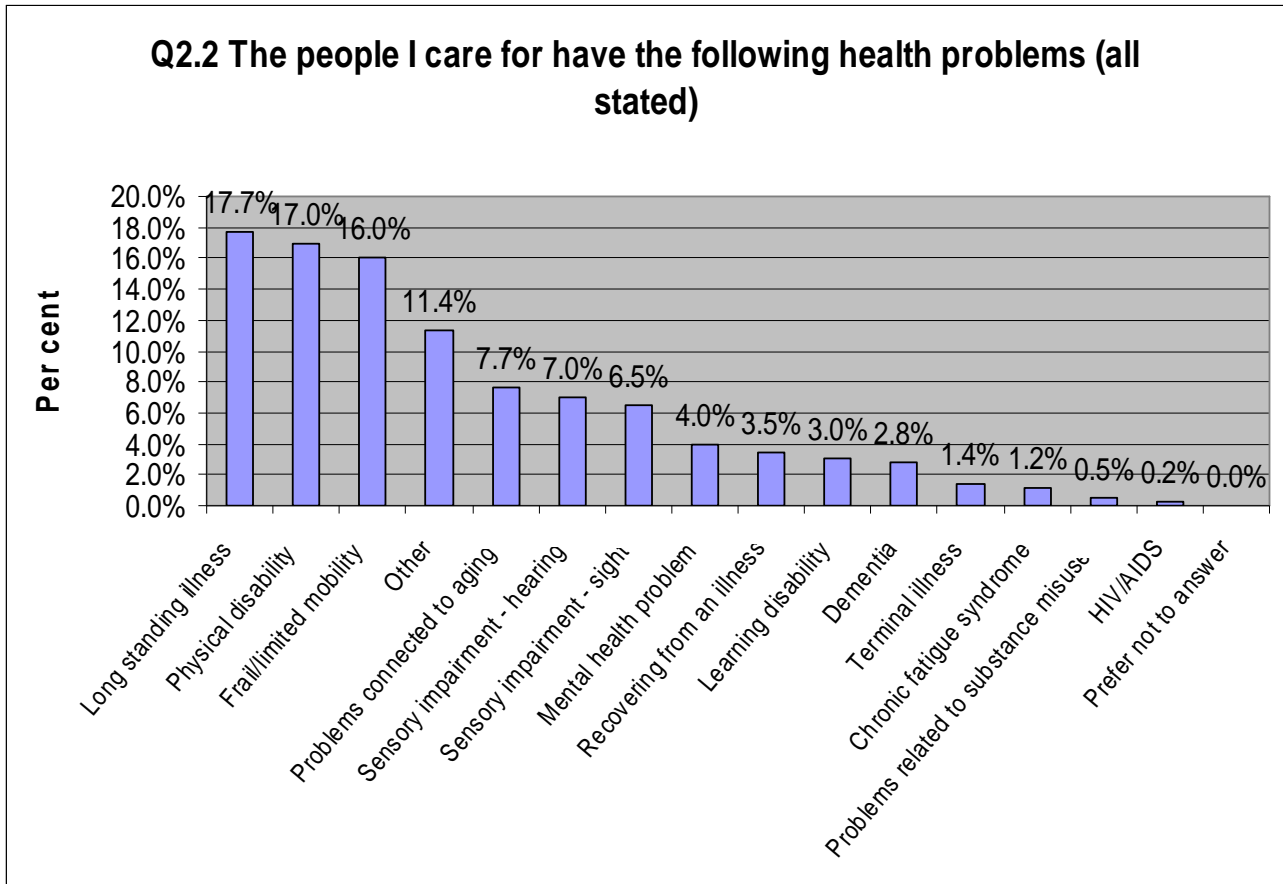
### Q2.1 What is your relationship with the person (s) you care for?

The graph below shows that the majority of carers who were involved in the Brandon Time for You project were caring for either a spouse (50.5 per cent) or a parent (24.8 per cent).



## Q2.2 The people I care for have the following health problems

Long standing illnesses, physical disabilities and frail/ limited mobility were the most common health problems or disabilities the cared for suffer from in Brandon Time for You survey:



Many of the health problems are listed below to give an idea of the seriousness of some of the health problems in Brandon:

### q2.2

Cared for is still recovering from stroke the he had 4 years ago in hospital.  
 Possibly terminal cancer of throat - chemotherapy as treatment - open appointment to return.  
 Mental health issues as result of cancer - depression.  
 Has had a severe stroke, left very handicapped, speech badly affected.  
 My wife has had MS for forty years, progressively getting worse over time.  
 My wife's physical condition is deteriorating quite quickly now.  
 Brain haemorrhage and subsequent injury leading to epileptic seizures.  
 Multiple sclerosis - no mobility.  
 V.H.L. (cancer of the organs) ongoing. Hereditary - which has taken my husband, one son and a daughter.  
 "Physically they are like caring for two babies", mentally they are very challenging. My daughter is like any other teenage girl - make-up, hair, clothes etc.  
 Arthritis, angina, has also suffered from IBS, very limited mobility, at night.  
 COPD Emsphesmia asthma walking difficulties.  
 Osteoporosis.  
 Right sided weakness due to stroke, diabetic insulin dependent, uses mobility scooter.

My dad has motor neurone disease diagnosed 18 months ago and is now totally unable to move, only able to speak. My mum has sight problems, arthritic knees, which make her mobility slow. Mum gets frustrated. Mum needs a lot of help. Mum's stroke year & half ago. Angina, vascular problems since 60. Alzheimer's diagnosed last year. Prostrate cancer and spinal cancer. Uses hearing aid. Damaged throat. Has had stroke - cannot use right arm. My wife has post polio, knee taken away on her left leg. Medication makes my wife confused and forgetful. Hip replacement, heart condition, blood clot in his leg which is improving. Arthritis in spine, spreading gradually through all main joints. Sleep apnoea (stops breathing in his sleep). Has diabetes, muscle weakness in legs. Stroke, only sight in left eye. In a wheelchair, frame at home, problems with legs. Lots wrong, has sleep apnoea so carer doesn't sleep properly. Cellulitis in both legs. Has had a stroke, heart attack in Dec 09 deaf, arthritis, house bound and bed ridden all day. Has had two falls and has gone downhill healthwise. Balance, depression, COPD, angina. Brain injury (due to drugs overdose) Dyspraxia, diabetes, ongoing health problem, related to all of the above. Spinal problems, narrowing of facet joint bone disorder, clinical depression, on morphine daily for pain. Left disabled as result of stroke followed by heart attack, major surgery at Papworth. Prostate cancer COPD, AF, angina, gall stones, cellulitis, vertigo. I look after my Grandmother most of the day. Mainly knees, diabetic (type 2), hearing problems. Heart problems and lung problems. Muscular dystrophy - progressive condition. Arthritis for 10 years, angina. Person 1. Diabetes, Parkinson's, heart attack and ongoing as a result of heart attack. Person 2. Diagnosed since 3 & 7 yrs old both autistic, oldest very severe. Serious learning disabilities both have epilepsy. Severe stroke last year, completely paralysed down left side.

**Q2.3 Which of these social support services had the person (s) you care for used in the past year? (Compared to Q3.5)**

The graph below shows that the many people in Brandon have not used social support services in the last year (13.5 per cent in Part 2). This supports the case that the Time for You project in Brandon has helped find hidden carers (or those carers who do not currently use social support services).

Of the social support services that have been used, having equipment and adaptations to the home, for example hand rails fitted in bathrooms, was the most popular response. Day centres and home care help were also popular social support services used in Brandon. Example of ‘other’ services used include:

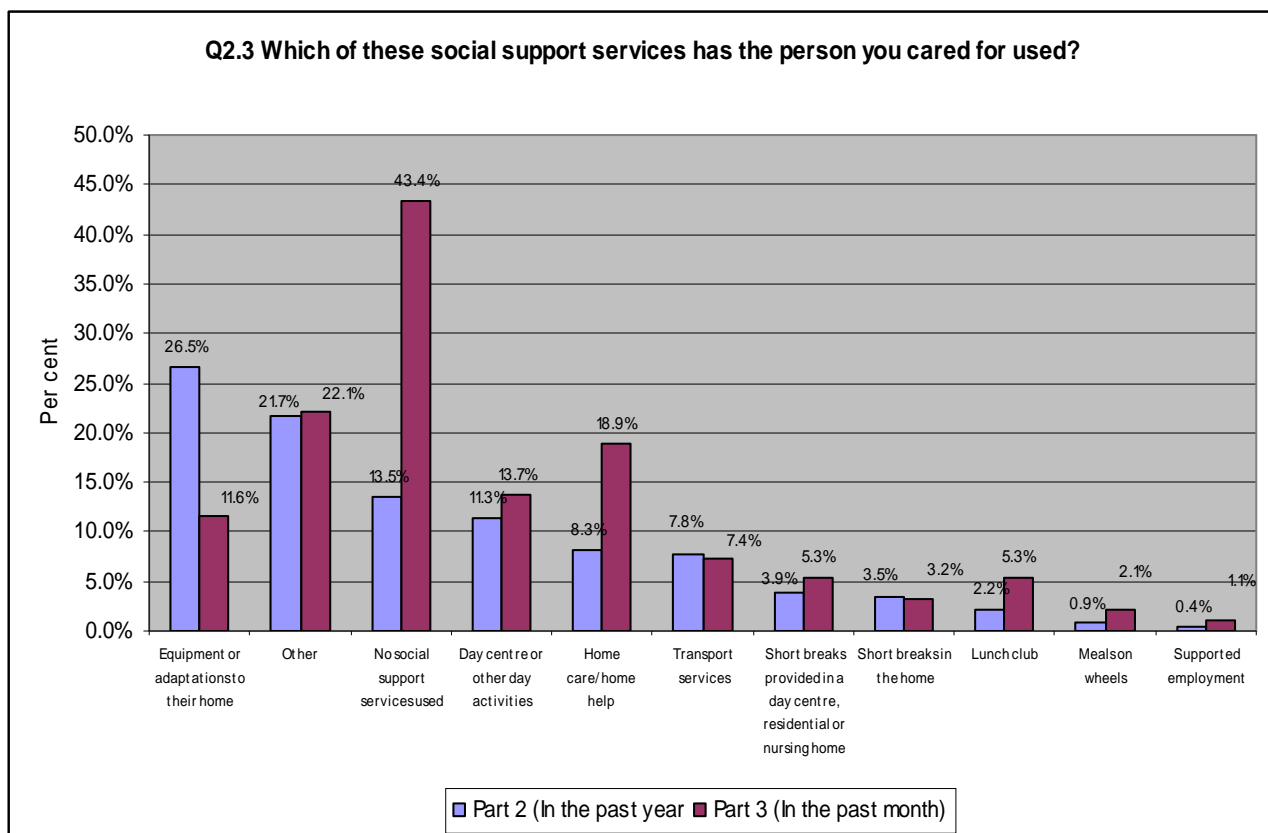
- Hospice day centres
- Blue badge scheme for the disabled
- Direct payments
- Age concern taxi vouchers

Many of the family carers had paid for support services themselves:

*‘Attends one day a week at day centre costing £27.00 per day, is picked up and brought back home. Uses Wiltshire Farm Foods home delivery. Does use handrail in bath - paid for by self’*

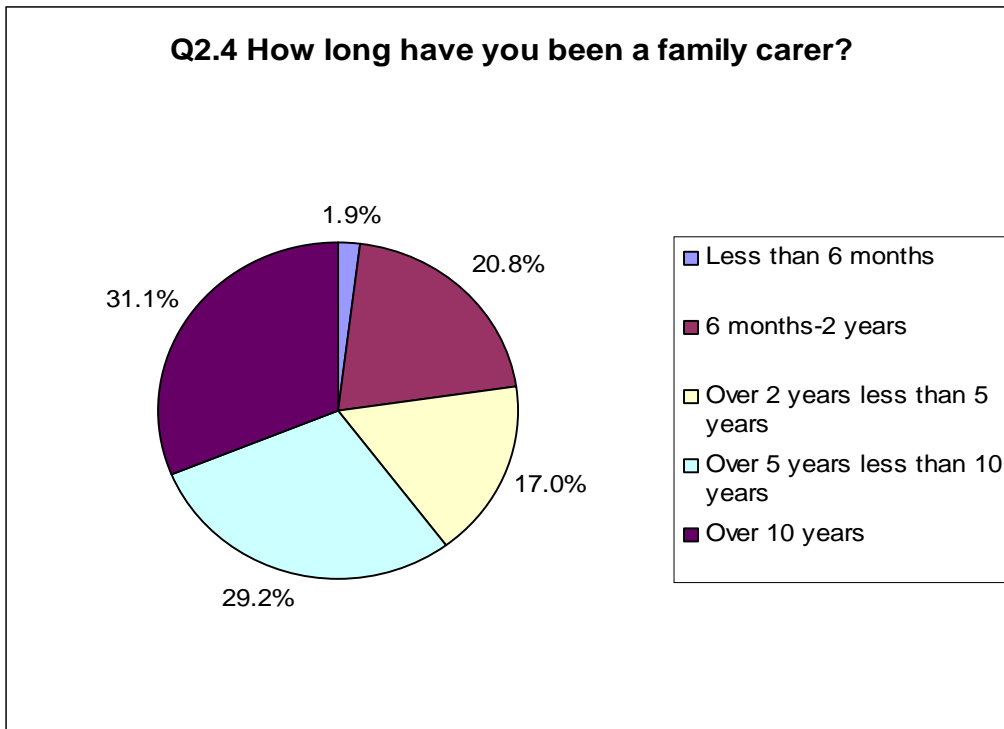
*‘Wheelchair/walker/bed - privately paid for’*

No social support services used was significantly higher in Part 3 as this question asked only about social support services used in the last month hence less services are likely to have been used in a month as opposed to the last twelve months.



## 2.4 How long have you been a family carer?

Interestingly, the pie chart below shows that the majority of family carers in the Brandon Time for You project have been family carers for longer than five years (60.3 per cent). Only 22.7 per cent had been family carers for less than 2 years.



**Q2.5a (compared-to Q3.6a)**

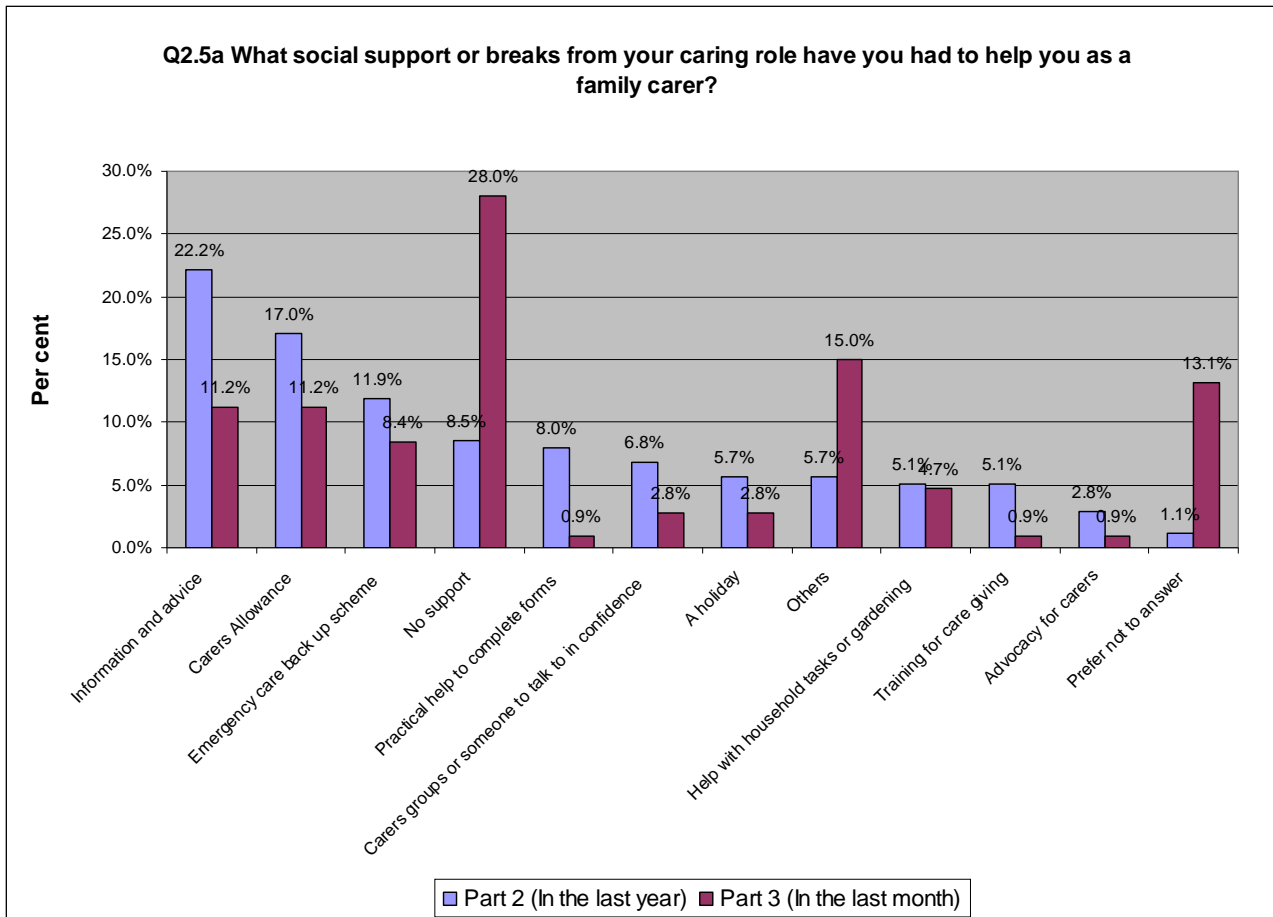
The graph below shows that many family carers have not received any support in the last year (Part 2) and even less have received any support or breaks in the last month (Part 3)

