

# **Always On Call, Always Concerned**

## **A Survey of the Experiences of Older Carers**

**The Princess Royal Trust for Carers**



The Princess Royal Trust  
*for Carers*

## **Acknowledgements**

The Princess Royal Trust for Carers would like to thank all the carers who participated in the survey for this report. We would also like to express our thanks to Carers' Centres in The Network of Carers' Centres across the UK, Crossroads Care, Counsel and Care, the National Family Carers Network and all other organisations who distributed or publicised the survey.

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## 1. Executive Summary

Of the UK's approximately six million carers, around half are aged over 50. A recent survey of carers in England showed that people near or over retirement age undertake a high proportion of caring. Although on average, 12% of the population provide unpaid care for a friend or family member, this increases to 18% for those aged 55–64, 16% for those aged 65–74 and 13% for those aged 75 and above.<sup>1</sup>

This comes at a time when others, who do not have caring responsibilities, are planning their retirement, looking forward to long put-off activities, getting involved in their local communities or enjoying their grandchildren. Others, perhaps into their retirement, are enjoying time for themselves, winding down and taking things a little easier as they get older.

*“We cannot have a retirement like other people do – there’s always a timetable to stick to.”*

For many older carers, planning or enjoying their retirement is simply not an option. At a time when their own health may be deteriorating, many find themselves exhausted and constantly anxious, rarely getting a break from caring. Carers aged 60–69 often juggle caring – perhaps for more than one person, for example a parent and an adult son or daughter – with the demands of work and financial pressures while those aged 70 and above often find it difficult to cope with the physical demands of caring. For those caring for a partner, the change to a relationship can be hard to adjust to. As well as the daily stress of caring, a feeling of loss – of a relationship or of precious time – can cause great distress. Almost all carers feel frustrated when health professionals do not involve them as a full partner in care. Almost all worry about what the future will hold for them and the person they care for.

The Princess Royal Trust for Carers carried out a survey in early 2011 of carers aged 60 and over from across the UK, to find out more about their lives and the challenges they face.

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<sup>1</sup> Census 2001, Office for National Statistics.

## 1.1 Key findings

- Carers aged 60–64 experience the most financial difficulty, often juggling work with caring responsibilities for more than one person.
- The majority of older carers report caring for 60 or more hours a week – particularly those carers aged 70 or over.
- Two thirds of older carers have long term health problems or a disability themselves. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities.
- Half of all older carers reported that their physical health had got worse in the last year and seven in ten said caring had had a negative impact on their physical health.
- More than four in ten older carers said their mental health had deteriorated over the last year.
- Over three quarters of carers ages 60–69 said caring had a negative impact on their mental health.
- Less than half of carers aged 70 and over who have to lift the person they care for do not feel they can do this safely and confidently.
- More than eight out of ten older carers have worries for the future, about what will happen to the person they care for if they can no longer care.
- More than one third do not get breaks away from caring, and a further third get a break only once every 2–3 months or less.

## 1.2 Recommendations

### **Financial support**

Local authorities and services supporting carers and their families need to be aware of the financial pressure on the 'sandwich generation' of carers – ensuring access to financial and benefits advice.

The Government should ensure that any future changes to benefits improve the financial situation of this group of carers.

### **Physical and mental health**

Older carers should be offered a physical health check once a year by their GP. Policy frameworks and commissioning throughout the UK should be adapted to ensure resources are available to meet this need.

All carers should be screened for depression at least once a year by their GP. Services which support carers and their families should be aware of the poor mental health often experienced by carers so that it can be addressed early on.

Effective methods of promoting mental wellbeing for carers in this age group should be developed by health and social care agencies in order to reduce their risk of becoming depressed.

Appointments, including primary care and hospital, should be flexible to meet the needs of carers. GPs should offer carers home visits, if necessary, to fit around caring. Where carers need treatment requiring time afterwards to recover, local authorities and health services should work together with the carer to develop an acceptable plan for how alternative care will be provided.

### **Training**

Carers who need to carry out lifting as part of their caring role should have access to the training and equipment they need to do this safely.

Support and training in dealing with difficult behaviour should be available to all carers, and particularly those caring for a person with a condition which is likely to mean their behaviour becomes unpredictable or challenging.

### **Planning for the future**

Emergency card and emergency care schemes, including support to plan for the future, can alleviate a great deal of worry. These should be offered to carers in all areas.

### **Recognition by health and care professionals**

Health and social care professionals should be trained in carer awareness and the importance of involving carers. Evaluation of clinical and social care practice should assess effective involvement of carers at all stages in care pathways.

### **Breaks for carers**

Access to carers' breaks should be increased. Carers should be offered activities which support all aspects of their health and wellbeing and which give them the opportunity to pursue their own interests. Support for carers' breaks should include access to high quality alternative care.

Ways should be found to promote carers' wellbeing in the way most useful to them – such as gardening schemes to make their home environment more manageable.

## 2. Methodology

The Princess Royal Trust for Carers published an online questionnaire available on the Survey Monkey website for one month in early 2011. Information about the survey was distributed by a number of organisations, and carers throughout the UK were invited to participate. Hard copies of the survey were also distributed. A prize was offered as an incentive to complete the survey.

The survey was completed by 639 older carers. All were asked to indicate their consent for the information they provided being used in this report. Questions were a combination of multiple choice options and free text responses.

Subscales from the Adult Carer Quality of Life Inventory relating to support for caring, caring choice, caring stress, money matters and carer satisfaction were included.<sup>2</sup>

Data was then collated and analysed using Survey Monkey, Excel and SPSS.

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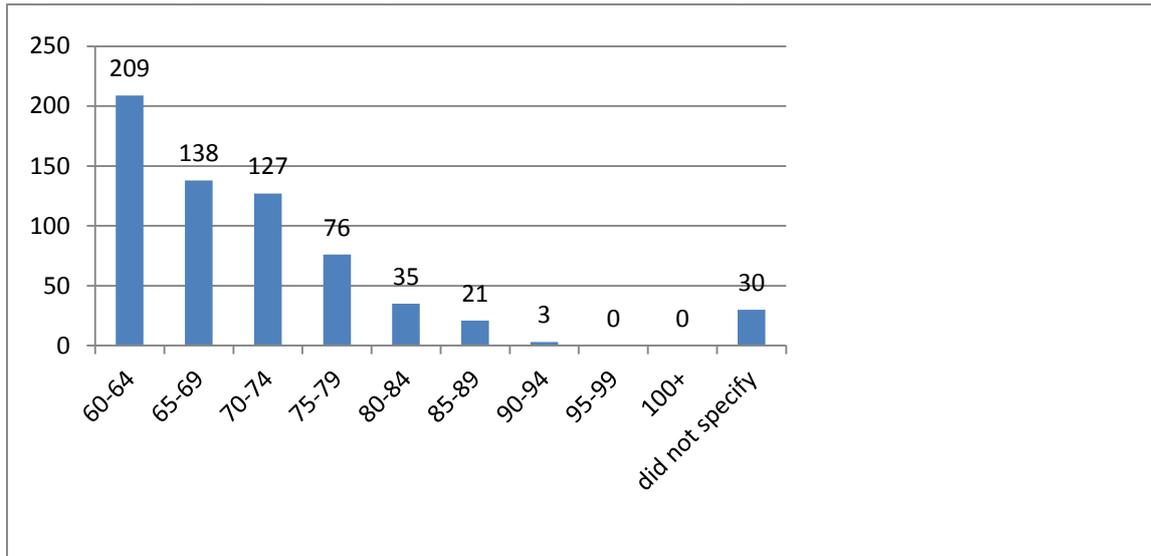
<sup>2</sup> Elwick, H et al (2010), Manual for the Adult Carer Quality of Life Questionnaire (AC-QoL). The Princess Royal Trust for Carers in association with The University of Nottingham.