The most common support received was either information and advice, carers allowance or the emergency care back up scheme. 'Other' support mostly consisted of support given by family members, friend and neighbours as the quotes below show:

*'Only [support] from my family'.*

*'Daughter-in-law helps out'*

*'My sister will find information'.*



## Q2.5b (compared to Q3.6b)

When trying to find information about services that are available to support family carers, the list below shows the Citizens Advice Bureau in Brandon is a very popular place to find information. Local Suffolk charities and support groups such as Suffolk Family Carers and the Alzheimer's society are also popular places to go to for information. Social workers are also mentioned a number of times as were occupational therapists, GPs, hospitals and family and friends as popular people/ places to go to find information about services:

### Q2.5b – If you answered yes to any of the above services where did you find information about these services?

- Carer rang O/T and got some advice. Also family members made enquiries, as did next door neighbour.
- My accountant, sent me the forms, because my mother pays me her attendance allowance and accountant picked up on this.
- Information and advice - Customer First, Macmillan Services. Carer's allowance - Customer First. Bill Bishop helped with issues with Kings Forest Housing. Local councillor.
- Job Centre advised carer on carers allowance.
- I would always pick up the phone and ask for help and support. CAB, were excellent they helped with my carers allowance and help and support.
- I'm not at all shy in coming forward, so I will always go and find information. My best source is Suffolk Family Carers.
- My sister and brother-in-law help me so I can have a holiday, and help to maintain my mother's property.
- 'Headway' - informed carers allowance or rehab find out himself - leaflet at hospital.
- Social Services magazine is a good source of information (No limits).
- Suffolk C Council sent lady to fill in form for attendance allowance, we pay a friend to help in garden and get a mag from S.F carers.
- Phoned Alzheimer's society in Bury and lady there helped get the family in touch with social services.
- From social worker and hospital.
- Mental health (CPN) - gave information.
- Use CAB to assist with forms.
- Alzheimer's Society services - found out about that myself and local authority and internet.
- Mainly support groups and GP.
- CAB and disability centre in Bury St. Edmunds.
- Social worker, prestige carers Fen house Ely, (B.I.R.T) brain injury rehab trust.
- Social worker is trying to put things in place and sort out what benefits to apply for, what would be best e.g.. Benefits re partner or mother, cannot have both for certain benefits.
- Through CAB, they contacted social services re: equipment.
- O.T. re: bathroom. O.T. provided a bed rail and commode
- Hospice very helpful with advice and information. (C) Carers allowance - hospice looking into it for me.
- Suffolk Family Carers.
- Emily from Alzheimer's has filled in forms for us generally get info from Alzheimer's club (Brandon).

**Q3.6b – If you answered yes to any of the above services where did you find information about these services?**

- Information on carers from personal accountant. Brochure about `Suffolk' has been helpful. Emergency back up scheme info came from Time For You project. Know of scheme and intend to register soon.
- From MS society.
- Following a recent Doctor's appointment, the family carer had a "funny turn" the surgery staff made all suitable arrangements for her husband whilst she was in hospital undergoing tests for the day.
- Emergency back up scheme - information in carers Time for You pack
- Social Services sent me leaflets.
- Carers and mental health visitors and age concern.
- Social Services, but this has been very difficult to arrange.
- Info pack given through time for your project.
- I saw information about Suffolk carer's in Brandon Life. I maybe saw some information in the post office (I can't remember).
- Crossroads, O.T. physio e.g.. Raising the sofa.
- Age concern gave me the info. Don't remember receiving E.care back-up leaflet but wants to register.
- Suffolk family carers and GP.
- Social worker

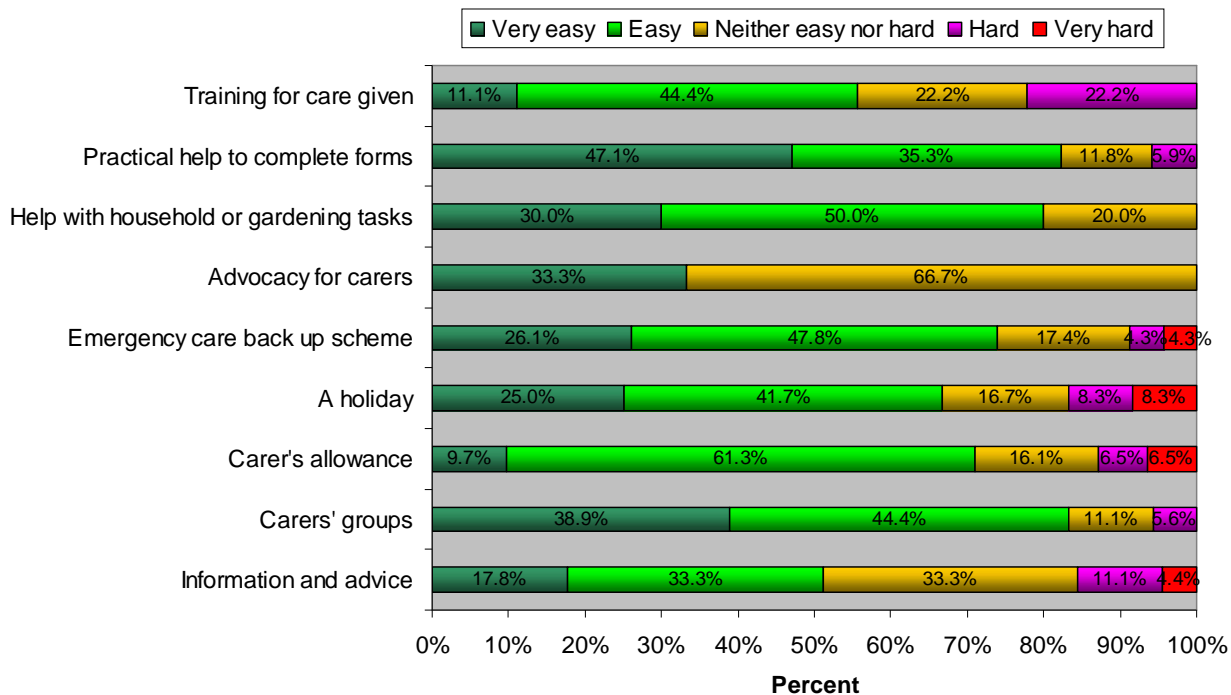
As can be seen from comparing the two lists the only real change has been through the information packs that each family carer received when taking part in the Time for You project.

**Q2.5c (compared to Q3.6c)**

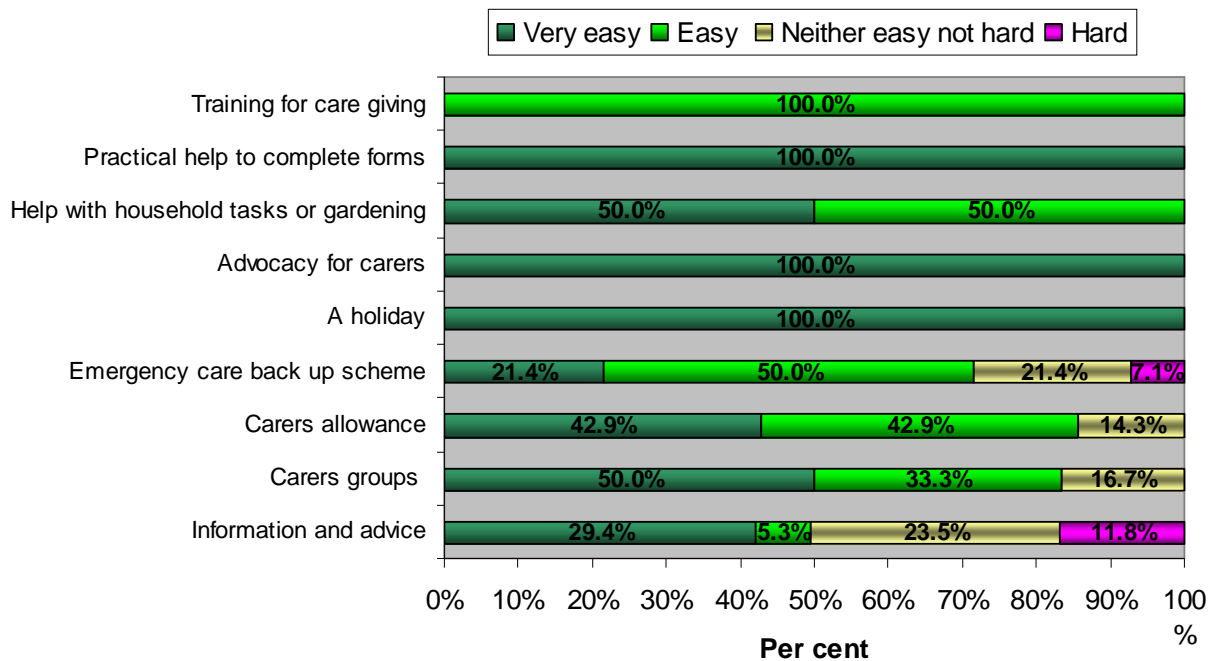
The tables below show how easy or hard it was for carers to find out about the social support services they have used. Happily most family carers have reported that they have found it either very easy, easy or neither easy nor hard to find out about social support services available to them. Very few have struggled to find out about services.

As the red columns below show the most difficult services to find out about have been the emergency care back up scheme, a holiday, carer's allowance and information and advice. Training for care giving, help with household tasks and gardening and advocacy for carers have all been found with relative easy by family carers.

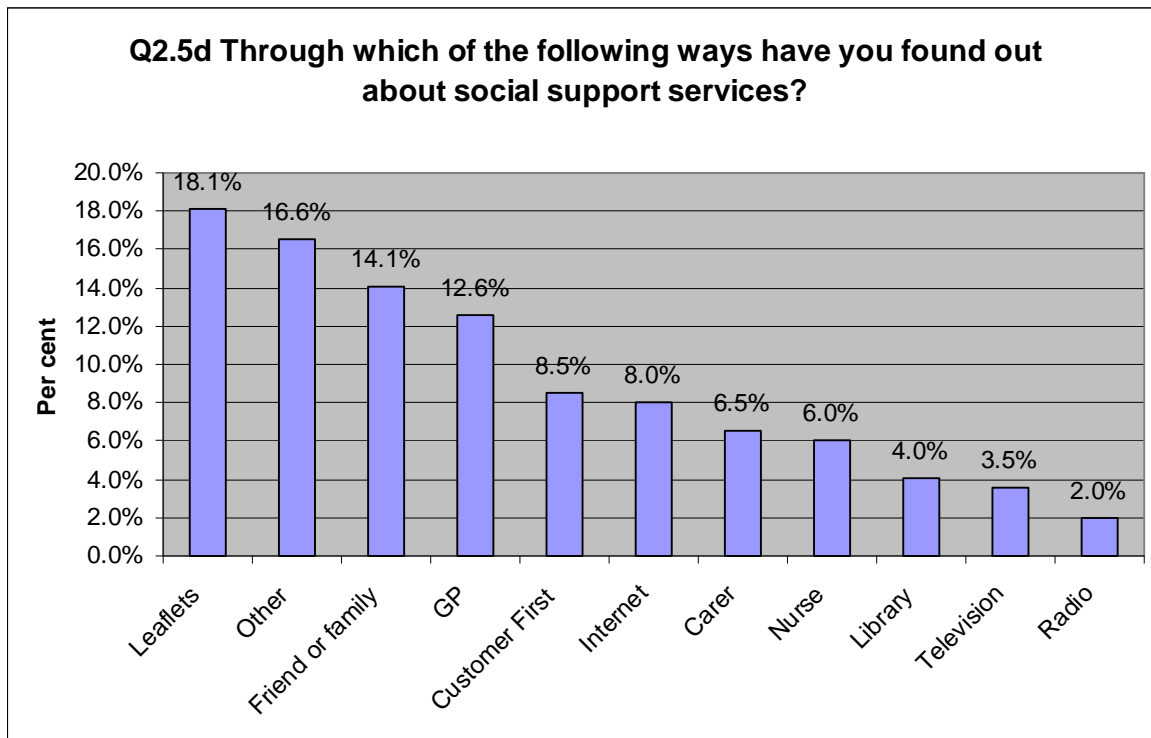
### Q2.5c How easy or hard was it for you to find out about the social support services you used?



### Q3.6 How easy or hard was it for you to find out about the social support services you used?



**Q2.5d Through which of the following ways have you found out about social support services?**



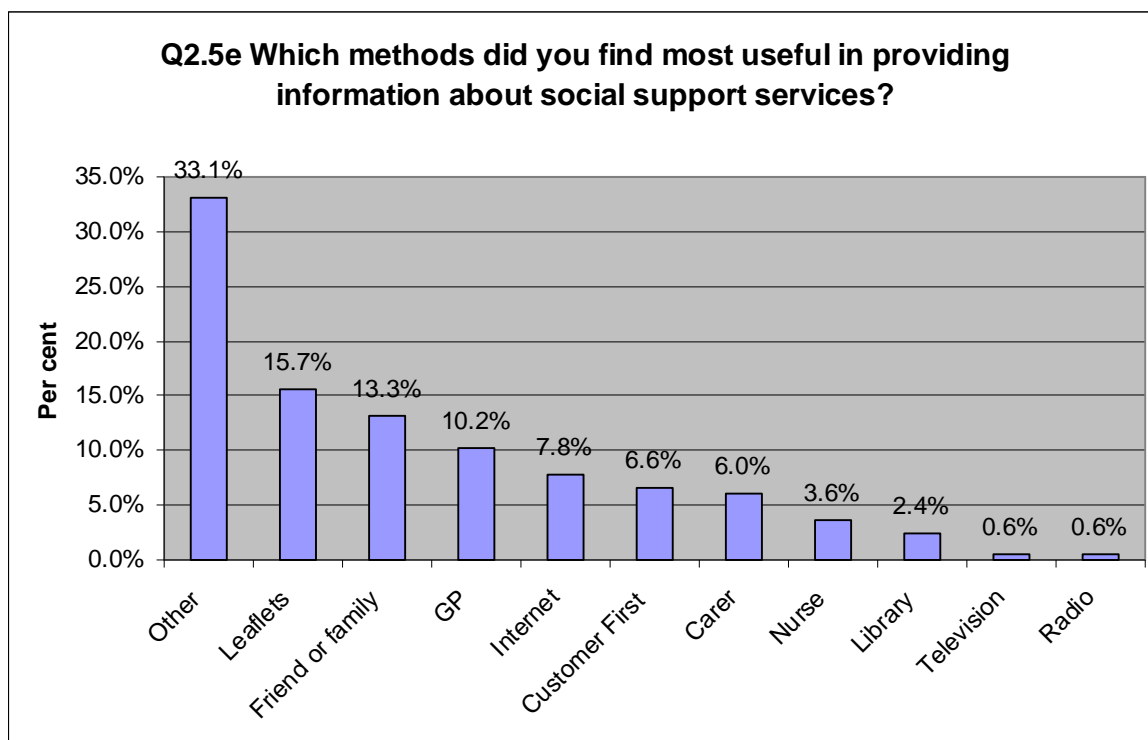
As the graph above shows the most popular way of finding out about social support services was through leaflets (18.1 per cent) 'Other' (16.6 per cent) and friends or family (14.1 per cent). The least popular ways of finding out about social support services was via the radio, television or library.

The 'Other' ways category includes:

- The Citizen's Advice Bureau
- Local support organisations/ charities such as Suffolk Family Carers, the Alzheimer's society, Crossroads, The 'De-Cafe'
- Hospitals
- Hospices
- Social workers and
- Occupational therapists

**Q2.5e Which methods did you find most useful in providing information about social support services?**

Interestingly the methods family carers in the Time for You project found most useful in providing information about social support services were 'other', (33.1 per cent) leaflets (15.7) and family and friends 15.7). Once again the library, television and radio were the least useful methods in getting information about social services in Brandon.