### 3. Who are the older carers who responded?

#### 3.1 Age

The age range of the respondents is shown below. The highest proportion came from the 60–64 age group (209), with progressively smaller numbers from each of the older age groups. The oldest carers who participated were 90–94 (three respondents).

**Figure 1 – Age range of respondents (Number of respondents)**



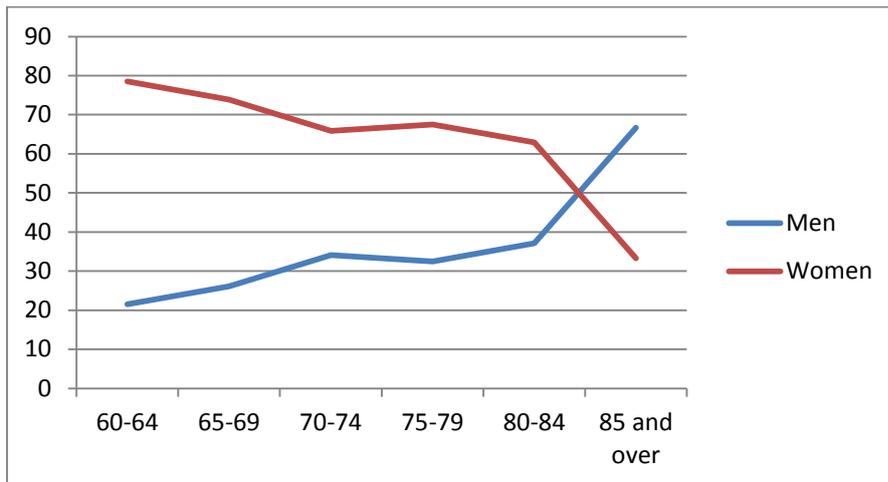
#### 3.2 Gender

A higher proportion of women responded than men (70.5% women, 29.5% men). However, the gender distribution varied with age. As age increased, a higher proportion of respondents were men, as shown below. A chi square test showed this difference in distribution between genders to be significant.<sup>3</sup> This suggests that as age increases, the gender balance in caring shifts as the likelihood of caring for a partner increases. This finding is in line with the findings of the 2001 census regarding the gender profile of older carers.<sup>4</sup>

<sup>3</sup>  $\chi^2 = 24.112$ ,  $df = 6$ ,  $P > 0.001$ .

<sup>4</sup> Census 2001, Office for National Statistics.

**Figure 2 – Percentage of men/women respondents by age**

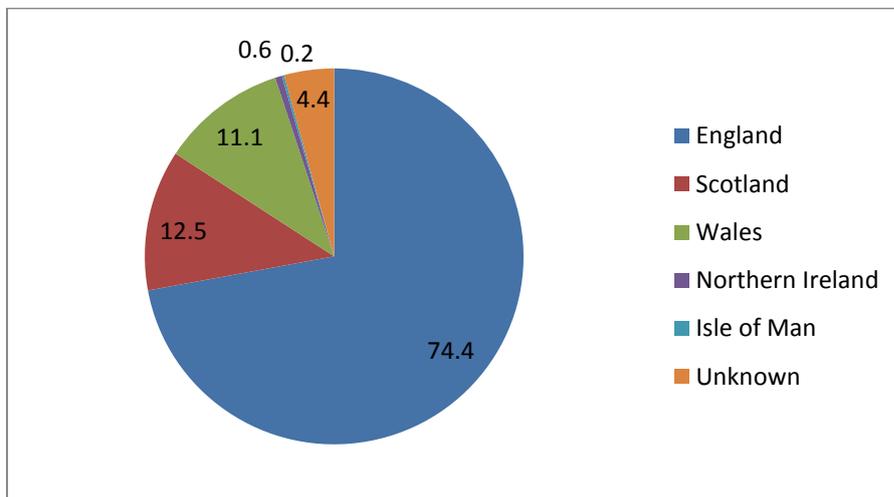


### 3.3 Geographical location

#### Location in UK

Almost three quarters of respondents (455) indicated that they live in England. 80 live in Scotland, 71 in Wales, four in Northern Ireland and one in the Isle of Man. 28 did not indicate where they live.

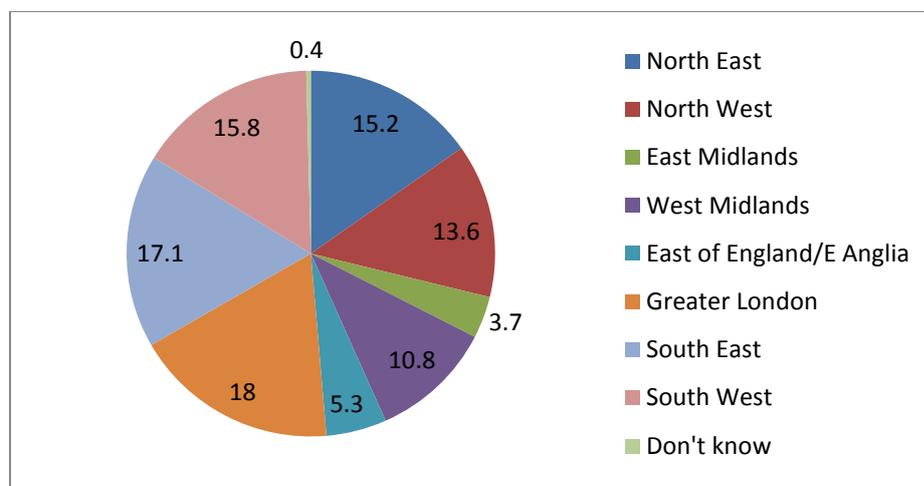
**Figure 3 – Breakdown of respondents by UK country/area (% of total)**



#### English region

Participants who reported living in England were asked to indicate which region they live in. The highest proportion lived in Greater London (18%), followed by the South East (17.1%) and South West (15.8%). The smallest proportion were from the East Midlands (3.7%).