'Other' ways of finding information was significantly the most useful method for family carers in Brandon. The quotes below from family carers involved in the project show some of the other methods they have used to find information. Once again local support organisations are really useful in providing information about services available to carers:

*'General information as above is got from Alzheimer's Assoc. (De-Café - B. St. Eds) staff.'*

*'We used a hospice - non-terminal care which was in Oxfordshire'*

*'Emily at Alzheimer's society.'*

*'The fortnightly Brandon Life is very useful with providing information on support groups'  
 'Will be going to a mobility exhibition to see what improvements or aids they can get to help with daily life. GP, SCC and Red Cross have helped mother-in-law in the past, with information. She has Parkinson's and they moved her in with them.'*

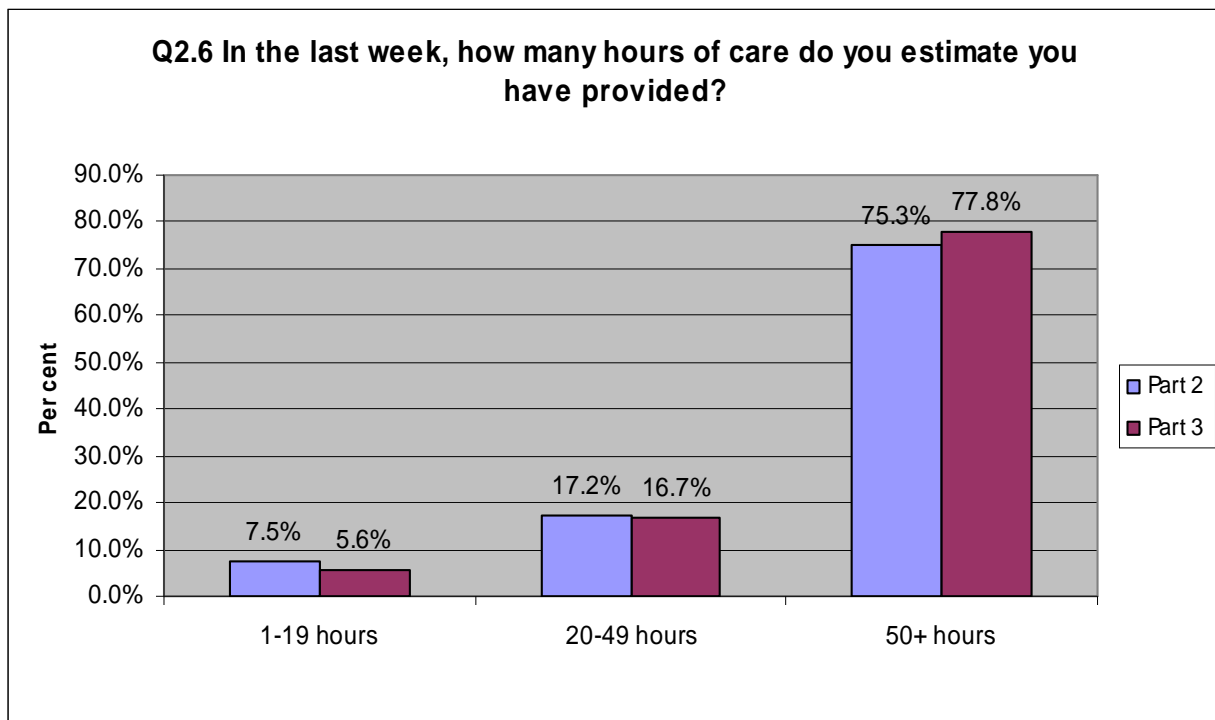
*'Association for blind, extremely helpful and supportive.'*

*'Next door neighbour and Emily, Alzheimer's',*

*'Hospice has been very helpful, and the community team.'*

*'MENCAP. Have belonged to mencap for many years.'*

**Q2.6 In the last week, how many hours of care do you estimate you have provided?  
(compared Q3.7)**

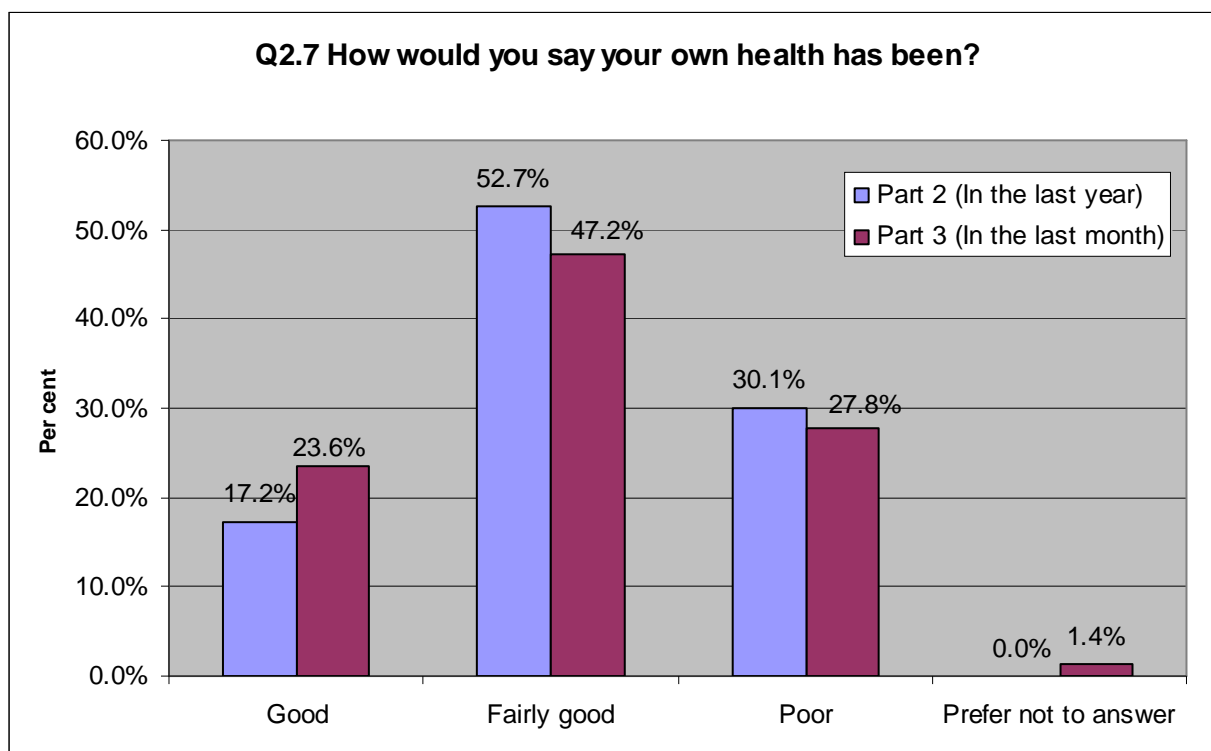


The graph above shows that the vast majority of family carers involved in the Time for You project are full time family carers and spend 50 plus hours a week caring. There is no significant difference between hours cared for in Part 2 of the questionnaire and Part 3.

In terms of family carers in Brandon, the census 2001 reports that 821 people living in Brandon classify themselves as providing unpaid care. Of these, 211 (26 per cent) said that they were caring for someone 50+ hours a week. The Time for You project was therefore very successful in finding family carers who provide 50+ hours of care.

This may have been because these family carers are more likely to identify themselves as family carers and so would be more likely to come forward to take part in the project. Family carers who care for 1-19 hours a week may not consider themselves to be family carers – they may just think that they are doing their family duty and helping out with looking after a family member. This group of people are therefore more unlikely to consider themselves as family carers and would have been less likely to have made contact with the Time for You project.

## Q2.7 How would you say your own health has been (compared to Q3.8)



The response by family carers in the Time for You project to the question 'how would you say your own health has been over the last twelve months' is note worthy.

A high per cent of the family carers we spoke to said that they own health has been either good or fairly good over the last twelve months (70 per cent in Part 2) and in last month (70.8 Part 3) However when you contrast this with a later question in Part 2 – do you have any long term illness or disabilities 60% of the family carers we spoke to said they have a long standing illness or disability. You would therefore not expect people to say their health is good or fairly good if a large number of them have a long term illness or disability.

Family carers in the Time for You project in Brandon therefore had a tendency to underreport their own health. This is particular evident in the extensive remarks made by my family carers in the comments section of this question. A small number of which are shown below:

*'Stress levels very high and high blood pressure, I'm also on anti-depressants, which make me quite unwell at times from side effects'*

*'Haven't been 100% all the time. Generally good'.*

*'Bronchitis's, pneumonia and every time it is cold she gets chest infections'*

*'Some hip and knee problems, which I see the doctor about'*

*'Thyroid problems. Exhaustion'*

*'I was in hospital due to mental health issues, take regular medication, see my GP every 2 weeks'*

*'Chronic heart disease, prostate cancer, spinal injury from being in the armed services'*

*'Suffers from arthritis and is disabled mainly spinal problems and will need a knee cap replacement in near future'*

*'She has a back problem, which can cause problems at times. Big problem with sleeping, sleeping tablets do not help at all'*

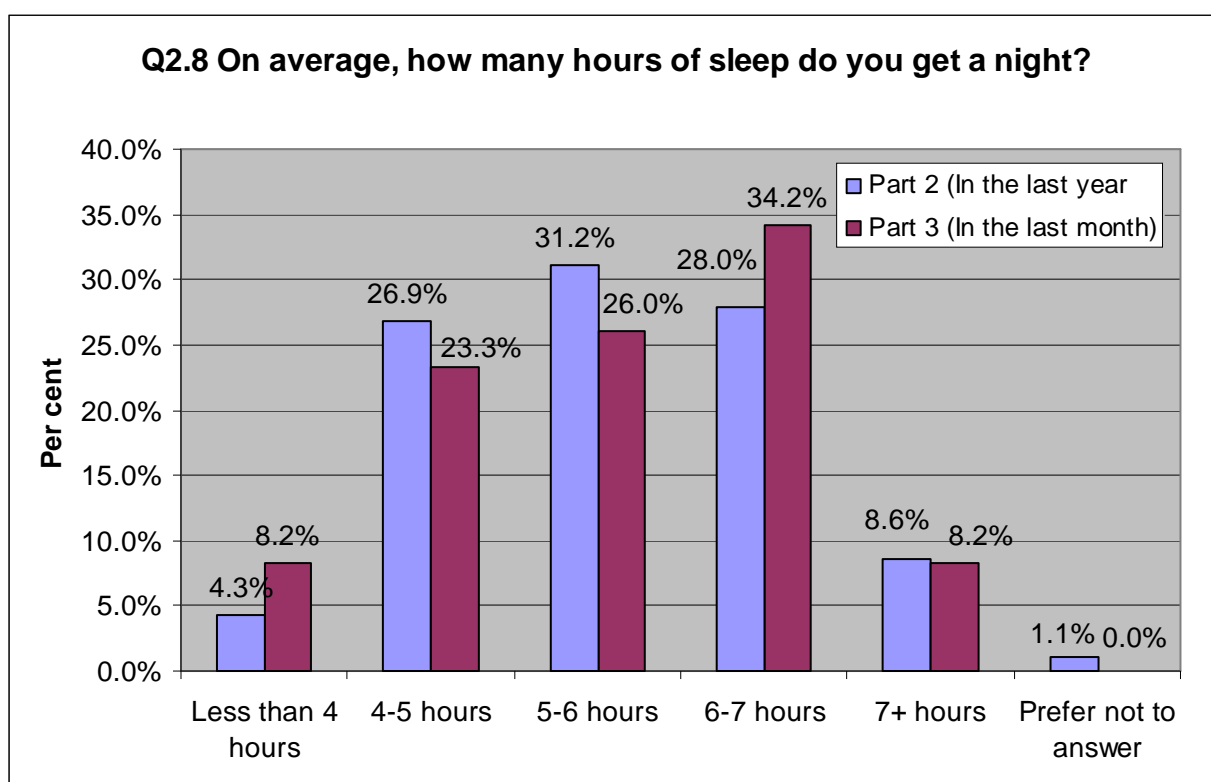
*'Mainly tired and depressed/stressed'.*

*'Had a couple of falls but puts this down to old age and getting clumsy'*

However since receiving a break of their choice, a number of family carers report having an improvement in their health as more family carers rated their health as good in Part 3 of the questionnaire and slightly fewer family carers rated their health as poor in Part 3.

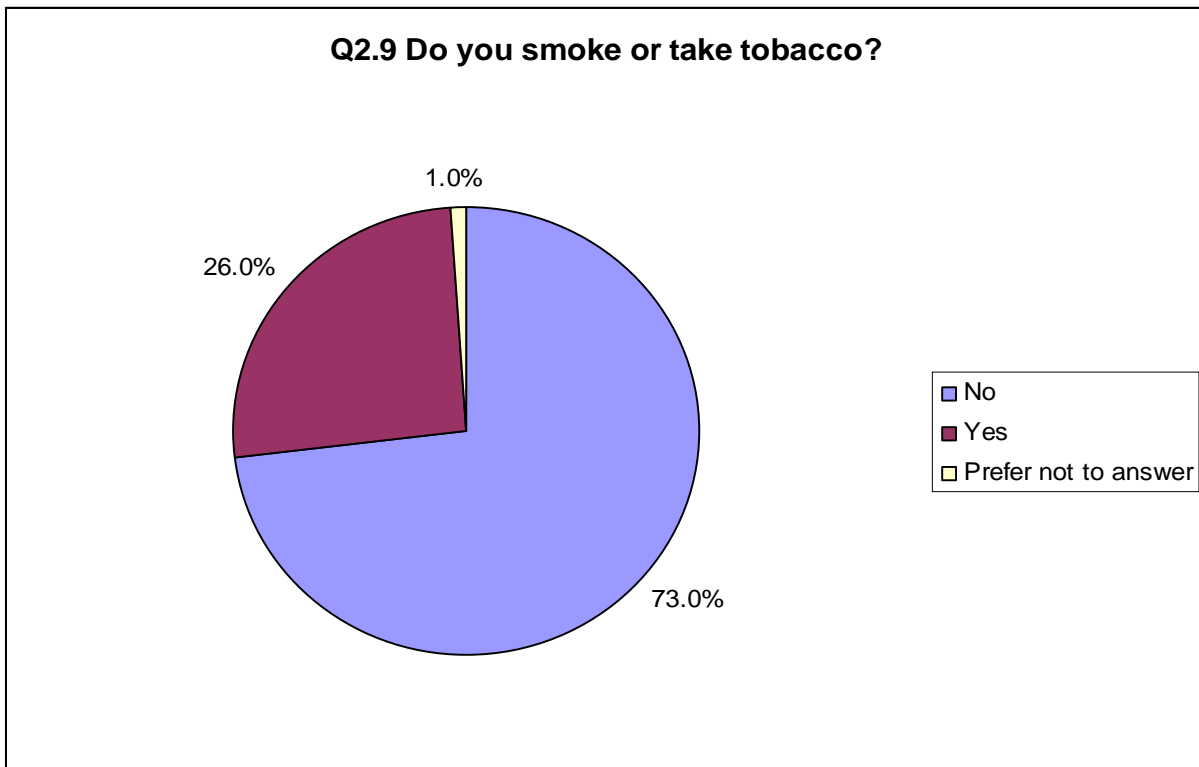
### Q2.8 On average, how many hours of sleep do you get a night? (compared to Q3.9)

The graph below shows that a significant percentage of family carers (90 per cent in Part Two and 91.7 per cent in Part Three) involved in the Brandon Time for You project do not get the recommended 7 + hours of sleep a night. A poor night's sleep is likely to have a significant impact on a family carer's feelings and their ability to fulfil their caring role.

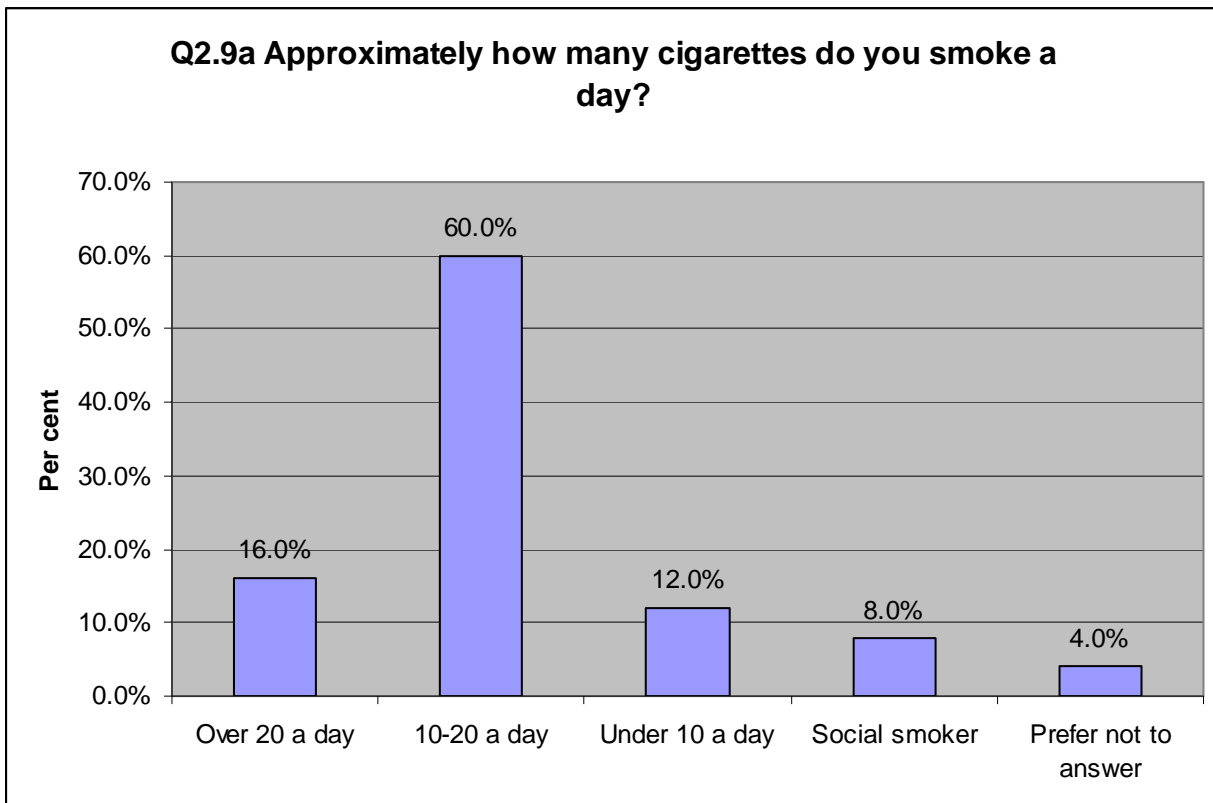


### Q2.9a Do you smoke or take tobacco?

The majority of family carers involved in the Time for you project do not smoke. However of those that do smoke or take tobacco, a high percentage (76 per cent) smoke over 10 a day.

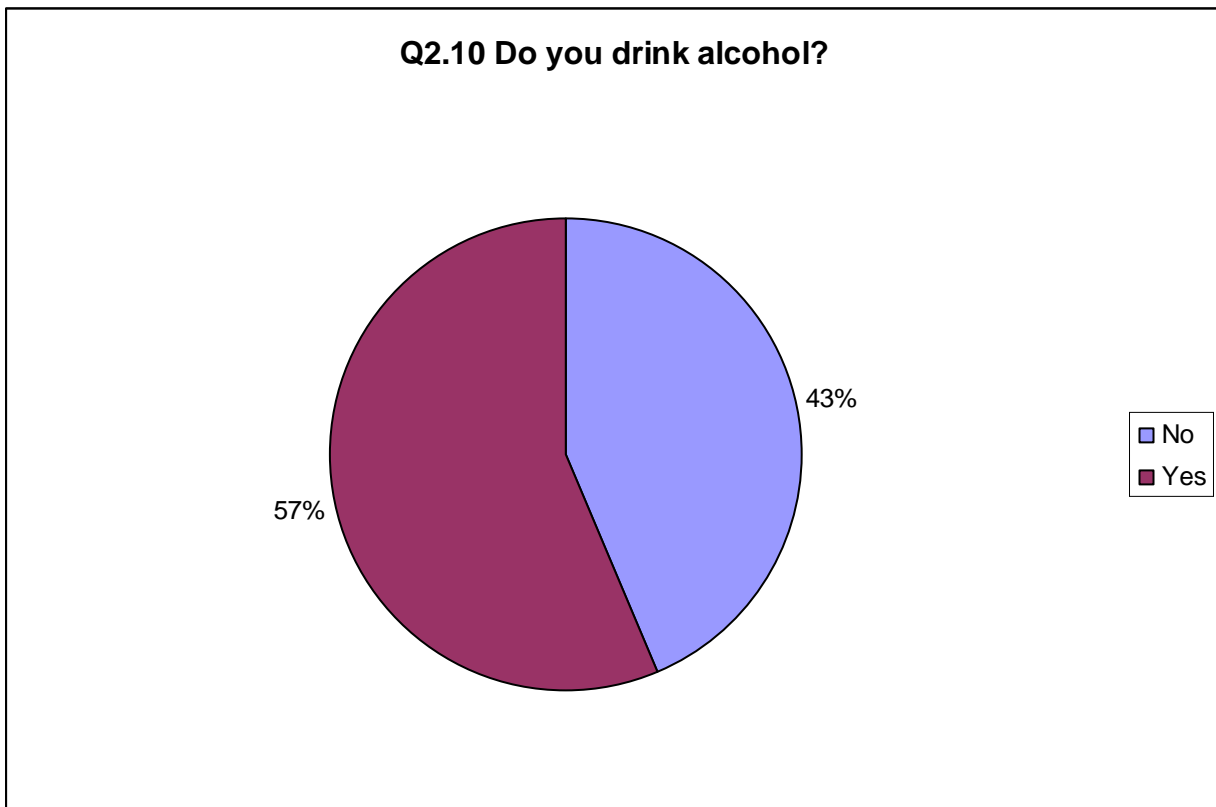


### Q2.9b If yes, approximately how many cigarettes do you smoke a day?

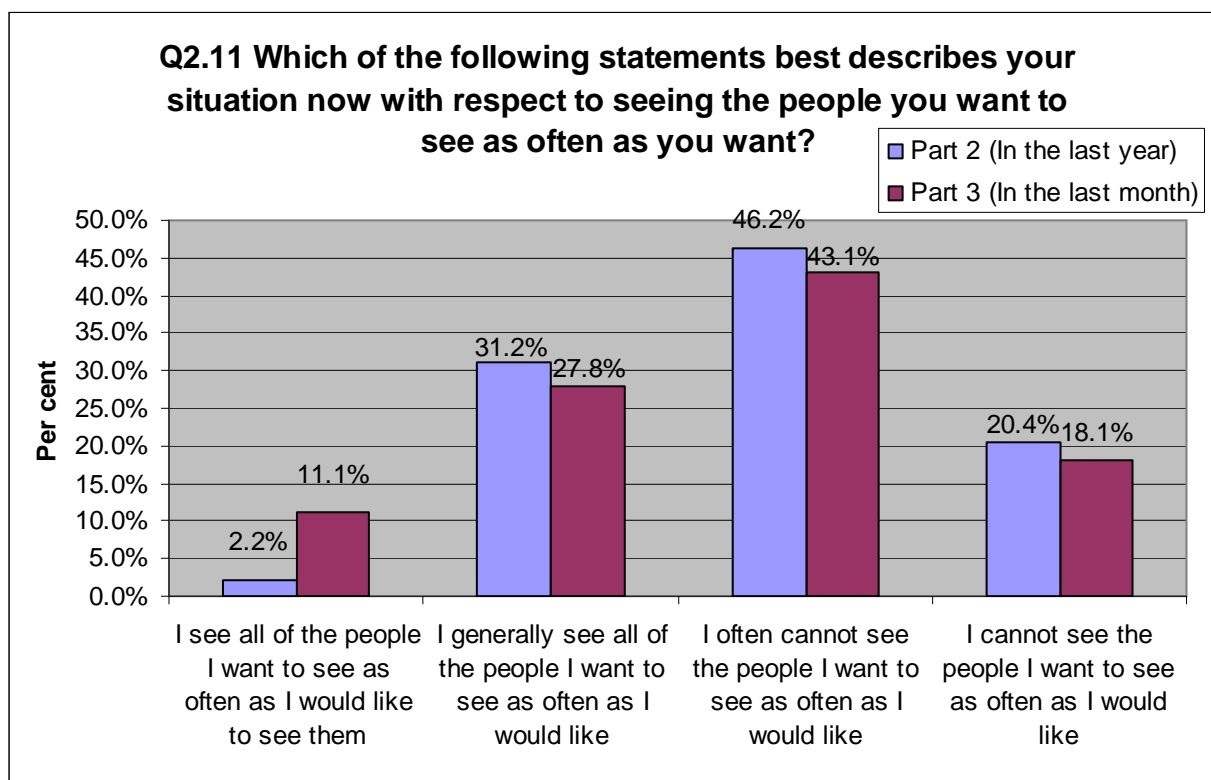


## 2.10 Do you drink alcohol?

57 per cent of the family carers we spoke to in Brandon drank alcohol. 43 per cent did not.



**Q2.11 Which of the following statements best describes your situation now with respect to seeing the people you want to see as often as you want? (compared to Q3.14)**



The graph above shows that the majority of family carers involved in the Brandon Time for you project do not get to see the people they want to see as often as they want too. The quotes below illustrate just how difficult it is to be a carer and see the people you want to see. The caring role can greatly impact on a family carer's social life:

*'I don't have any friends because of our caring role, we have no social life, only family at weekends.'*

*'Friends come to us because I can't really leave my mum. But like always take my mum out when friends visit.'*

*'It is difficult to visit friends some distance away as cannot leave mother overnight'*

*'My family do get upset when I can't go out during the week as I always cook my mum's dinners.'*

*'The only time I do go out is when Crossroads visits.'*

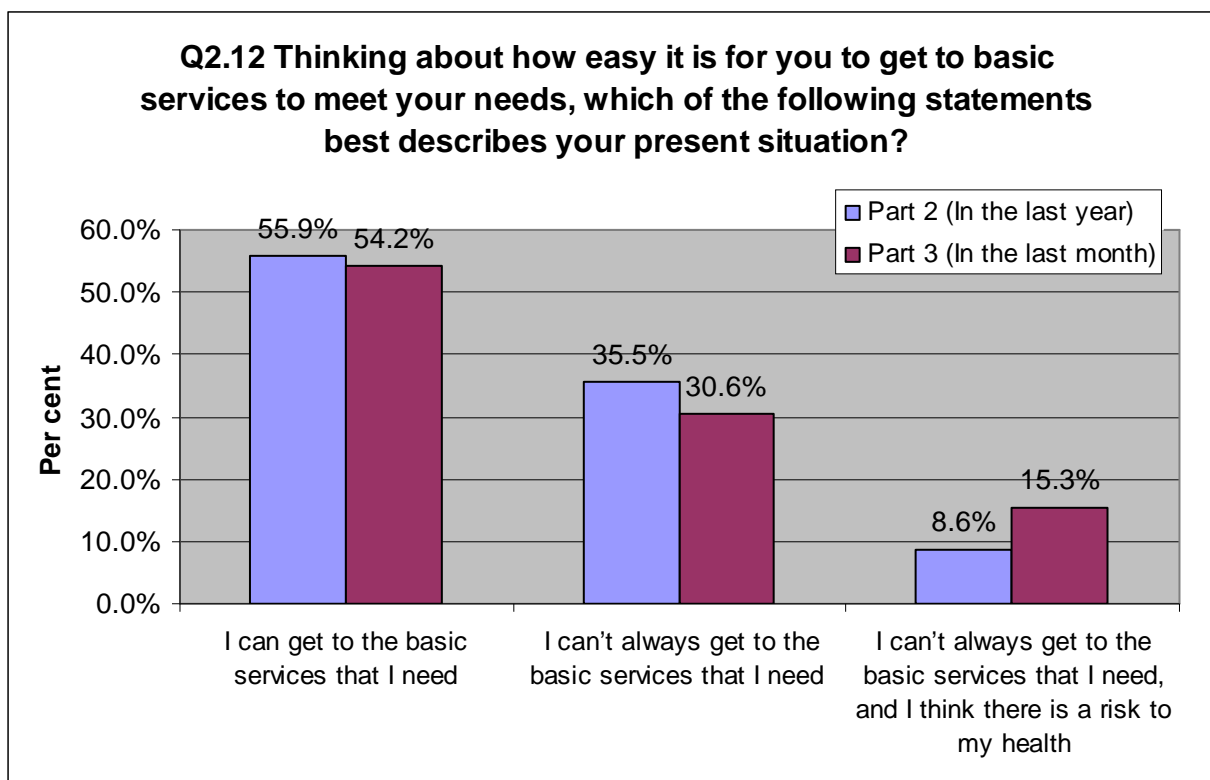
*'Has no social life as her obligations revolve around her caring role, so no time for herself. Friends and relatives have to come to me'*

*'Miss friends, not able to see very often at all, also family as they live quite far away and husband unable to travel very well.'*

However since receiving a break of their choice more family carers reported that they were able to see all the people they would like to see as often as they would like to see them.

**Q2.12. Thinking about how easy it is for you to get to basic services to meet your needs, which of the following statements best describes your present situation? (compared to q3.15)**

The graph below shows that the majority of family carers in the Brandon Time for You project can usually get to the basic services that they need. Worryingly a small but significant percentage do think that there is a risk to their health as they are unable to get to the basic services they need and in Part 3 of the questionnaire the situation had escalated with a higher number of family carers reporting a possible risk to their health.



Despite the majority of people saying they can get to the basic services that they need, the remarks from family carers in the comments section of this question do show that family carers often have to carefully plan their trips to the doctors/ basic services:

*'We can get there, but it has to be planned. I need people to be here to help them with day to day chores'.*

*'I do try to fit appointments in when my daughter's at the Day Centre or is out with friends'.*

*'Gets neighbours in when going to doctor's etc'*

*'I nearly always can get to the GP as my sisters' will always pop in'.*

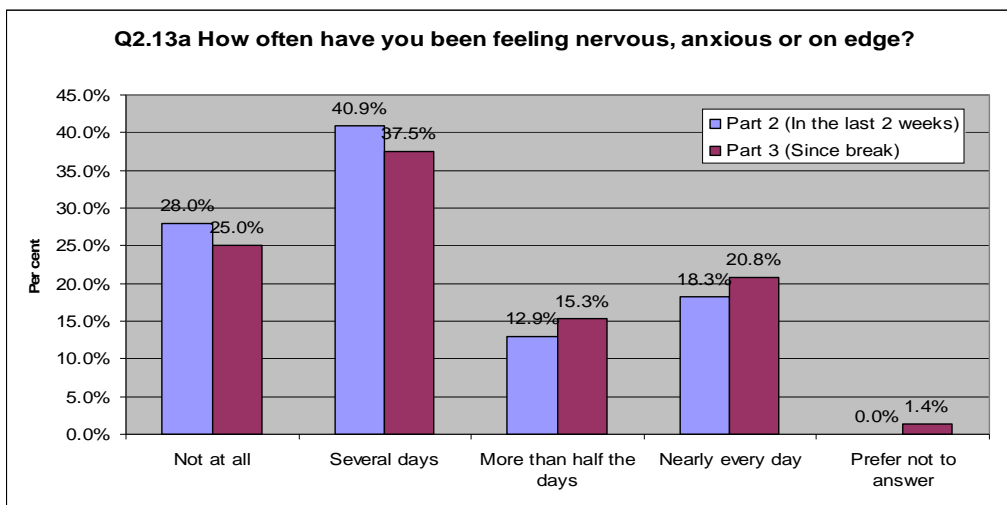
*'I try to make appointments when someone can come and sit with my husband'.*

*'[If] my husband did not go to day care, I would not be able to get to some of the basic services'.*

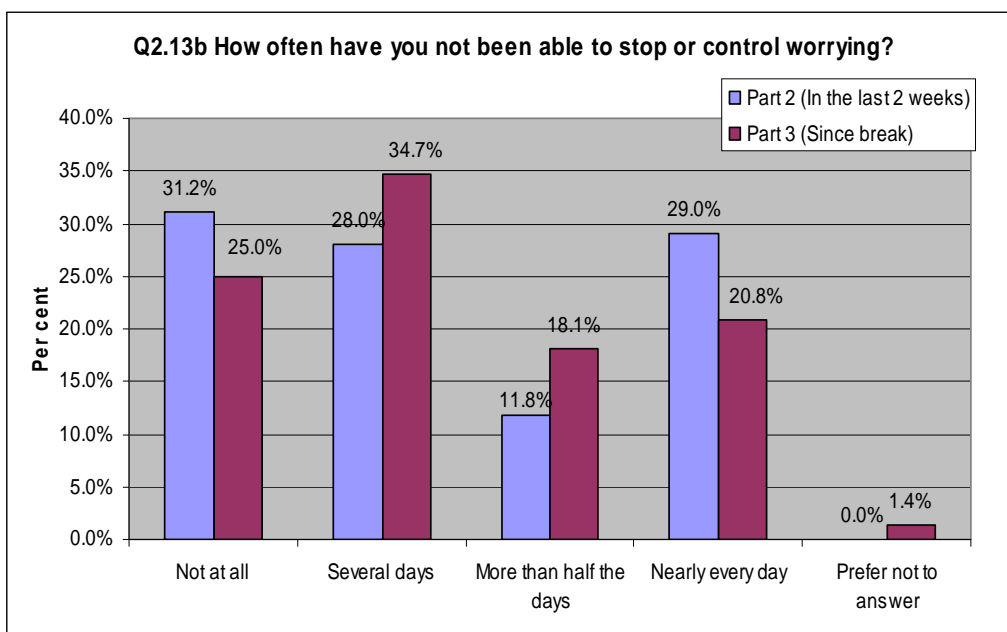
**Q2.13 .Over the last two weeks, how often have you been bothered by any of the following problems (compared Q3.16)**

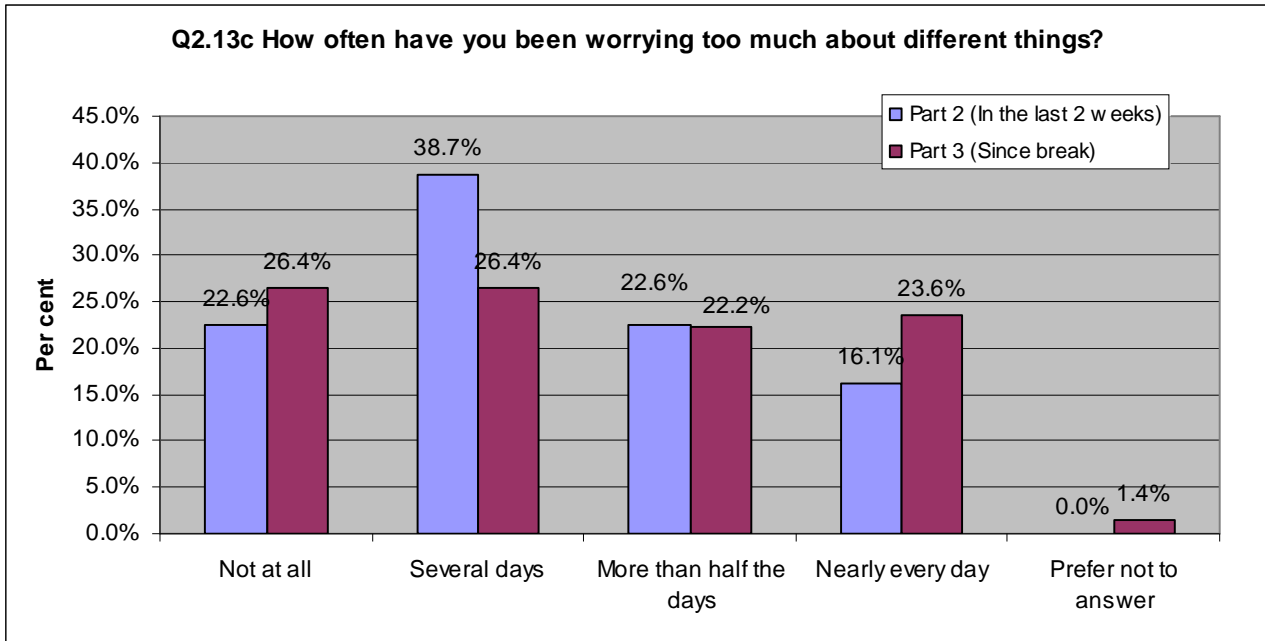
All the graphs in the section below show the wide variety of different feelings family carers have experienced in either the two weeks before they completed Part 2 of the questionnaire or since they received the £100 award (Part 3). However it must be noted that it is not possible to completely associate the family carer's feelings to their caring role. Other issues outside of their caring role, for example financial worries or relationship problems, may well have affected how family carers have responded to these questions.