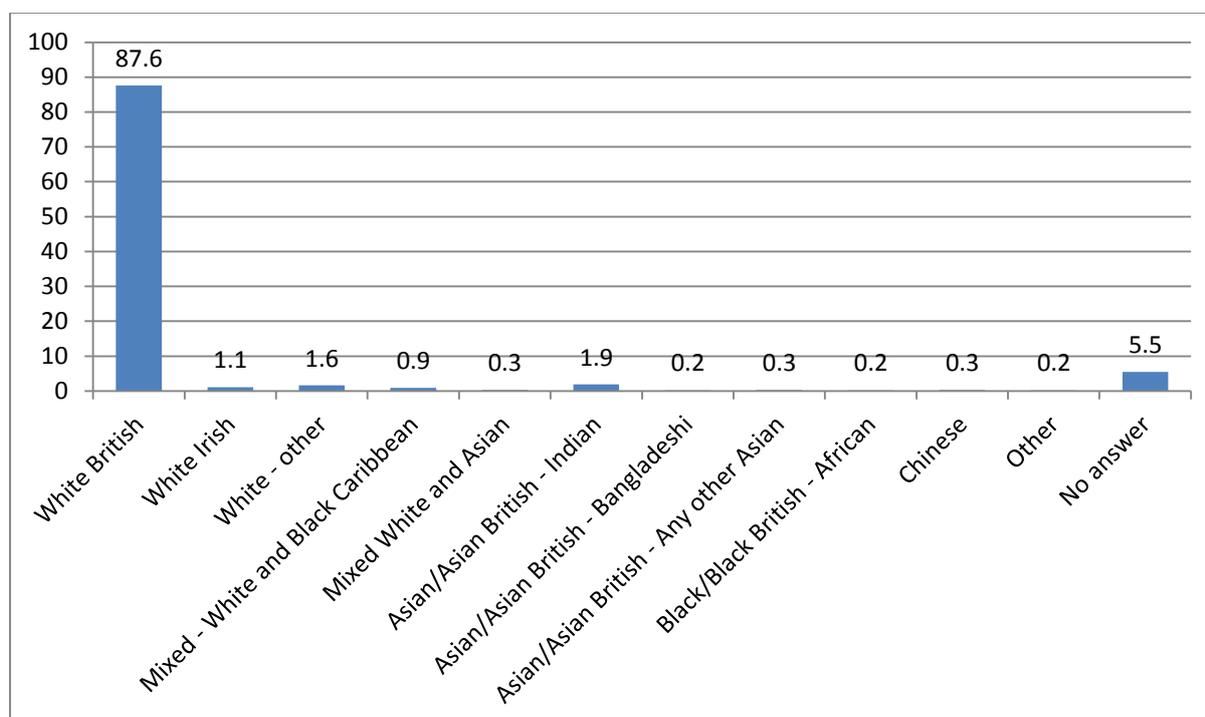
**Figure 4 – Breakdown of respondents by English region (% of those living in England)**



### 3.4 Ethnicity

Participants were asked to indicate their ethnicity. 87.6% of respondents reported that they are of white British ethnicity. Of those who answered the question, 4.5% reported being from ethnic groups other than white, compared with 7.9% in the population as a whole.<sup>5</sup>

**Figure 5 – Ethnicity of respondents (% of total)**



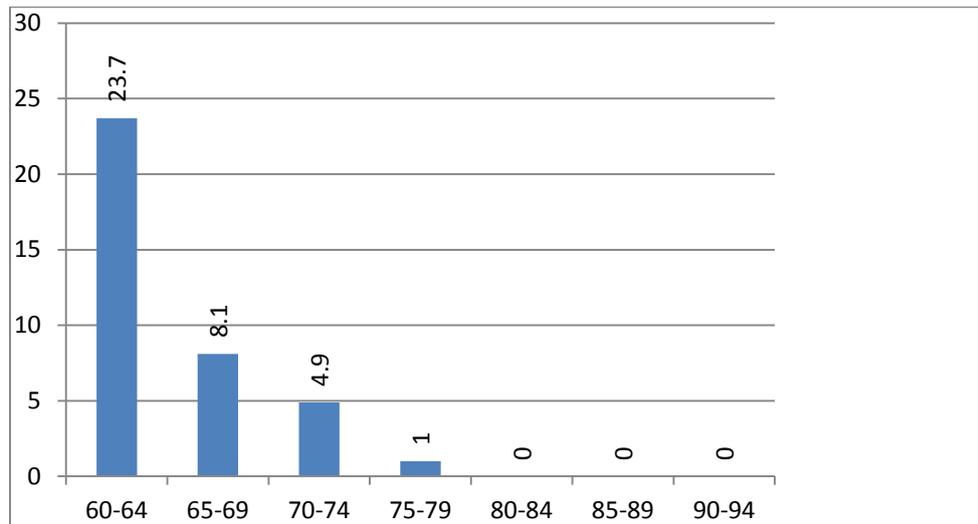
<sup>5</sup> Census 2001, Office for National Statistics.

## 4. Work and finances

### 4.1 Paid employment

Around a quarter of the carers in the 60–64 age group are still in work. This reduces in the older age groups, although in the 65–69 and 70–74 age groups there are still a significant number of older carers in paid work – 8.1% and 4.9% respectively.

**Figure 6 – Carers still in paid employment (% of each age group)**



Those still in work often commented that this added to the aspects of their life they had to juggle and often their levels of tiredness.

“An average day for me is 6am–12pm nearly every day. This is due to the combination of my caring role looking after my daughter and two grandsons as well as having a part-time job.”

“Very tiring physically and mentally, especially as I have to work full time to pay for the things I need to carry out my caring role.”

### 4.2 Carers' finances

Carers in the youngest age group surveyed (60–64) reported having the most difficulty financially. Few of this group said they felt able to save money a lot of the time or always (20%) and only 30% said they are satisfied a lot of the time or always with their financial position. When all of the financial elements of the Adult Carer Quality of Life Questionnaire were summed and compared between groups, there is a significant difference between the 60–64 group and the older age groups.<sup>6</sup>

<sup>6</sup>  $t=-2.519, df=413, p=.012$

These results show that although money is an issue for many carers, the younger age group does feel significantly more financially disadvantaged than the older age groups, worrying more about going into debt, and generally feeling less comfortable with their financial situation. This is an issue which needs consideration for this group in particular.

This issue is a key current concern with significant change in welfare benefits taking place and the long term future of Carer's Allowance is unclear. For those eligible to receive it, it is clear that Carer's Allowance is extremely important, not only as income but as a recognition of their caring role. A number of carers receiving State Pension stated that they felt the fact they could no longer receive Carer's Allowance to be particularly unjust.

"The one thing that makes me very angry is that my Carer's Allowance ceased when I became a pensioner. Do the govt believe that my caring role ceased just because I became 60? ... I do more caring now than I have ever done, with far less money to pay for ever increasing expenses."

### **Recommendations**

Local authorities and services supporting carers and their families need to be aware of the financial pressure on the 'sandwich generation' of carers – ensuring access to financial and benefits advice.

The Government should ensure that any future changes to welfare benefits the financial situation of this group of carers.

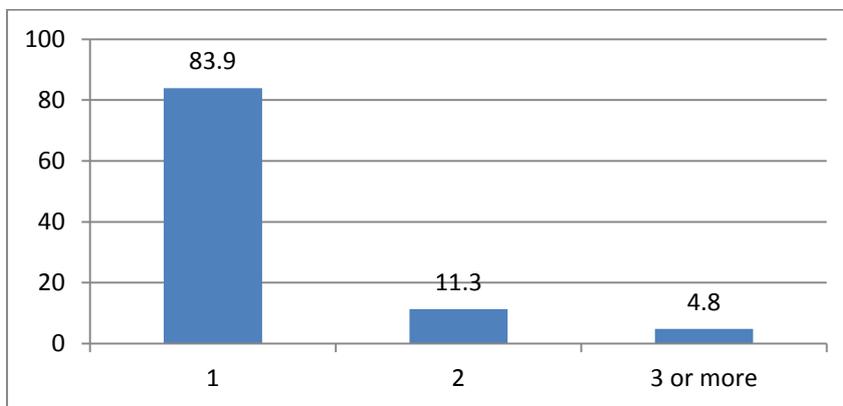
## 5. Who are older carers caring for, and for how long?