Again it is also difficult to make comparisons between Part 2 and Part 3 responses as a significant number of family carers have not completed Part 3 of the questionnaire. In general there have not been significant differences between responses in Part 2 and Part 3.

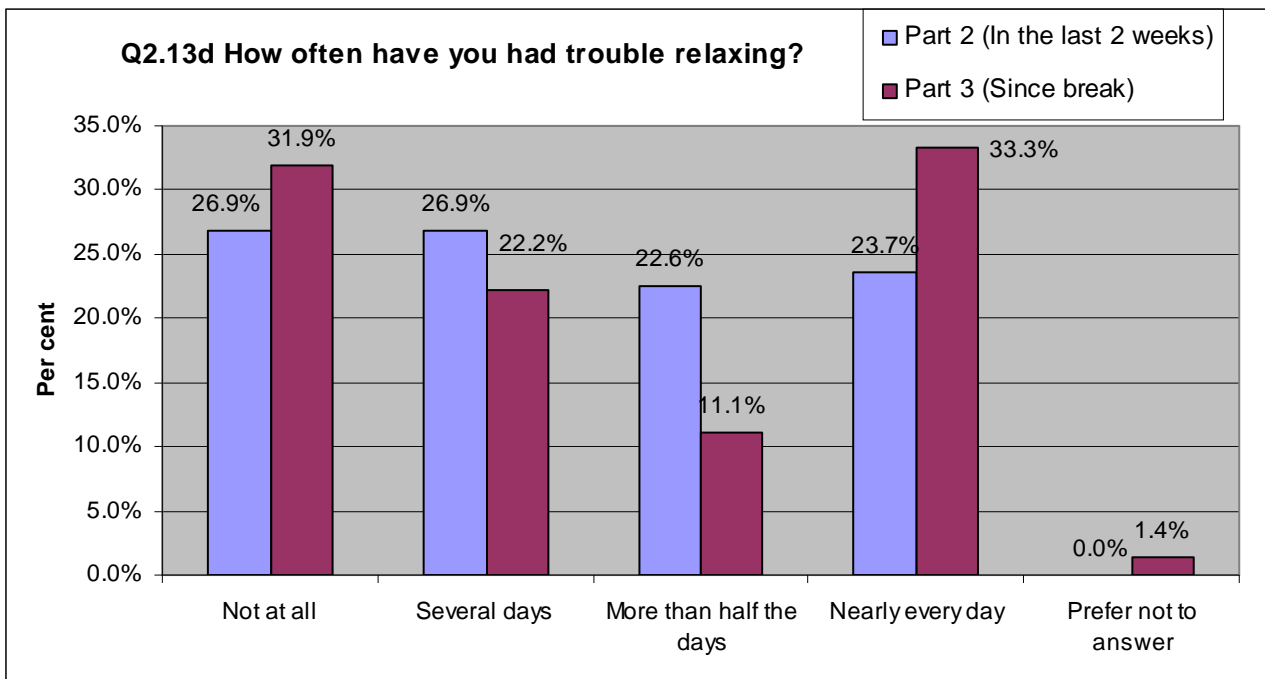


Graph Q2.13a shows that family carers have been feeling slightly more nervous, anxious or on edge since they received a break of their choice. Graph Q2.13b shows a slight increase in family carers not being able to stop or control worrying since having a break of their choice.

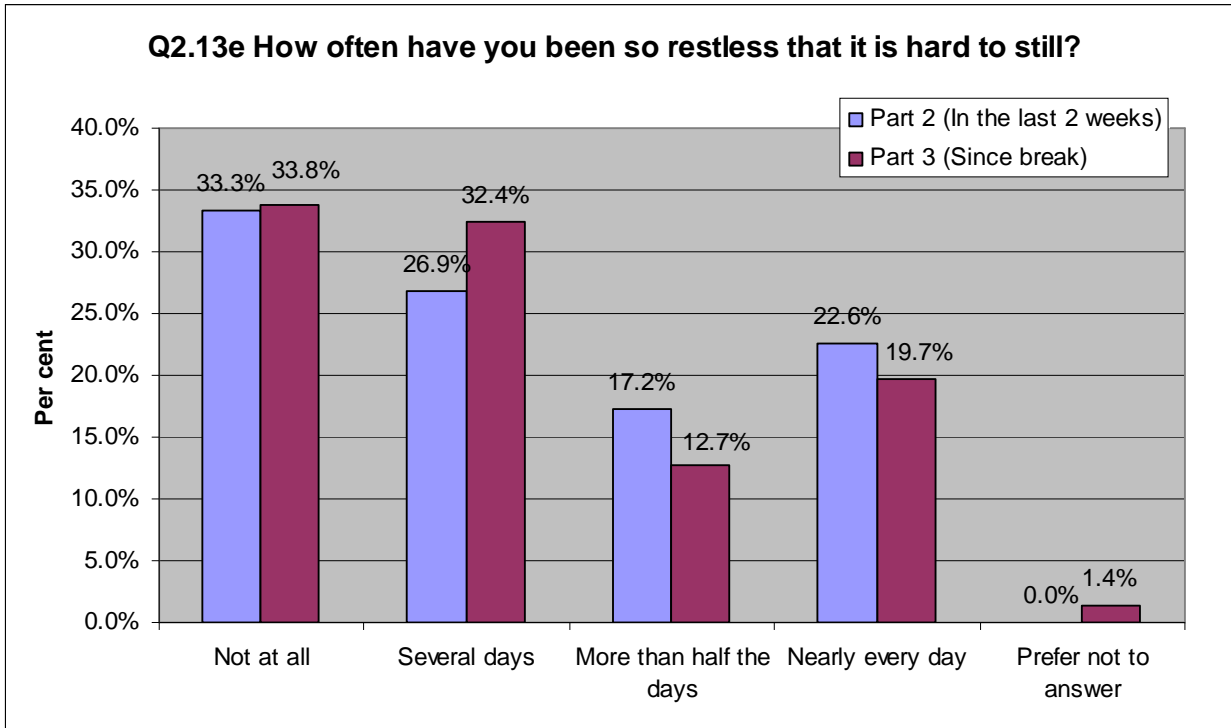




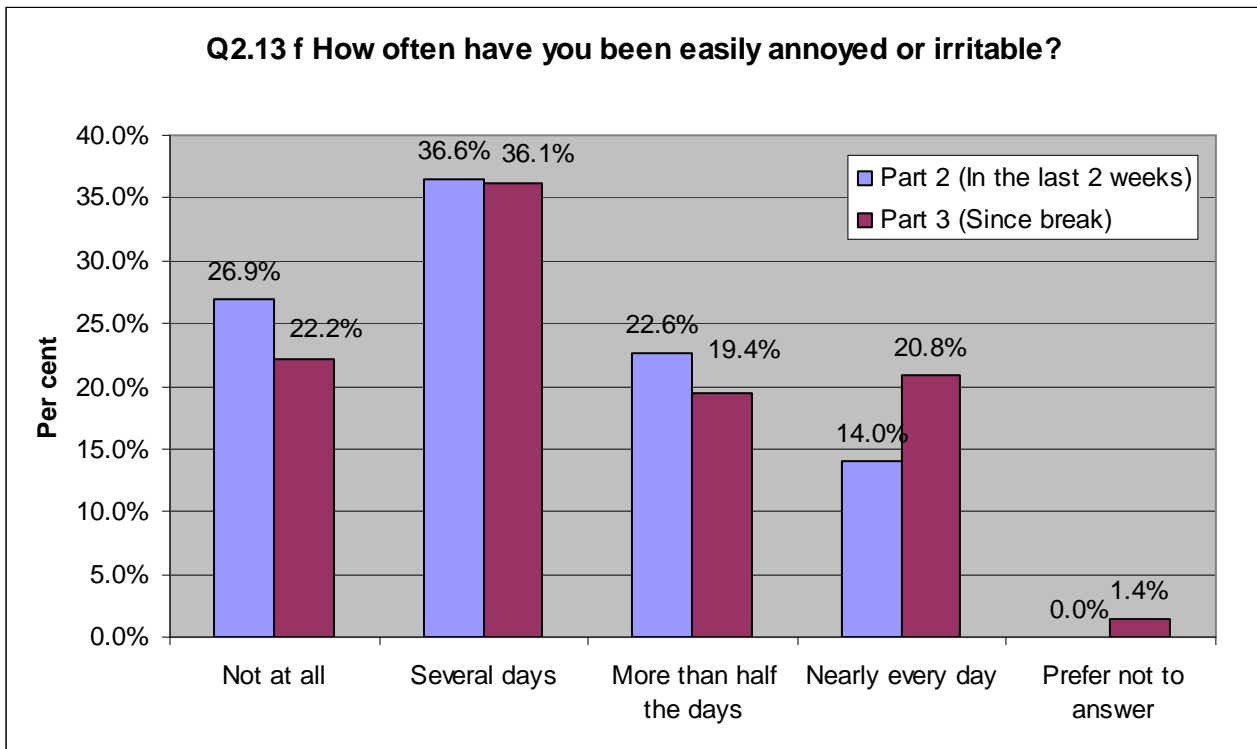
Graph Q2.13 c shows a slight increase in family carers worrying too much about different things since they received the £100 award.

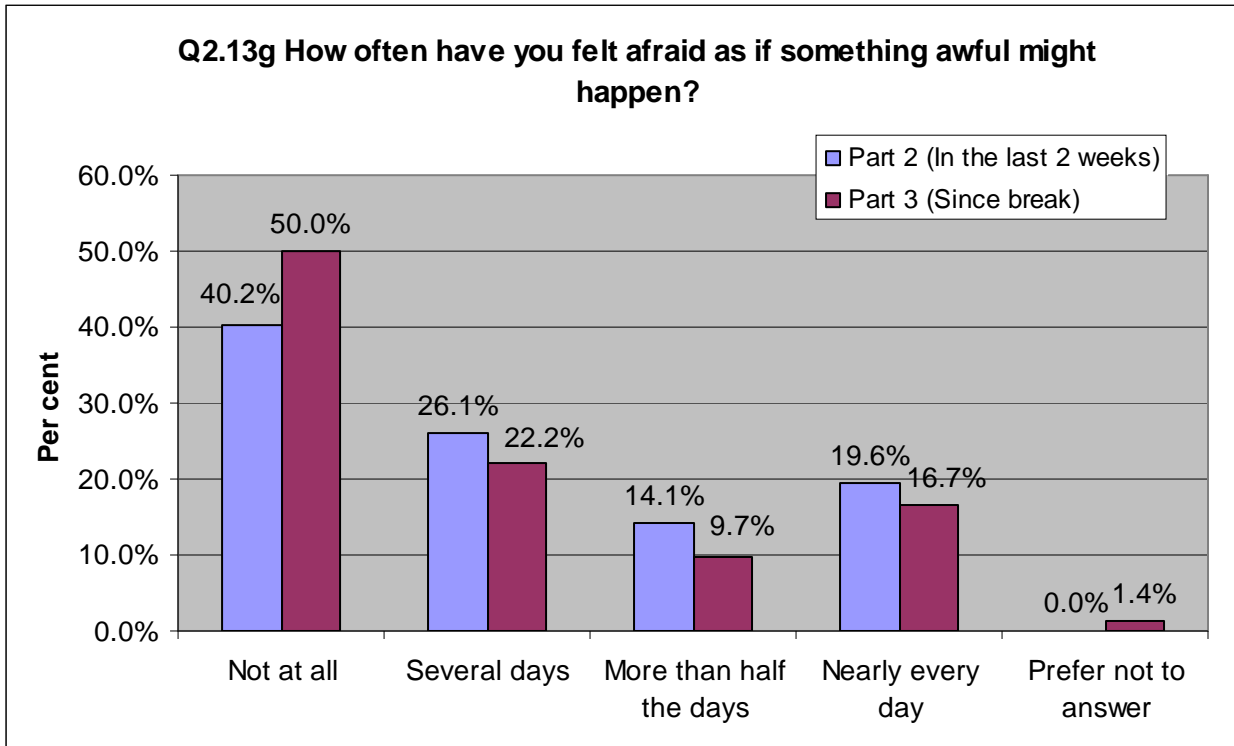


Graph Q2.13d and Q2.13e show mixed results. For example with Q2.13d, some family carers in Part 3 reported that they had no problems relaxing, yet other family carers said they had more problems relaxing since they had a break of their choice.



Graph Q213.e above shows that family carers reported mixed feeling around restlessness since having a break of their choice. Some reported feeling less restless and other's felt more restless. Graph Q2.13f below shows that family carers felt more easily annoyed or irritable since having a break of their choice.





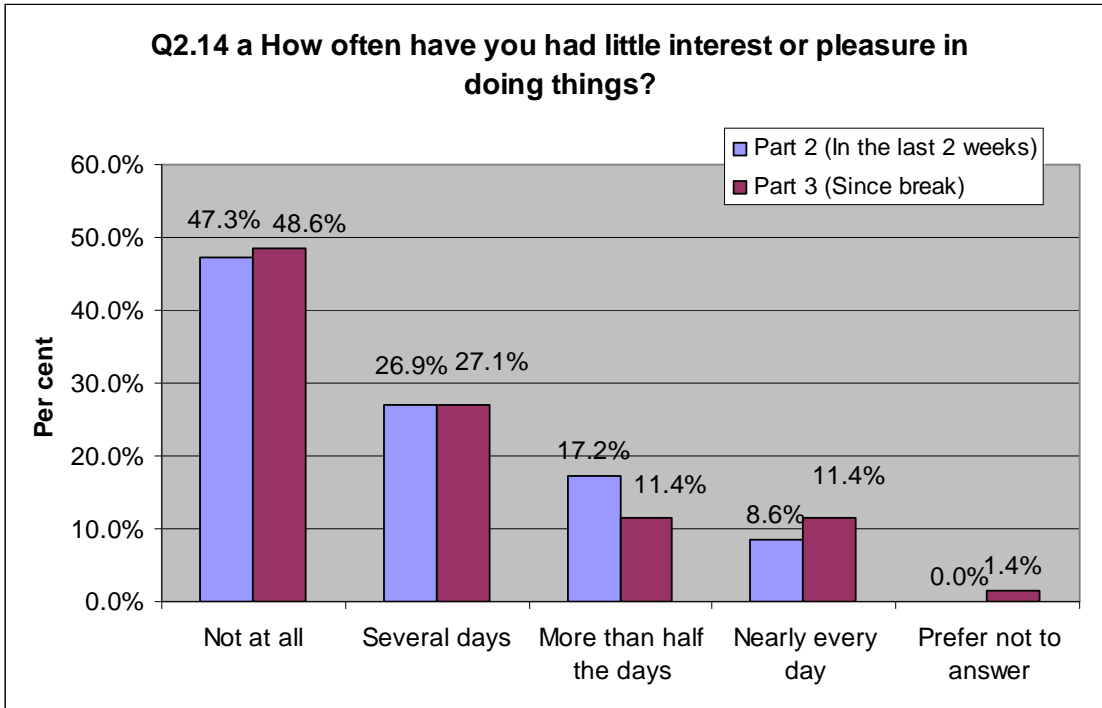
Graph Q2.13g below shows that family carers felt less afraid of something awful happening since they had a break of their choice with the £100 award they received.

**2.14 Over the last two weeks, how often have you been bothered by any of the following problems (compared to Q3.17)**

All the graphs in the section below again show the wide variety of different feelings family carers have experienced in either the two weeks before they completed Part 2 of the questionnaire or since they received the £100 award (Part 3)

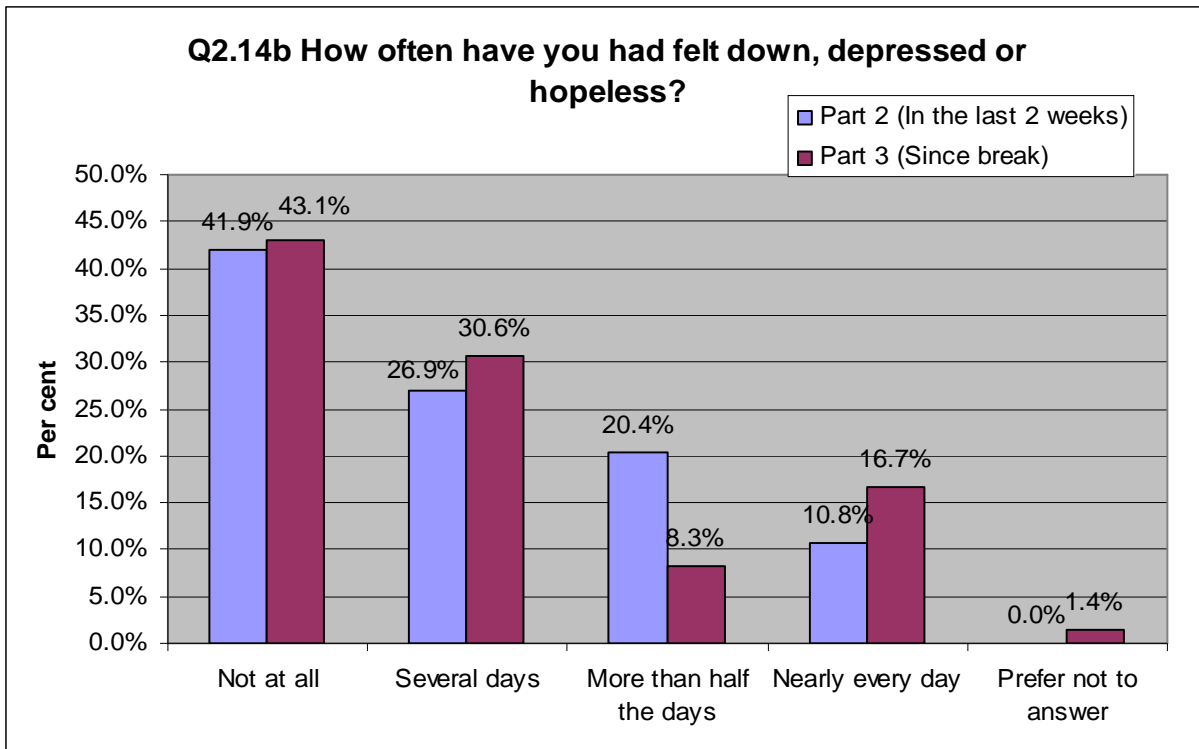
It must be noted again that it is not possible to associate the family carers feelings completely to their caring role. Other issues outside of their caring role, for example financial worries or relationship problems, may well have affected how family carers have responded to these questions.

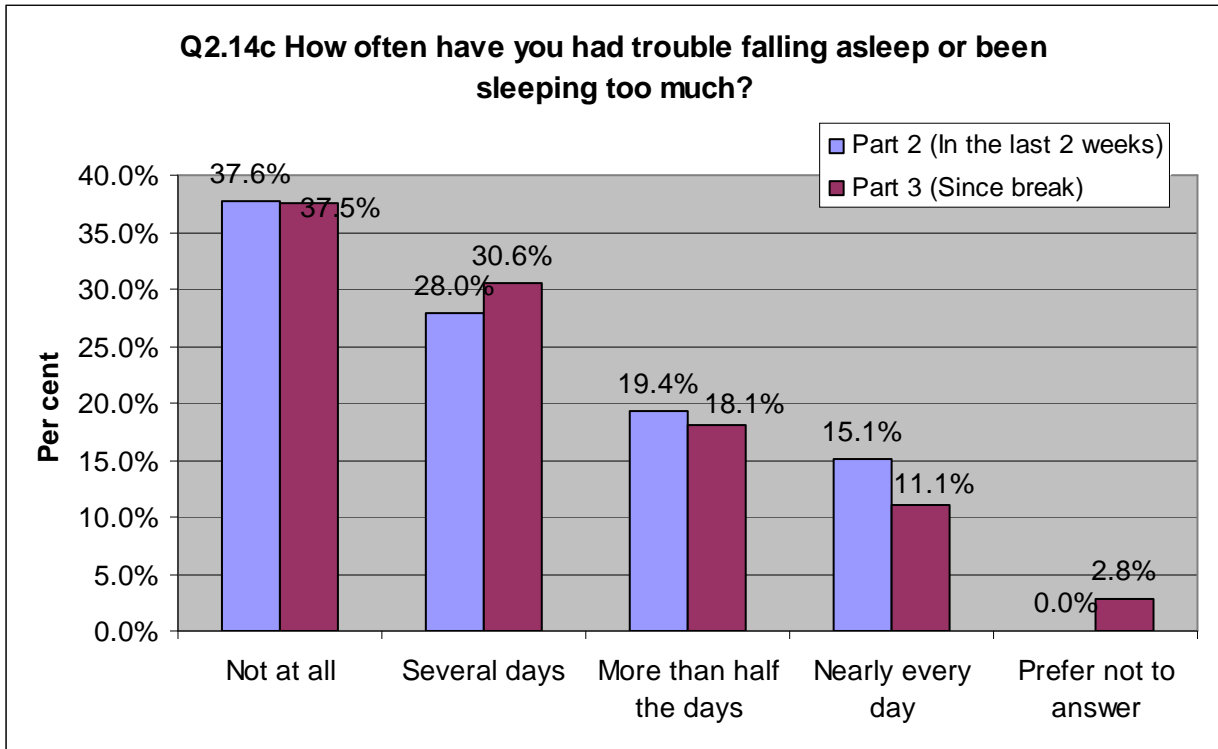
Again it is also difficult to make comparisons between Part 2 and Part 3 responses as a significant number of family carers have not completed Part 3 of the questionnaire. However with the data set as it stands it is interesting to note that generated so far shows that there is very little difference in the responses between Part 2 and Part 3. In general there have not been significant differences between responses in Part 2 and Part 3.



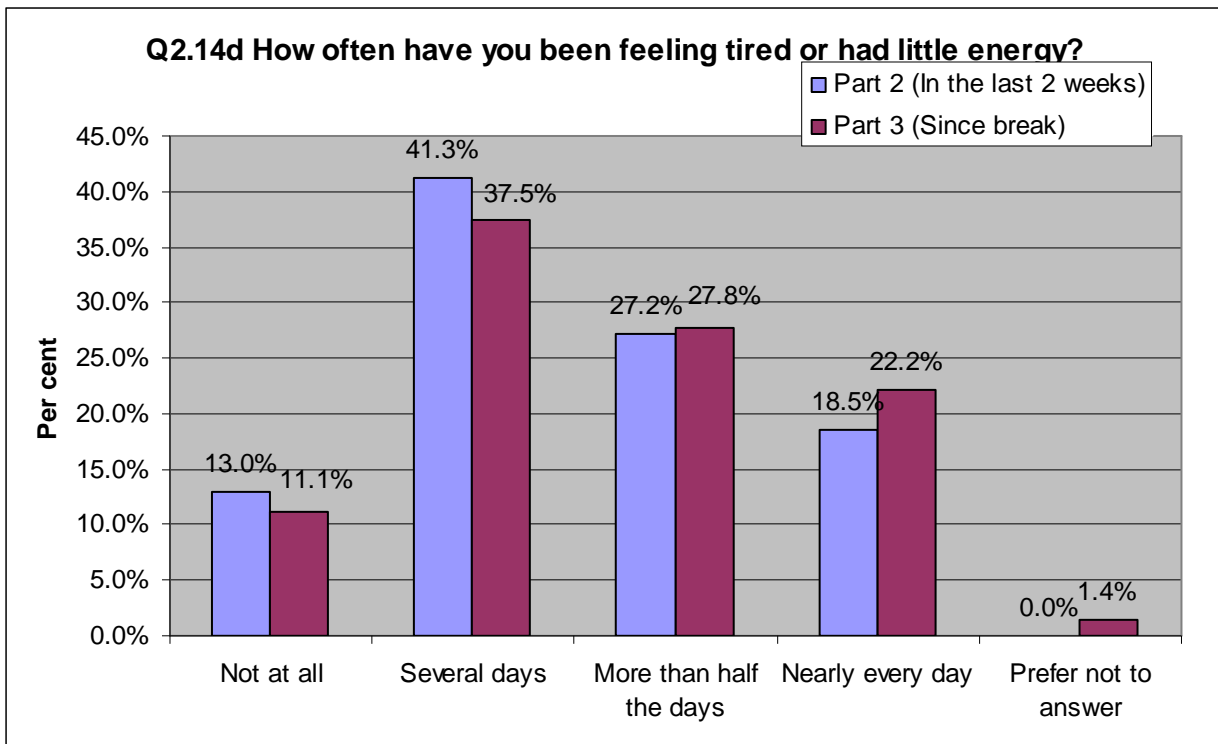
Graph Q2.14a above shows that family carers report having slightly more interest and pleasure in doing things since they were able to have a break of their choice.

Graph Q2.14b below shows that family carers have felt somewhat less down, depressed or hopeless since they had a break of their choice.



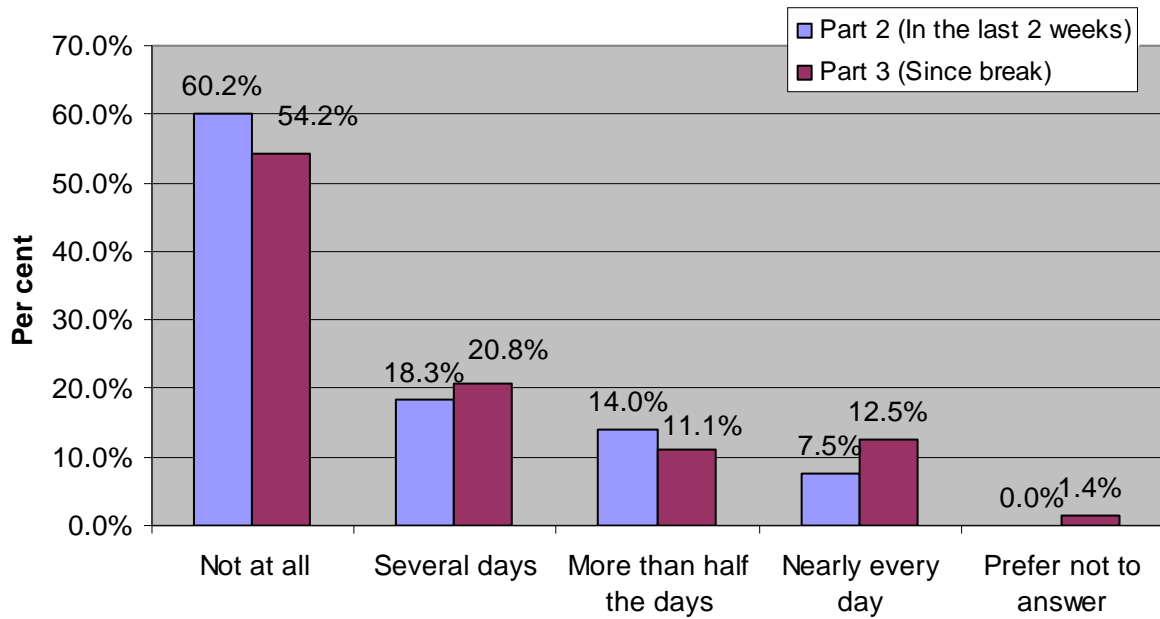


Graph Q2.14c shows that family carers have had slightly less problems with their sleep since having a break of their choice.

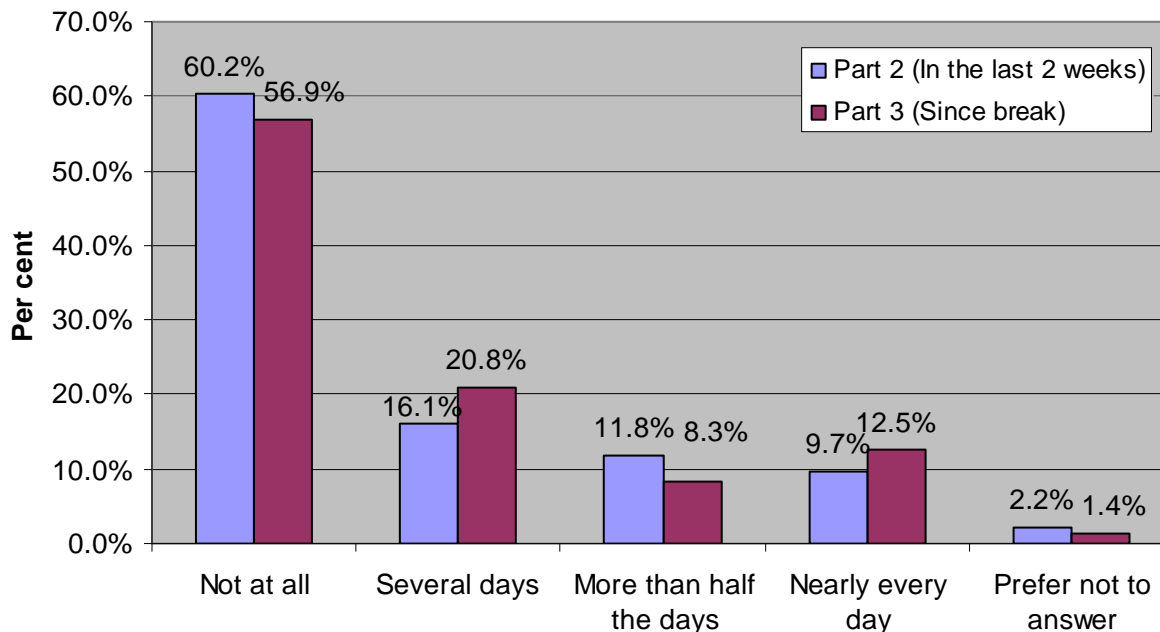


Graph Q2.14d shows that family carers have been feeling somewhat more tired and have less energy since they were able to have a break of their choice. Graph Q2.14e shows that family carers have been slightly more likely to have a poor appetite or overeat since they had the £100 award.

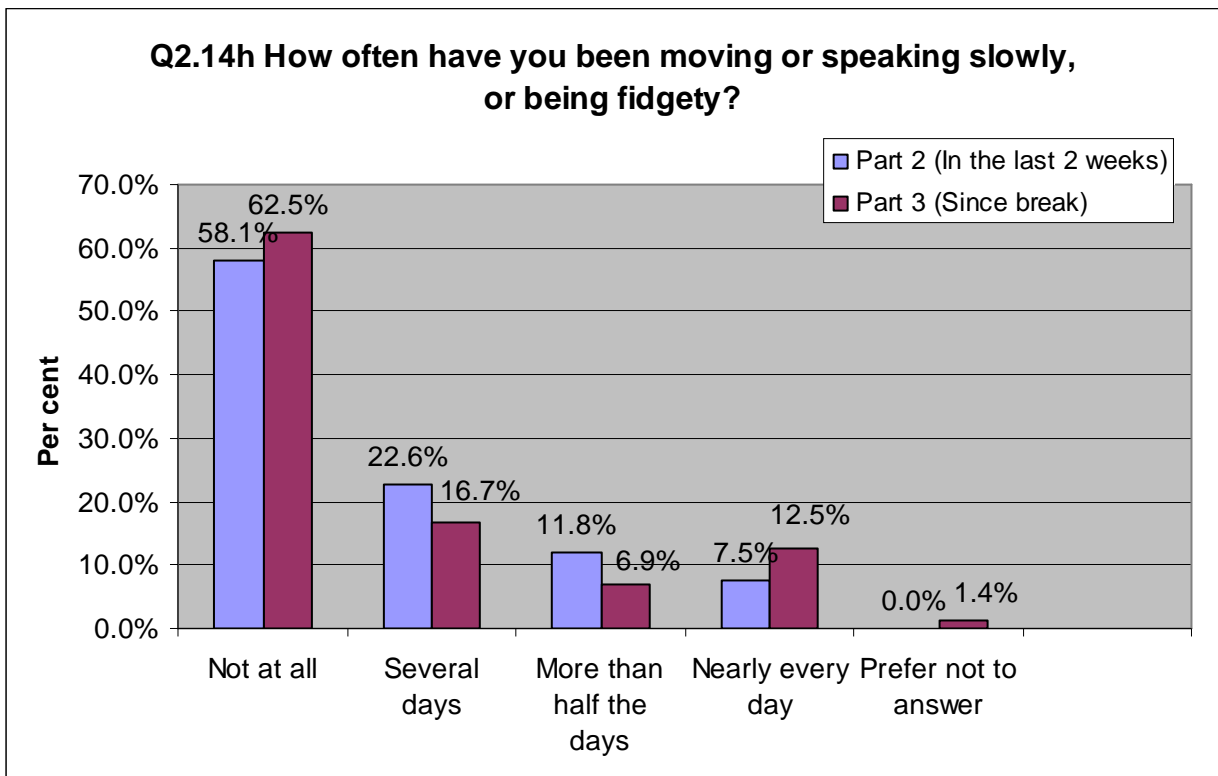
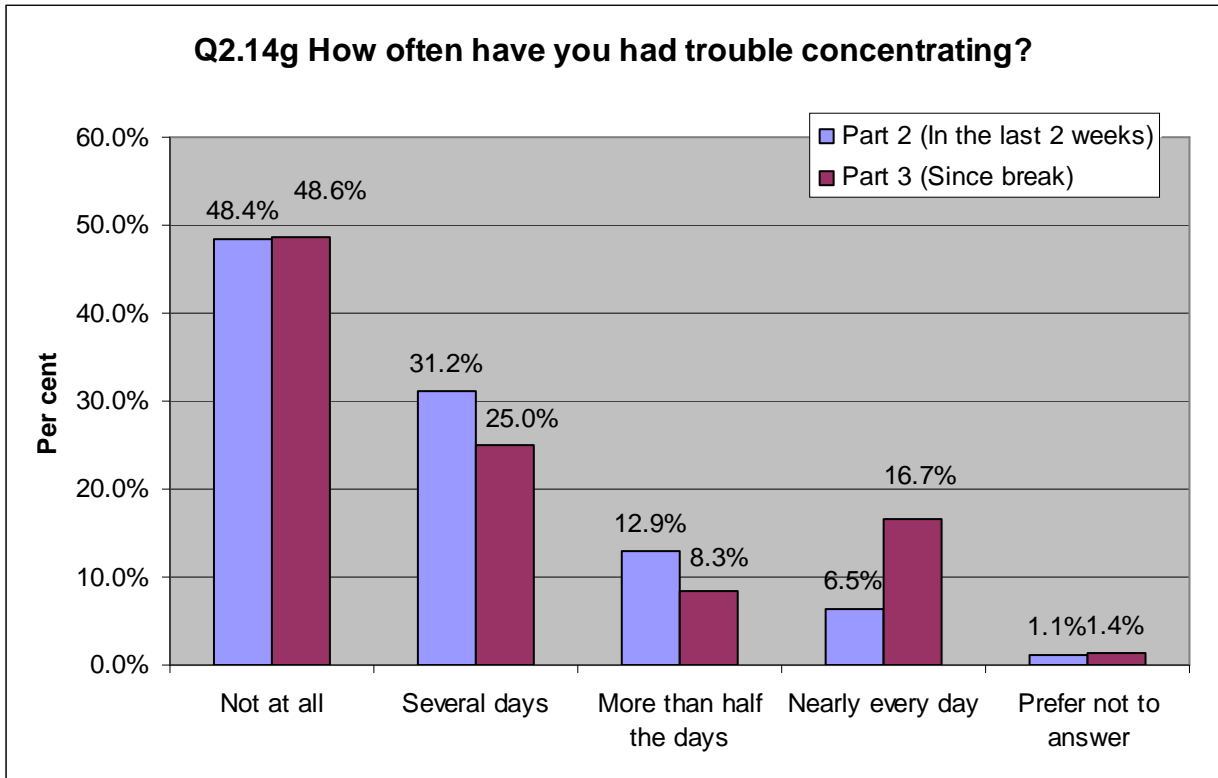
**Q2.14 e How often have you had a poor appetite or been overeating?**