Older carers have diverse caring roles. At the younger end of the spectrum, they are likely to be caring for adult children and/or parents, whereas at the older end, the balance shifts with a higher proportion of carers looking after a partner.

### 5.1 Number of people being cared for by each carer

83.9% of all respondents cared for one person, with the remaining 16.1% caring for more than one.

**Figure 7 – Number of people being cared for by each carer (% of total)**

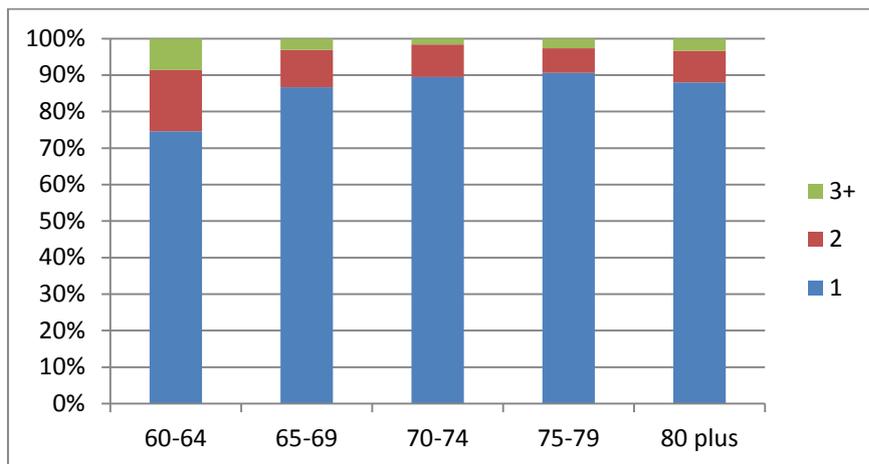


Further analysis showed that the pattern varied according to age, with the younger age groups more likely to care for more than one person. In the 60–64 age group, 25.4% cared for two or more people, compared with 13.3% of the 65–69 age group, 10.5% of the 70–74 year old and 9.4% of the 75–79 year olds. A correlation showed that this relationship between age and number of people cared for was significant.<sup>7</sup>

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<sup>7</sup>  $r = -.157, p > 0.001$ .

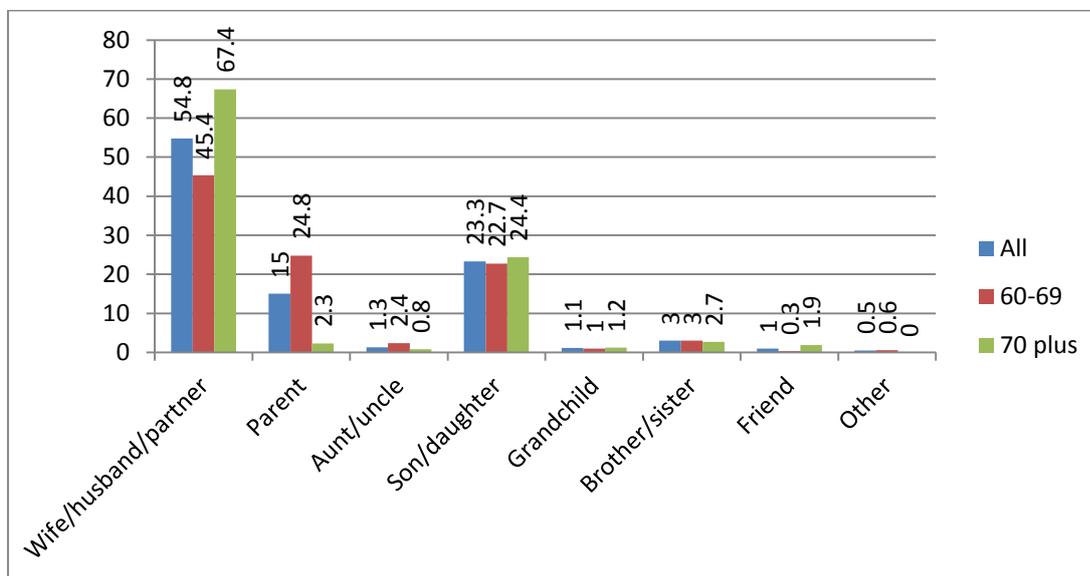
**Figure 8 – Number of people cared for by age of carer (% of total)**



### 5.2 Relation of person cared for to carer

Most older carers in the survey care for a wife, husband or partner (54.8% of the total). This proportion increases in older age groups – for the 70 and over group, 67.4 % primarily care for a wife, husband or partner. A high proportion of all groups care for a son or daughter – around a quarter for all groups.

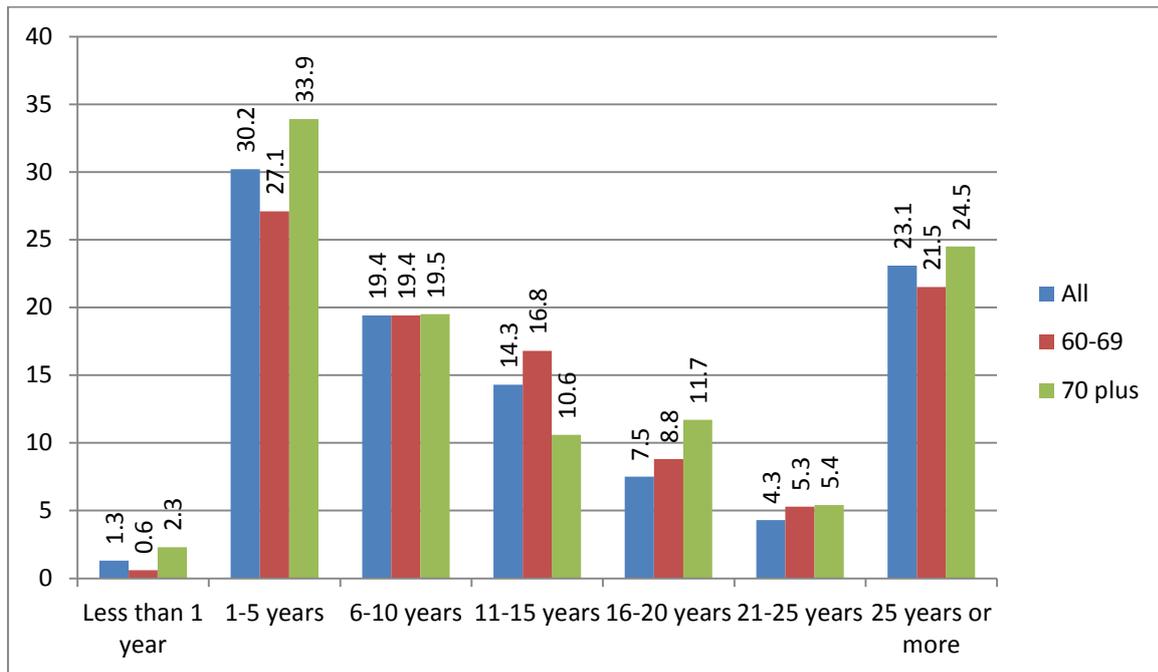
**Figure 9 – Relationship of person cared for to carer (% of total)**



### 5.3 How long have they been a carer?

Respondents had been caring for an average of 11–15 years. Just under a quarter of respondents overall had been caring for 25 years or more.

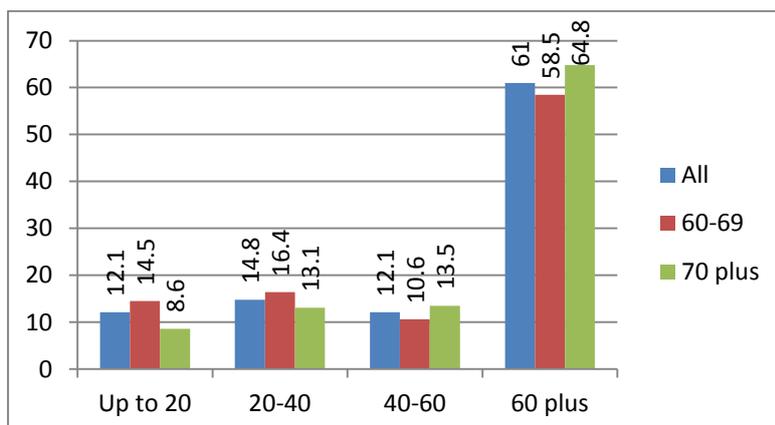
**Figure 10 – Number of years in caring role (% of total)**



#### 5.4 How many hours a week do they spend caring?

Respondents reported caring for an average of 60 or more hours per week. The older group of carers are spending a particularly high proportion of their time caring – almost two thirds (64.8%) in the group aged over 70 reported spending 60 or more hours per weeks caring. A t-test showed that this difference between age groups is significant.<sup>8</sup>

**Figure 11 – Number of hours a week in caring role (% of total)**



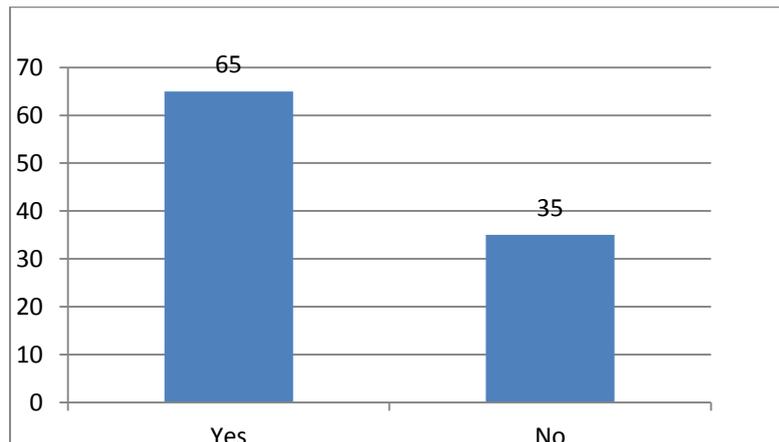
<sup>8</sup> t=-2.375, df=564, p=.018

## 6. Older carers' health and wellbeing

### 6.1 Long term health problems or disability

Approximately two thirds of older carers, of all ages, stated that they have a long term health problem or disability themselves. There was no significant difference between age groups.

**Figure 12 – Older carers with a long term health problem or disability (% of total)**



Respondents were invited to state what kind of health condition or disability they had. The range of health conditions mentioned by carers was broad, with many describing multiple conditions. The conditions named were often those associated with ageing, for example arthritis and joint problems, back pain, heart conditions, high blood pressure and diabetes. Many also had experienced cancer currently or in the past. A number mentioned mental health problems such as depression, and sensory problems such as sight or hearing loss.

“Difficulty walking – need two sticks. Hip joint problems including arthritis.”

“Back problem and lymphedema as a result of surgery for breast cancer. High blood pressure and high cholesterol.”

“Kidney problem which causes tendency to have low sodium causing several emergency episodes of collapse.”

“Apart from depression, I also have been diagnosed with a heart problem.”

“Cancer (in remission at the moment) and I’m a wheelchair user because of neurological problems.”

“I have arthritis in feet and high blood pressure. Cannot walk too far – use taxis when I can afford them.”

“Have had treatment for prostate and testicular cancer. Balance problems, serious hearing problems.”

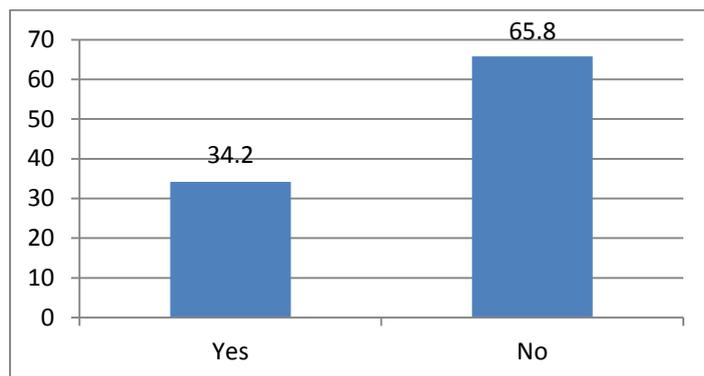
“Blind one eye, back problems, foot problems, difficulty walking/carrying shopping.”

It is clear from these findings that the health needs of older carers are significant. Many of the conditions commonly mentioned, such as arthritis and heart disease, cause pain, reduce quality of life and also cause difficulty in carrying out tasks associated with caring.

## 6.2 Delaying or cancelling treatment

A third of respondents stated that they had delayed or cancelled treatment for a health condition due to the demands of caring. Given the serious nature of the conditions mentioned by carers, this potentially could have a serious impact on their long-term health.

**Figure 13 – Proportion of carers who had delayed or cancelled treatment due to caring (% of total)**



“I need an ankle replacement but surgery is impossible as I would be in plaster for 12 weeks and I am the sole carer.”

“I am always too busy caring for my son and my mother so you forget about your own health.”

“I get physically and emotionally exhausted and cannot deal with health appointments for myself when the choice is catch up on sleep versus seeing the doctor – especially as I am trying to keep working.”

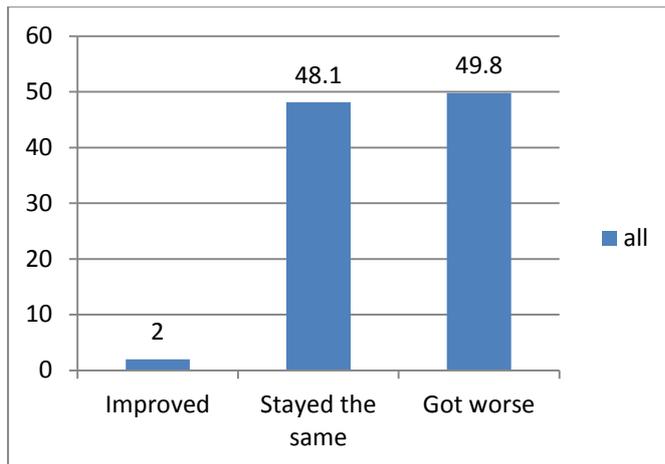
## 6.3 Physical health

Carers were asked about their rating of the quality of their physical health, on a scale of 1= excellent to 5= very poor. The average score was 2.92, with around half saying

their physical health was average. There were no significant differences between the age groups in the rating of their physical health.

Of particular concern is the proportion who said their physical health had deteriorated in the last year – 49.8%. If a carer’s physical health declines they may be unable to continue in their caring role and also have a lower quality of life themselves. Ensuring they retain good health must be a priority.