**Q2.14f How often have you been feeling bad about yourself?**

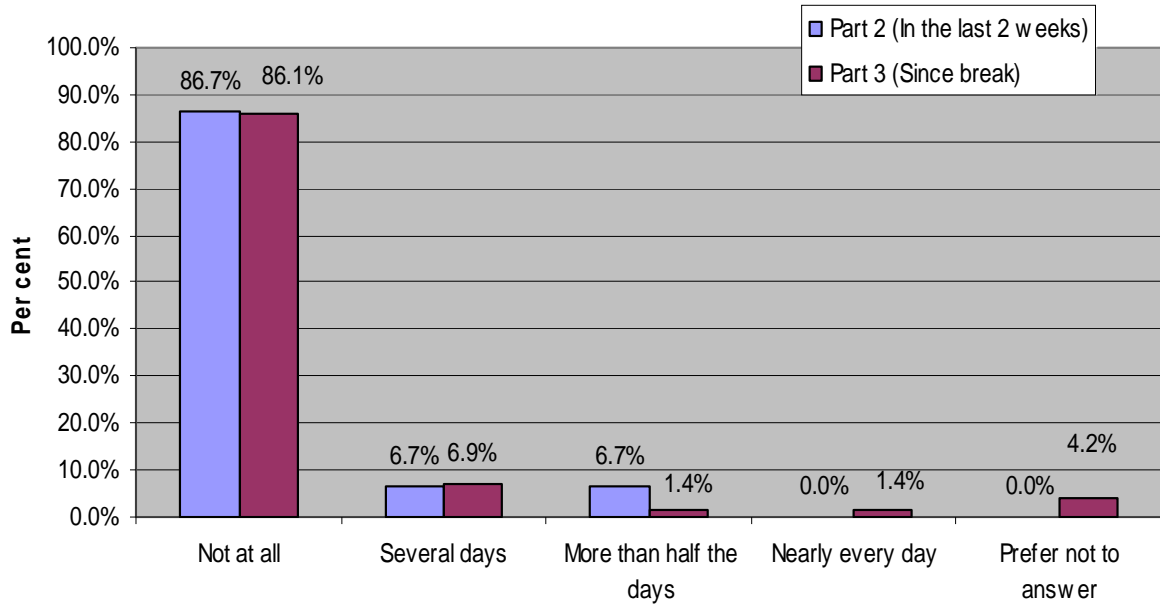


Graph Q2.14f shows that family carers have felt slightly worse about themselves since having a break of their choice. Graph Q2.14g shows that some family carers are had more trouble concentrating since having a break of their choice.



Graph Q2.14h shows that family carers have been less fidgety since having a break of their choice and graph Q2.14i shows that the level of suicidal thoughts amongst family carers has remained largely the same since the family carers had a break of their choice.

**Q2.14i How often have you had thoughts that you would be better off dead?**



## Qualitative Responses

The result below show some of the responses to more qualitative/ open questions asked in the Time for You questionnaire. These questions all focused on what family carers would spend the £100 award they received on and the type of short breaks they would like to receive.

The responses have been coded using the computer software programme NVivo into themes for each question. Interestingly there has been a maximum of 13 themes or areas in which people planned to spend their money.

The most popular themes/ spending areas have been; day trips out (often with a meal out included in the day trip), shopping trips to local places, putting the £100 towards the cost of a holiday or using the £100 as spending money once on holiday, pamper sessions, a weekend or short break away, home improvements, equipment – such as assistive technology and laptops etc, lessons and course and trips to see other family members.

Another key theme to emerge in the qualitative data is that family carers who care for a spouse generally wanted to go on a break which the person they cared for could go along with them too. They did not want to be separated from the person they cared for. However family carers who were caring for a parent tended to want to take breaks without the person they cared for. They generally wanted time away from the cared for so they could spend quality time with other family members and have a break from their caring responsibilities.

### Q 2.15 – What might you spend £100 on for you or a family member to gain a break from your caring role?

The table below shows the key areas the family carers thought that they would spend their £100 on in order of popularity. As can be seen having a day out and a meal out were the most popular responses, followed closely by putting the money towards a holiday and going on a shopping trip.

What they might spend £100 on	No of family carers spent in this area	Examples of spend
Day out	17	* Would like to go on two trips with the cared for = a mystery tour bus trip and then a trip to Brighton on 15th May. Likes bus trip day out with her Husband (cared for) Gives the cared for something different to do and the carer enjoys it too * Take his wife and 11 year old grandson to the seaside for the day with a fish and chip lunch * Day boat on the broads together. Have a meal in the middle of the day whilst out on the boat
Meal out	17	*Trip to the cinema with a meal out *Would like to go on a shopping trip to Bury St Edmunds and have a meal out *I am definitely going to Kings Lynn to go shopping and have a meal out.
Put towards a holiday/ holiday spending money	13	*The £100 will go towards my holiday in Jersey. My wife will be cared for at home. I need some time on my own. *Will go towards a holiday to Wells with husband and dog (without cared for)
Shopping trip	11	*Shopping trip to Norwich with the cared for as she loves Norwich and he is a Norwich City fan

		*I would like to go on a shopping trip with a friend for a weekend
Pamper sessions	9	*Pampering day - knowing Mum (cared for) is taken care of. *Will treat herself to a couple of massage sessions.
Weekend away/ short breaks	8	* A lovely weekend away and I would leave my daughter (cared for) with her sister * I would like to pay for myself and my girlfriend to have a break away (without cared for) * Towards a weekend break with husband and mother in law at a caravan site with disabled facilities
Equipment	8	*Intercom - doorbell monitor for my husband to use if I am out. *An alarm - button and pager for cared for to alert carer if there are any issues whilst I am out gardening for example
Home improvements	5	*A carpet cleaner. Her's has broken and it's going to cost a fortune to fix. She would like to go away for a break but her husband is not good around crowds. *New lighting for conservatory *I could be moving soon, so would like to buy a new bed.
Trip to see family members	4	* I will use the money to pay for a trip to Cornwall to see my family * Is going to visit her parents in Berkshire with her son but without the cared for
Courses and lessons	3	*Wants to go to a local art club which starts in September. *I will use the money for driving lessons. I did learn to drive years ago, but I lost my confidence and gave up years ago *I would like to go on a flower arranging course or a crafts course
Give money to other family member	3	*Would put the money into our daughter's sports fund (Daughter plays basketball for the England squad and they have to transport her to events across the country). *My son is getting married so the money will help pay for some things for that.
Cinema trip	1	Trip to the cinema with a meal out
Evening out	1	Tickets for a music gig or an evening out.

### Q 3.1 – What did you spend the £100 on and what difference has this made to you?

What the family carers actually spent the money on does not widely differ from what they said they would spend the money. Days out and meals out were still the most popular spending areas. And putting the money towards a holiday was again the third most popular choice. One family carer brought a new dog with the £100 on. This was completely different from their response in Part 2 but has brought the family a huge amount of happiness.

What did they spend the £100 award on	No of family carers spent in this area	Examples of spend
Meal out	19	* Took mother (cared for) out and went out for a few drinks in the pub. Then went out for a posh Indian meal in Brandon. Was good to have a night out and nice to take mother out as we don't usually do this. * Mother (cared for) was in respite for a week, so she and her husband went out for dinner together. Only time together since

		<p>caring for her mother since April.</p> <p>* I also had a meal with my friends and the sun shone for us with a nice fresh breeze all day. It made me feel good to be able to relax and have the pressure taken off me. My sister went in to see mum while I was away, so I could relax. I would certainly like to do the same thing again or something similar.</p>
Day out	14	<p>* We went to the football to see Norwich City and then for a mothers day meal at the Bridge Hotel. A trip to see the London Eye has also been booked.</p> <p>* Sister and carer went to Brighton had lunch (coach trip) whilst her brother sat with the cared for. She brought some pink shoes. It was nice to have extra money to treat herself, rather than the normal essentials</p> <p>* Went to Waveney Centre near Beccles (took their beloved dog) and hired a river cruiser for the day. It was their wedding anniversary. They had an amazing day, and one they will never forget. They couldn't thank us enough for their £100.</p>
Put towards holiday	11	<p>* The carer put the money towards a 3 day respite break at a hotel in Jersey (for himself) which he really enjoyed. Whilst he was away he had a full time carer to look his wife 24 hours a day</p> <p>* We put it towards a four day break in the lake district. It was wonderful. Very relaxing and someone came and looked after my daughter.</p> <p>* I used the money to book a campsite at Hemsby. We are both going for the weekend in 3 weeks time. I can't wait to get away for a break. They couldn't afford the campsite without the £100 and are really looking forward to it. This has cheered them up already, even though it is 3 weeks to go.</p>
Equipment	8	<p>* Towards garden shed for husbands mobility scooter. Taken scooter off grass and it can now be electronically charged in the shed and out of the way of the elements. Previously had to put wire through bedroom window and then leave open. One less thing to worry about. Couldn't have afforded a new shed without the £100</p> <p>* Brought a giant airbag to help him get in and out of bath - £100 money has gone towards the costs of it. Hadn't managed to have a bath for 3/4 years and now has managed to have a nice long bath! Loves being able to take a bath - made a real difference to him.</p>
Shopping trip	7	<p>* Sister and carer went to Brighton had lunch (coach trip) whilst her brother sat with the cared for. She brought some pink shoes. It was nice to have extra money to treat herself, rather than the necessities</p> <p>* Had a lovely day. Went shopping and brought extras for our holiday. Make up etc. Excellent day. It really cheered me up</p>
Home improvements	6	<p>* Went towards costs of electrics in conservatory, Conservatory can now be used all year round. Added an extra room e.g. decluttered and can have meals round the table</p> <p>* We spent it on a gardener/handyman, it has made a big difference to our lives. My garden was cleared out, patio cleaned, grass cut, I can plant my seedlings and do all my large pots and cut my grass regularly. We can now sit in the garden when we have some nice weather and enjoy this space.</p>
Give money to	4	<p>*Son is getting married and have put it towards buying him a</p>

other family members		wedding present. * Put some of the money towards their daughter's travelling expenses for Basketball training and matches (Daughter plays for Junior England Squad)
Trips to see family members	4	* I visited my mum with my sister and son (7 years old) who lives in Berkshire. This money paid for petrol to get there and we also went to Legoland, we went to Windsor Castle and saw the changing of the guard and went into the state rooms, which my son enjoyed very much, as well as my mother and father. This is the first time we've been together to have a full week with them all together. Windsor Castle was a full day, Legoland was a full day, including lunch and evening meals together. * Went on a break with brother and wife, went to Portsmouth and visited uncle - hadn't seen him in eight years. Lovely time - the money came in handy and had great weather. Made a lot of difference having time off - came back refreshed and revived.
Pamper session	3	*She is going on holiday next week and will spend the money on a pamper session at the resort. (Massage, sauna, nails etc).
Courses and lessons	3	*Flower courses at Bunches and Bows - one has been completed, two more to do. Really appreciated being able to do the courses and get away from the normal everyday stresses of being a carer * I joined gymophobics in Bury St Edmunds. I go three times a week which gives me time to myself, and I really enjoy it.It was £80 to join and induction, and now I pay £29 a month. *Put it towards driving lesson. She learnt to drive years ago but has totally lost her nerve. Now she desperately needs to drive for her part time job and more importantly to take her disabled children out and about (25 and 20 yrs old) 8 Driving lessons for £95
Evening out	2	*Evening out at old time musical and meal out with partner (cared for)
New pet	1	* Last time we spoke their pet dog was being treated for cancer. They planned to use the £100 on a day trip to Yarmouth. But their dog had to be put down and her husband was so depressed they decided to put the money towards a puppy, which they now have. They are delighted and it has really cheered them up

**Q 3.2 – If you were to receive another £100 in the future for you or a family member to spend on a break from your caring role, what might you spend this money on?**

Family carers were also asked to think about breaks that they would like to take if they were to receive another £100 in the future. Once again the themes were largely comparable with the past two questions and the family carers said that they would spend the £100 on similar things as the last £100 they received. For example family carers wanted to have weekends or short breaks away or take day trips to the coast or nearby towns. A number of family carers want to have more trips to see family members that live in other areas of England, the £100 could help towards the travel costs of visiting relative in other counties:

What they might spend £100 on	No of family carers spent in	Examples of spend
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	<b>this area</b>	
Weekend/ short break	20	<ul style="list-style-type: none"> <li>* Weekend break away - not too far away.</li> <li>* Spend it on a little weekend away. Yarmouth maybe - seaside. Would also like to see brother in Buckinghamshire. Would like to go with people she cares for.</li> <li>* If they could get their mother (cared for) into respite would go away for the weekend on their own.</li> </ul>
Day trip	12	<ul style="list-style-type: none"> <li>* I would very much like to go to the theatre - perhaps in London (as long as it fitted in when my husband was in care in Glastonbury Court in Bury St Edmunds. Also I would love to do another shopping trip in Bury or in London</li> <li>* Would do a similar thing - look for more short coach trips to interesting place</li> <li>* Take a trip to the coast together for a day (with their puppy!!)</li> </ul>
Shopping trip	6	<ul style="list-style-type: none"> <li>* Share an evening out with friends or a shopping trip</li> </ul>
Trip to see family	5	<ul style="list-style-type: none"> <li>* Put it towards going to see son in Spain</li> <li>* We would like to visit my mother and father again or have a caravan with them, which would mean we could all spend time together again.</li> <li>* A short break to visit daughter.</li> </ul>
Put towards a holiday	5	<ul style="list-style-type: none"> <li>* Would take a short break with his wife to a local hotel where they have all the facilities for his wife's special needs. This would not come cheaply!</li> <li>* Mini breaks at holiday camp (4 days with husband)</li> <li>* They'd like to go to a caravan park at "Pine Lodge" in Bath (£120 per week) together</li> </ul>
Meal out	5	<ul style="list-style-type: none"> <li>* Would do the same again and have dinner out</li> <li>* meal with family in London - they could collect us by car</li> <li>* A meal or lots of mini meals out with family</li> </ul>
Equipment	5	<ul style="list-style-type: none"> <li>* I would definitely buy another bicycle - to go out and get the shopping for mum or emergency visits, my present one is rather in need of repair.</li> <li>* Mobility equipment.</li> <li>* Put it towards a laptop to call son in Spain, to stay in contact with him better.</li> </ul>
Evening out	4	<ul style="list-style-type: none"> <li>* Cinema and meal out for us both</li> <li>* Would try and get out to see a show - she misses it so much but can only do this when husband is in respite.</li> </ul>
Home improvements	4	<ul style="list-style-type: none"> <li>* I would be spending it on the garden to keep it regularly looked after so we can like it. I love the idea that maybe £100 a year would be great to keep my garden tidy.</li> <li>*Doing up the house</li> </ul>
Pamper session	4	<ul style="list-style-type: none"> <li>* A mini break - day spa - day of relaxing. Would be happy if Nan (cared for) came with her.</li> </ul>
Lessons or courses	2	<ul style="list-style-type: none"> <li>* Craft or flower courses. An opportunity to shut off from the stresses of normal life and some time for me</li> </ul>
Spend on caring for family	1	<ul style="list-style-type: none"> <li>* She looks after her mother and has 2 sons, the youngest son (23yrs old) lives at home. All government and social services funding for respite has now stopped, so would put money towards extra care support</li> </ul>

**Q 2.16 – What other breaks from your caring role (that are not restricted by a one off sum of £100 do you think you would benefit from?)**

The family carers were also asked what breaks they would like to receive that were not restricted by a one off sum of £100 in Part Two of the questionnaire. The most popular responses by far were to have a holiday or a short break or weekend away.