**Figure 14 – Changes in physical health over last year (% of total)**



### **Impact of caring on physical health**

68.8% of older carers reported that caring had had a negative impact on their physical health. Much of this came from the physical impact of stress and exhaustion. The physical strain of lifting and moving the person they care for is also causing injury or long-term damage. Many carers also described the lack of opportunities they now have for exercise and other activities – either due to not being able to leave the person they care for or because they are too exhausted, this in turn contributes to poor physical health.

“Unable to leave house unless ‘sitter’ relieves me – hence lack of fresh air/exercise.”

“I have had 2 knee replacements, arthritis in my wrists and hips and now have a womb prolapse – I do wonder if this has all been made worse by the lifting and moving I have done.”

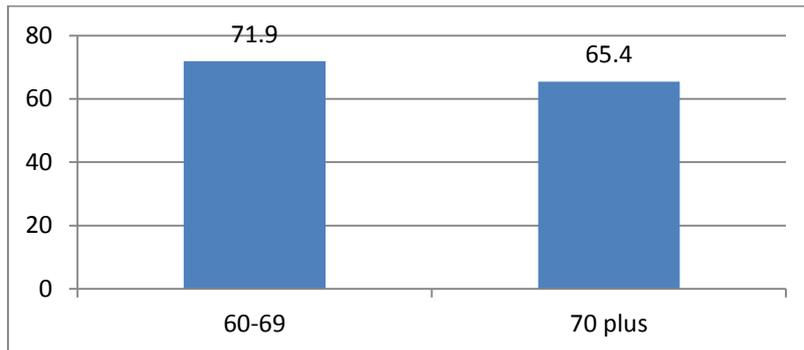
“I have had to lift my wife and her wheelchair on occasions ... and this has given me a crumbling spine which I have to be careful about but it’s not too bad.”

“I am now on my legs a lot more because of looking after my mother. My leg muscles are very weak and I have severe pain in my ankles and feet. By the end of the day I struggle to walk because of the pain.”

“Little or no time for exercise. No option other than to carry on when ill. No time to rest when that would be beneficial.”

“Lifting my daughter becomes more difficult as we get older. Interrupted sleep because of her needs.”

**Figure 15 – Older carers reporting negative impact of caring on physical health (% of total)**



### **Recommendations**

Older carers should be offered a physical health check once a year by their GP. Policy frameworks and commissioning throughout the UK should be adapted to ensure resources are available to meet this need.

Appointments, including primary care and hospital, should be flexible to meet the needs of carers. GPs should offer carers home visits, if necessary, to fit around caring. Where carers need treatment requiring time afterwards to recover, local authorities and health services should work together with the carer to develop an acceptable plan for how alternative care will be provided.

### **6.4 Mental and emotional health**

Carers were asked about the quality of their emotional or mental health, on a scale of 1= excellent to 5= very poor. The average score was 2.99 – almost exactly on the average rating. However, differences were found between age groups, with carers in the 60–64 and 65–69 age groups in particular judging their mental health to be poorer. A t-test was carried out and significant difference was found between the

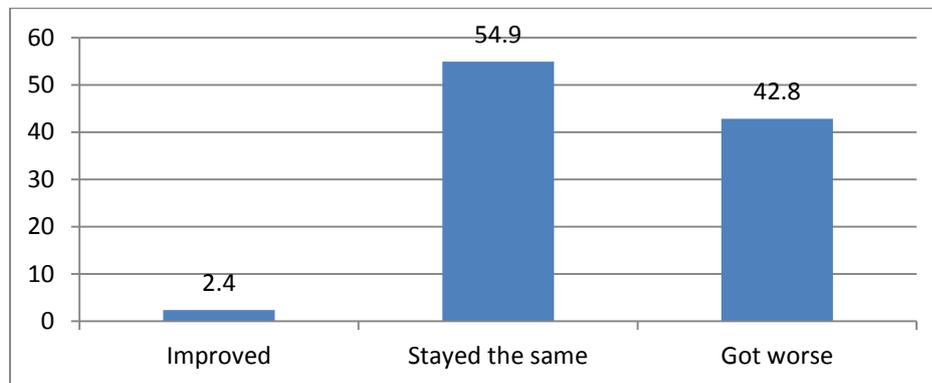
average rating of mental and emotional health between the carers aged 60–69 and the carers aged 70 and over.<sup>9</sup>

### Changes in mental or emotional health over the last year

42.8% of carers said their mental or emotional health had deteriorated over the last year. However, there were again differences between groups with the carers in the younger age group saying their health had deteriorated more – 48.3% of the 60–69 age group compared with 35.6% of the 70 and over age group. A t-test showed this difference to be significant.<sup>10</sup>

This indicates that while there are concerns about the emotional wellbeing of all older carers, the younger age group – the 60–69 year olds seem to be particularly at risk. This may be due to their multiple roles – caring for a number of people while also possibly continuing to work – as well as financial difficulties they may face.

**Figure 16 – Changes in carers’ mental or emotional health over last year (% of total)**



### Impact of caring on mental health

A high proportion of all carers said caring had had a detrimental effect on their mental health, with 68.8% of all older carers saying this was the case. Again, the results were higher in the 60–69 age group, with 76.7% of carers of this age reporting a negative impact. 58.4% of carers in the 70 and over age group reported a negative impact of caring on their mental health. The difference between these groups is significant.<sup>11</sup>

Carers’ key concerns focused around their ability to cope and the constant worry about the person they care for, combined with constant tiredness. Many worry for the future whereas for others, the daily caring role with no prospect of things becoming easier can cause a feeling of hopelessness. Some carers commented that the

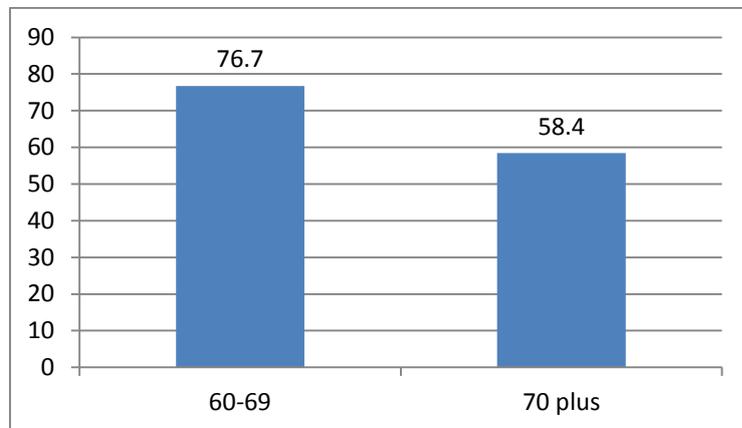
<sup>9</sup>  $t=3.595$ ,  $df=579$ ,  $p<0.001$

<sup>10</sup>  $t=2.648$ ,  $df=572$ ,  $p=.008$

<sup>11</sup>  $t=-4.751$ ,  $df=572$ ,  $p<0.001$

change in their relationship as a result of a partner's deteriorating health causes great sadness, while others feel isolated and less connected to friends and family.

**Figure 17 – Carers reporting negative impact of caring on mental health (% of total)**



“I get depressed thinking about the future as my dear husband gets worse and worse Alzheimer’s symptoms. I worry and feel anxious and sad for him.”

“If I really stopped to think about what I was doing, and for how long I might be doing it, I could despair.”

“I am not a wife any more – I am a carer. I am not a partner in life any more, going out, doing things together, holidays ... etc ... I am a carer”

“Always on call. Always concerned. All the extra work of washing, cooking etc.”

“One is always worried. The longer I care the less friends I keep. Many have drifted away. This was something I thought may happen.”

Those caring for more than one person mentioned that this could be particularly stressful – and for some, combining this with paid work, may explain the stress of those in the 60–69 age group.

“I get depressed and very low at times being in the house sandwiched between generations.”

“Caring for two family members with a depressive mental condition does drag you down.”

These findings indicate that this group may be at particular risk of poor mental health conditions such as depression and anxiety.

**Recommendations**

All carers should be screened for depression at least once a year by their GP.

Services which support carers and their families should be aware of the poor mental health often experienced by carers so that it can be addressed early on.

Effective methods of promoting mental wellbeing for carers in this age group should be developed by health and social care agencies in order to reduce their risk of becoming depressed.

## 7.0 Safety and confidence in caring tasks

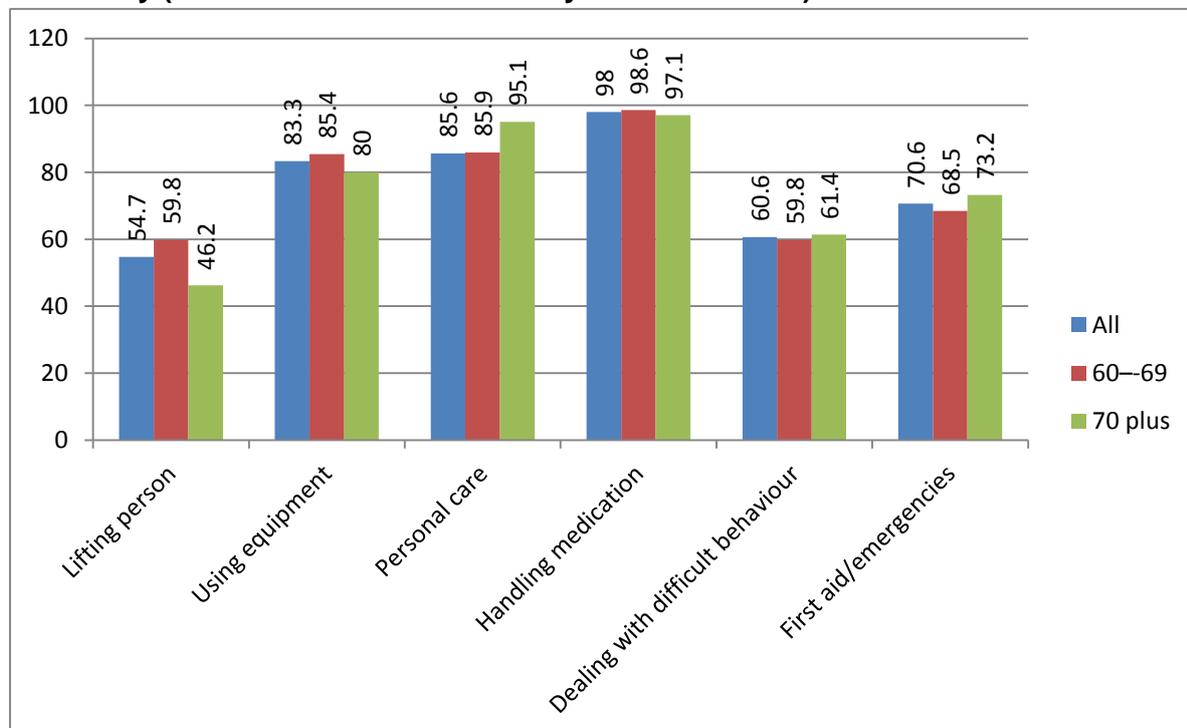
Carers were asked about a range of caring tasks and how safe and confident they feel doing these. They were also asked whether they have received training in these areas.

Their particular concern was lifting – with more than half of the older age group saying that they did not feel safe or confident in lifting the person they care for. This was reflected in carers' comments, with many referring to injuries or long-term physical problems caused by lifting. This has obvious safety implications, both for the carer and the person they care for.

It may be that these carers are being expected to carry out too much, may not have the right adaptations or equipment, or may not have the support from care workers or others when it is needed. In general, there is a great deal of scope to improve the training available to carers. For example, training on caring for a person with dementia often includes an element of dealing with difficult behaviour.

Of those who had to lift the person they cared for, only 32.3 % said they had had training to do this. Fewer – 17.7% – had received training in dealing with difficult behaviour. Although a higher proportion – 41% – had had training in equipment they need to use, this is still not an acceptable level.

**Figure 18 – Carers reporting they can carry out a range of caring tasks confidently and safely (% of those who have to carry out these tasks)**



“Lifting my daughter gets more difficult as we get older.”

“When caring for my elderly/infirm parents it left me with spinal etc problems through lifting.”

“I have to carry out tasks in moving my husband that would not be allowed in a hospital or care setting.”

“Stress, lack of freedom, mental strain because husband has mood swings. Life isn’t the same.”

“The demands of a stroke recoverer can be discouraging. It is difficult to be consistently patient.”

“The worst thing is coping with his moods and his imagination – eg thinking someone on the tv is talking to us or that someone’s stolen something he’s misplaced. I find this hard to manage.”

### **Recommendations**

Carers who need to carry out lifting as part of their caring role should have access to the training and equipment they need to do this safely.

Support and training in dealing with difficult behaviour should be available to all carers, and particularly those caring for a person with a condition which is likely to mean their behaviour becomes unpredictable or challenging.

## 8. Choices and satisfaction about caring

### 8.1 Choices and control in life

Carers were asked about the extent to which they feel they have control over their lives, measured by a subscale of the Adult Carers Quality of Life Inventory. The average score for the whole group was 6.65 out of 15, suggesting there are concerns from all older carers about their choices in life. This was particularly pronounced for the 60–69 group, who had a lower average score 6.21 compared to 7.21 out of 15. This difference is statistically significant.<sup>12</sup> Differences between the age groups particularly exist in the areas of “I feel my life is on hold because of caring”, “I have less choice about my future due to caring” and “I feel I have no control over my own life”. All of these are significant.

Of particular concern is where carers were asked whether they felt they have fewer choices about their future due to caring. The 60–69 age group had an average score of 1.08 on a scale between 0 and 3, which is very low and equates to an answer of “a lot of the time”. This indicates an area where further support for this group of carers is needed.

Many carers commented on feeling trapped or missing out on opportunities to have a life which others take for granted, including social activities and time on their own.

“I feel trapped by my husband’s dependency on me; I am unable to envisage a happy future for either or both of us, given the inevitable deterioration in his neurological condition. I am often overwhelmed by a feeling that life is hopeless and lacking in joy.”

“Feel I am having my life taken away from me and at 85 years of age I do not have many years left.”

“Felt trapped with no way out until my GP prescribed antidepressants.”

“I feel it has limited my opportunities in life and upsets me when people speak of their opportunities and are not sensitive to any caring situation.”

“I feel like my retirement years have been basically taken from me and I am not able to do much that I would like to.”