Interestingly when asked effectively if money was not a problem what short breaks would you like to receive, a significant number of family carers said they would for the first time pay for respite care so they could have some time away from their caring role. This was the first time any responses mentioned formal respite care. Perhaps this is because family carers are aware of how much respite care costs.

What they might spend £100 + on	No. who would spend £ in this area	Examples of spend
Holiday	27	<ul style="list-style-type: none"> <li>* Holiday to the South of France/ Caribbean with a friend or sister</li> <li>* Holiday with all the family</li> <li>* A lovely cruise around the world, I would take my daughter (cared for) with me and of course I would pay for a carer to come with us and look after her</li> </ul>
Weekend/ short break	21	<ul style="list-style-type: none"> <li>* Short mid week holiday to the coast with his wife (cared for) in adapted accommodation to suit his wife's needs</li> <li>* Take a short holiday for both of them to Eastbourne to a hotel that specialises for the blind</li> <li>* Would like to go away for a weekend to forget about her caring role. But would worry about the cared for so they would need a carer for the cared for</li> </ul>
Respite care for cared for	12	<ul style="list-style-type: none"> <li>* A daily carer to visit my mother, take her shopping, help her with her medication</li> <li>* Would like more carers or respite for her husband and brother (cared for) She would like to have time to spend on her art and gardening.</li> <li>* Would like a total break from caring, Would like her father in law (the cared for) to be in respite care - even if only for one night a month so she can have an evening off and relax</li> <li>*Would like someone to come and sit with wife so that he can have some time from caring</li> </ul>
Trip to see other family members	7	<ul style="list-style-type: none"> <li>*I would dearly like to visit my family in Ireland or have a day visit to the coast</li> <li>*Would love to go to Scotland to visit his Aunt whom he hasn't seen for 15 years</li> <li>*Would love to go to their daughters for a weekend, but daughter has ME and poor health so would have to stay at a local hotel.</li> </ul>
Lessons or courses	5	<ul style="list-style-type: none"> <li>* Further education. I would really enjoy going back to school, learning a language or different subjects</li> <li>* To try and find some sort of physical activity (i.e. swimming) that they can enjoy together - both are disabled</li> </ul>

Day trip	5	* Days out - museums, garden centres, places of historic interest. * Don't get away at all. Would like to go to the coast for a day, have fish and chips, would pay for the petrol and food.
Spend on family	4	* I would like to pay for my daughters home and help my grandchildren * I would spend it on myself and my family and would buy new carpets for my home
Time to self	4	* Regular, quality time to do what I want to do e.g. music gigs or meal out, or trip to London or a weekend away. At the moment I have to be back by 10pm or carers paid for becomes very expensive, so feels unable to stay out too late. * a day out on your own - a whole day!
Home improvements	3	* Would have a wet room done for husband
Equipment	2	* Upgrading computer * a new car
Pamper session	1	* If she could organise the care for her mum and sons, she would love to have a pamper session
Shopping trip	1	* Go and buy some clothes and have a meal out

**Q 3.3 - Other Breaks - What other breaks from your caring role (that are not restricted by a one off sum of £100 do you think you would benefit from?)**

The same question was asked in Part Two and Part three of the questionnaire and again responses have not greatly varied. Family carers wanted to have holidays abroad, weekends or short breaks away and once again they wanted respite care for the person they cared for.

<b>What they might spend £100 + on</b>	<b>No. who would spend £ in this area</b>	<b>Examples of spend</b>
Holiday	24	* Holiday cruise while partner was in respite * We always have a big holiday in the summer when we all go. It would be nice if myself and my partner went away (without the cared for) * I would love to go on holiday on my own and just relax and have time to myself
Weekend/ short break	21	*Newland B&B Southwold and self catering bungalows with access for disabled is wonderful * I would like to have a long weekend with my son and husband, just to have a few things to do on our own away from home. Even a small break would be nice. * Would love to go to the Isle of Wight together (by coach and ferry with a company which specialises for their problems. She is physically disabled and husband has Alzheimer's and also disabled).
Respite care for cared for	13	* More respite care for husband so she can get out more. * Crossroads - regularly. Or day trips out knowing that wife is cared for. * perhaps employ more home care help to give them both a better and easier life

Home improvements	9	* We would like to have the house redecorated * New carpets for the house
Day trip	7	* Have some days out, maybe to the Zoo or something they would both enjoy together
Equipment	4	* Laptop - just a small one! * . Need a new walk in shower. Unable to currently afford to have it and cannot get help financially with it at this moment * a laptop
Spend on family	3	* be able to spoil the grandchildren. * She looks after her mother and has 2 sons, the youngest son (23 yr. old) lives at home. All government and social services funding for respite has now stopped, so would put money towards extra care
Lessons or courses	2	* yoga or computer classes * Possibly a college course
Trip to see other family members	2	* seeing son in Spain * To travel to Cornwall to stay in hotel so we can see son and grandchildren.
Meal out	1	* going out for meals. Take a break from cooking
Put towards savings	1	*To be able to put some money away for a rainy day
Hobby	1	* Season ticket for Arsenal football club

## 6. Project impact

### Externally

#### Found / Consulted Family Carers

95 family carers in Brandon have had £100 to put towards a short break that they otherwise would not have received. To date 15 family carers who have scored very highly on Q3.16 and Q3.17 have also been referred on to Suffolk Family carers to access some further short break funding to support them in their role as family carers.

The project has helped raised awareness of family carers in Brandon. By holding market stall events people and having articles in the local papers about the project generally awareness of the important role family carers play in Brandon has been raised.

The family carers involved in the Time for You Brandon project have also had the chance to meet the carer community researchers and have a conversation about their caring role. Many of the community researchers said that they felt many of the family carers they spoke to had enjoyed the opportunity to meet another carer and talk about their caring role and the difficulties they face. Just having a conversation with another carer who was able to emphasise with their situation was often greatly appreciated by the family carers involved in the project.

#### Family Carers who did not meet criteria

Family carers who did not meet the eligibility criteria for the Time for You project – all received an information pack about services that are currently available to family carers in Suffolk. As the majority of ineligible family carers did not need a break from their caring role they did understand that why they were not eligible. Many of the family carers who did not meet the eligibility criteria said they thought it was right that they were not eligible as they felt that there were other family carers in Brandon who are in greater need of a break than they are.

#### Community Researchers

The carer community researchers have all learnt new skills though being involved in the Time for You project. They have learnt research skills, such as how to conduct questionnaires and interviews. They have made new friends and contacts in Brandon – a particular bonus for those family carers who were isolated by their caring role.

They have also learnt much more about carers in their Brandon. Many of them have been surprised at how many family carers there are in Brandon and how many people are struggling with their caring role. The community researchers have also learnt more about the rights of family carers and what family carers are entitled to.

*'I was surprised to learn how many disabled people there are in Brandon and Weeting'  
(Trisha, Community Researcher)*

*'I have learnt a lot through this project – I know that there are people far worse than me out there, but also that there is help available once you are in the loop'. (Jan, Community researcher)*

Their confidence has developed hugely throughout the project. At the start of the research many of the community researchers were really nervous about doing a questionnaire with a family carer. At

the end of the project all of the carer community researchers were confident enough to do a questionnaire by themselves for Part 3 where necessary.

All of the community researchers have thoroughly enjoyed taking part in the Time for You project and have contributed so much to both the project and family carers in Brandon.

## **Social Capital**

Perhaps one of the biggest impacts of the project has been on social capital levels in Brandon. The Time for You project has brought together a team of people who had not worked with each other before or knew each other and strong relationships have been formed. The group has worked very effectively together and have supported each other throughout the duration of the project. Team meetings were an opportunity for the community researchers to talk about any issues they were struggling with when doing the research. New friendships have emerged as a result of the Time for You project and members of the team would very much like to continue working with each other:

*'I have thoroughly enjoyed being part of this team. We are a great team with members having different point of view, but we all seem to work well together and have empathy for others and want to help. I hope that we can one day work together again (Lisa P, Community Researcher)*

*'I have also enjoyed working as a team. It has been great fun. I feel that if this project finished now most of us would still be friends or stay in touch' (Jan, Community Researcher)*

*'We were able to make friends with the other members of the group and it has become quite a sociable occasion to come to the meetings' (David, Community Researcher)*

Carrying out the research has also meant that the community researchers have also met many other carers in Brandon, often twice. This has also meant new relationships have developed in Brandon and the community researchers know much more about other carers who live in Brandon.

Many of the family carers involved in the Time for You project have really enjoyed being interviewed and have the opportunity to speak to other carers about the issues they face with their caring role. Simply being able to speak to another person about the problems they have has been cathartic for a number of family carers:

*'I felt that I have made many carers feel a bit better by both the £100 and the chats we had'. (Jan, Community Researcher)*

We even received one letter of thanks from a family carer who had greatly enjoyed taking part in the Time for You project and who especially enjoyed being interviewed by two of the community researchers:

Suffolk.

23/03/10.

Dear Claire.

I apologise for the delay in acknowledging the £100 you paid into my account as I had to wait for my statement to confirm.

Thankyou so very much to include me in your Project. It is very welcome & I have made an appointment at the opticians & will spend it on a decent pair of frames - receipt for which I will forward to you.

There was no pressure on me from Lisa & Les who interviewed

Pto

me.

What a lovely couple! no embarrassing or intrusive questioning. They were very kind & said I did not have to answer anything I did not want to, you really have 2 treasures in them on your team.

Thankyou so much for this unexpected & generous gift.

Sincerely,

Pam Corbett

## **Internally**

### **Project impact on your organisations**

The Time for You project has been the first project on which the Connected Care team at Turning Point has worked primarily with family carers. Although carers have been part of other Connected Care projects around the country, the focus of work has never been purely on family carers. Taking part in the Time for You project has therefore greatly increased the teams knowledge of government policy around family carers and also more practically on how to work effectively with family carers.

The Connected Care team is now far more aware of policy and legislation surrounding carers and the benefits and help family carers are often entitled to receive. On a more practical level the team now has far greater knowledge on the best ways of working with family carers as community researchers and as research participants.

In future Connected Care projects we will make every effort to recruit family carers as community researchers. We are now aware of the strong connections family carers have with carer support organisations such as Crossroads and Suffolk Family Carers. In the future we will ensure that in every Connected Care area we work in we will make contact with the local Crossroads and other carer support organisations. Job advertisements will be sent out to local family carers through their networks if the organisations would be willing to work with us. The community researcher role is a flexible role by its very nature and it would be great to offer part time flexible employment and learning opportunities to family carers who may not be able to take standard employment but would like to be more involved in their community and earn some extra money.

### **Mainstreaming family carer awareness within your organisation**

Family carer awareness will be mainstreamed throughout the whole of Turning Point once the project is completed. A project summary article will be put in the next internal staff bulletin 'Talking Point' which goes out each month to every one of Turning Point's 4,000 staff.

An article on good practice that has been learnt from working with family carers on the Time for You project working will also be developed and put with other good practice articles on Turning Points Intranet. Kate Jones, project lead for the Brandon Time for You project will also be listed as a family carer expert on the intranet so if any members of Turning Point staff need advice on how to work with and support family carers they will be able to contact Kate directly.

As Turning Point is predominantly a charity that works with people with substance misuse issues, learning disability and mental health issues, Turning Point staff come into a lot of contact with family carers and there is likely to be a lot of interest in good practice in working with family carers.

## 7. Project Recommendations

### 7.1 Finding Hidden carers

One of the main learning's for the Brandon Time for You team has been the length of time it has taken to find hidden family carers. At the start of the project the team expected to easily be able to find 200 eligible hidden family carers to engage with in three months. By offering a £100 award as an extra incentive to take part in the research we expected to be inundated with carers who wanted to take part in the project.

However, it took six months to find 95 eligible family carers and carers only really started coming forward in larger numbers in the last two months of the project. At the start of the research in March 2010, only very small numbers of family carers came forward and many of them had to be prompted by friends, family, neighbours and the community researchers to get involved.

From speaking with family carers at Market Stall events, and out door knocking there are many different reasons why many family carers in Brandon chose not to get involved in the Time for You project or were so slow to come forward.

Some people in Brandon were very suspicious of being offered £100 for they considered to be 'for nothing'. Many family carers we spoke to said that they did not want a £100 payment for what they considered to be their job. A large number of family carers – especially older family carers who were caring for their spouse or partner told us that they did not want a £100 for what they considered to be their marital responsibility. We were told on a number of occasions that when they married their partner the vows they took were for in sickness and in health and they did not want any payment for their caring role. When asked if they would like to take part in the project and not receive any payment they declined to get involved as again they did not see themselves as family carers – just that they were doing what they considered to be their duty.

Anecdotally from talking about the project with other Brandon residents we learnt that many family carers in Brandon are very proud and do not want to come forward for anything that they perceive to be help. A number of other family carers in Brandon are also very private people and do not want to talk about their situation to other people.

A number of other family carers we spoke to said that they had seen the adverts for the project in the Brandon Life but did not contact us as they assumed that they would not be eligible for the £100. Many family carers have been assessed for other benefits such as carers allowance or by social services and were not eligible for any support or assistance. This put them off from contacting us.

We therefore struggled to find family carers who wanted to be involved in the Time for You project. However as word of mouth and trust grew in the project more and more family carers started to contact us. Family carers who had taken part in the research encouraged other carers to get involved in the project and reassured them that the project was legitimate and that it was an enjoyed experience to take part in. If the project was to continue for another six months we believe that we would have involved 200 eligible family carers, but the process of engaging family carers took far longer than the team anticipated.

**Our key recommendation around finding hidden family carers is to allow plenty of time to do community engagement work to build trust in the project**

## **7.2 Employing family carers**

The Turning Point team is also now more aware of the limited time family carers have to be able to dedicate to employment. Working with family carers on the Time for You project has meant that we have learnt how flexible we need to be as an organisation in employing family carers. Their caring roles often mean that, at times, family carers are simply not able to carry out their caring role as well as focus on employment. For example hospital appointments and any illness with the cared for meant that the carer community researchers were unable to be involved at that time with the project. We learnt that the time they are able to dedicate to the project would vary considerably throughout the duration of the research.

We also learnt that we needed to offer the family carer community researchers support for their cared for in order for them to be able to work on the project. One of the family carer community researchers we employed was unable to leave the person she cared for more than half an hour. We therefore employed a Crossroad carer to care for her husband whilst she came to the training and next step sessions and also whilst she was carrying out the research. Although expensive, offering this service meant we were able to employ a family carer who would otherwise be unable to get involved in the project. We will ensure that this support is offered to other family carers who are involved in any Connected Care projects.

**Our key recommendations around employing family carers is to give them as much flexibility around the hours they work as possible . We would also recommend employing professional carers where possible to look after the cared for to allow carers the opportunity to participate in employment/ project.**

## **7.3 Doing research with family carers**

In terms of working with family carers as research participants we have learnt how the majority of family carers prefer to take part in research which is carried out in their own home. The majority of the family carers involved in the Brandon Time for You project wanted the questionnaire to be conducted in their home. This meant that they did not have to leave the person they care or worry about them for whilst participating in the project.

Many family carers also wanted to community researchers to meet the person they were caring for. In some instances it was very useful having pairs of community researchers doing interviews as it meant that, if needed, one researcher could carry out the interview with the cared for, whilst the other community researcher could sit and talk with the cared for. This was especially useful in cases where the cared for had dementia.

**Our key recommendation around doing research with family carers is to conduct the research where is most convenient for the family carer. This is most likely to be in their own home. We would also recommend that researcher's work in pairs when caring out research with family carers.**

## **7.4 Providing short breaks to family carers in Brandon**

From the qualitative research conducted by the Time for You community researchers it is easy to conclude that in Brandon family carers would like more to have better access to short breaks.

The breaks they would most like to receive are not terribly expensive. They would like to have more day trips out, meals out, short breaks and weekends away, shopping trips to nearby towns,

pamper sessions, equipment and home improvements to make their home life easier and some family carers would like to take part in courses and further education.

Family carers who are caring for their partners generally would like to have breaks with the person they care for. Family carers who are caring for their parents or an older relative would generally like to have breaks away from the person they are caring for.

The community researchers found that many of the family carers really appreciated the flexibility of the £100 award. It is not often that family carers receive funding that could be spent on any type of short break that they require. This finding fits neatly with the Governments personalisation agenda and shows direct payments could have an important role to play in helping family carers cope with their caring role.

**Our key recommendation around provided breaks to family carers is therefore to offer carers flexibility and a choice in the breaks they receive. In Brandon for Stage two of the Time for You project we fully support the idea to establish a Brandon Carers Support group. We recommend that family carers are offered a choice of short breaks based what family carers spent their £100 award on. We would also recommend that some breaks are offered where the cared for can accompany the family carer, and some breaks are offered where the family carer has some time away for the cared for and respite care is provided.**