### 8.2 Satisfaction with being a carer

Despite the difficulties they face, carers of all groups expressed high scores on the scale which measured overall satisfaction with their role as a carer in general. This means that although it is hard, most think their caring role is worthwhile and

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<sup>12</sup>  $t=-2.541$ ,  $df=503$ ,  $p=0.011$ .

valuable. The average score for all older carers was 9.12 (out of a maximum of 15). Although the 60–69 age group showed less satisfaction on all but one of the subscales, these differences were generally small. Although all carers are not necessarily satisfied with their life and the way caring has impacted upon it, or enjoy being a carer (both with an average of 1.23 out of 3), caring is regarded as being important to them and they rarely resent being a carer (averages 2.38 and 2.34 out of 3). However, some did comment that feelings of resentment can come through, especially when life is particularly stressful.

“Will cope, do cope. Could cry at times, love them both.”

“Still want to care for my husband as I love him and I think he benefits from that love.”

“Both mother and I have been in hospital over the last three years. I just hope I am well enough to continue. I won't be parted from my mother. She is in a good environment here at home. I speak to her in her own language.”

“It's just that if my husband refuses to go to daycare, nothing can be done about it, and I can't get away for a few hours relief and I resent it, I feel that nobody cares about me, and I'm just left to get on with it”

## 9.0 Worries for the future

Many carers were deeply concerned about how the person they care for will be looked after in the future – whether related to their own ability to care, or how else this would be provided.

Overall, 80.7% of older carers said they were worried about the future. There was very little difference between age groups.

Concerns related to the carers' own health and ability to care in the longer term, and tended to focus on what will happen once they are no longer able to care or have died. Even those who do know of a family member who might take on the caring role expressed concern about the impact this will have on the new carer.

Carers also worry about the quality of care services available, the cost of these and how they will afford them, along with concerns that the person they care for may need go into residential care.

“As I am now 71 years old, my disease is getting worse, and other things which are age related kick in making all the work I have to do myself in the home much harder.”

“What happens when our money runs out and how will the person live after one dies and there is no money left? We pay £650 a week for our care.”

“Because I still work and my mother is almost 88, how will I manage if she becomes more disabled?”

“What will happen to him if I ever become really incapacitated. He needs nursing care and good nursing homes are few and far between in our area.”

“One of my other daughters is kind enough to offer to look after my disabled one when I am no longer able, but I worry about this daughter's own life.”

“Basically, I dare not be ill.”

“If my physical strength goes we are both sunk.”

“At age 85 I am getting too old to care. Our son cannot live independently and I do not know where or how he will live. He has learning difficulties and Asperger syndrome.”

Some carers mentioned support which has helped them to deal with some of this worry:

“I have a carer's emergency card. I am diabetic with angina, this has given me peace of mind when I go out.”

“When you get older you need to plan for alternatives before it is too late, eg I looked after both my wife since Xmas 2000 when the stroke occurred and son till I was 80. Then social/services/family sorted out the live-in carer.”

The peace of mind offered by emergency card and emergency care schemes was also highlighted in a recent survey where carers stated that these enabled them to have the confidence to live their own lives, knowing that a back-up plan was in place if needed.<sup>13</sup>

### **Recommendation**

Emergency card and emergency care schemes, including support to plan for the future, can alleviate a great deal of worry. These should be offered to carers in all areas.

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<sup>13</sup> Elwick, H, and Becker, S (2011), Emergency Schemes for Carers In Britain: Results of a National Survey. University of Nottingham and The Princess Royal Trust for Carers.

## 10. Support for caring

### 10.1 Do older carers get enough support?

In general, older carers did not feel they were getting all the support they needed in their caring role. The younger age group felt this particularly and the difference between age groups is significant.<sup>14</sup> Where they were asked whether they felt their needs as a carer are considered by professionals, there was a particularly low average score of 1.05 on a scale of 0–3. The average for the 60–69 group for this element was a score of 0.94 – meaning that most feel their needs are never or only some of the time considered by professionals. Professional support provided and difficulty in obtaining the practical support carers need are both areas of concern – the scores from the 60–69 age group were significantly worse than those from the 70 and over group.

“As a grandparent carer I resent beng treated as senile by some consultants.”

“My daughter lives in care, out of county. I receive no information whatsoever from my social services dept that might keep me abreast of new topics etc. She and I have become a paper transaction between two counties, and we as people don’t exist.”

“As my daughter has many hospital visits and she has learning disabilities I would like medical staff to keep me informed when she is admitted to hospital. I am told there is someone in some hospitals who deals with this situation, but in the 25 years my daughter has had physical problems I have never met this person.”

Although a number of initiatives have sought to address the issue of involving carers, clearly many still feel excluded. Carers are a key part of the support structure and without access to full information it is more difficult for them to care effectively. In addition, if they do not consult carers, professionals cannot get access to the range of information they need to assess and treat a person more effectively. This is an issue which needs to be addressed by health and social care professionals in terms of changes in culture and practice.

#### **Recommendations**

Health and social care professionals should be trained in carer awareness and the importance of involving carers.

Evaluations of clinical and social care practice should assess effective involvement of carers at all stages in care pathways.

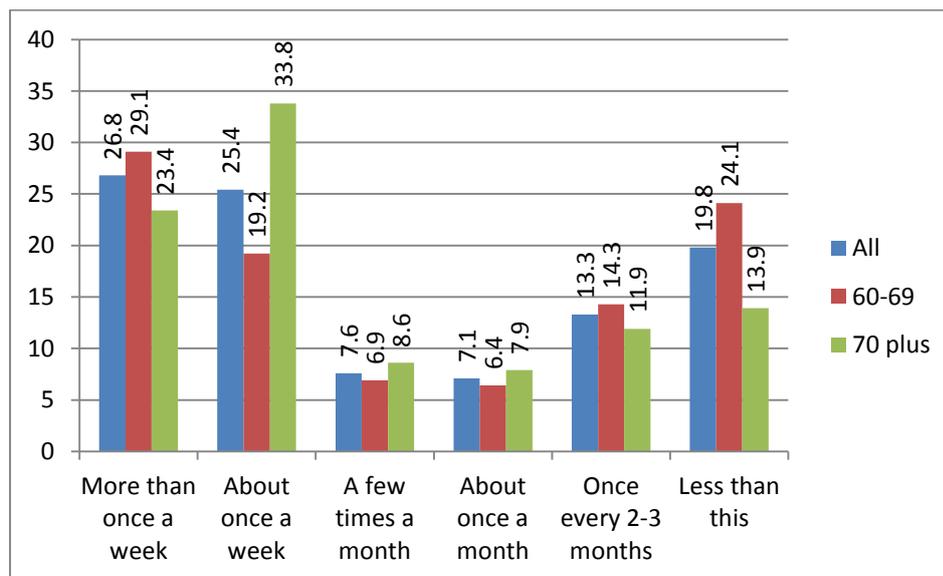
<sup>14</sup>  $t=-3.919$ ,  $df=504$ ,  $p<.001$

## 10.2 Breaks from caring

61.5% of older carers reported that they are able to have breaks away from their caring role – meaning that more than one third do not. Of those who do get breaks, text responses showed that many of these are for a few hours, rather than longer breaks. There were no differences between age groups in the proportion of those reporting they were able to take breaks. However, the frequency of breaks was a little different between age groups, although the differences are not statistically significant. The 60–69 age group were less likely to be able to get a break once a week and more likely to only be able to get a break every 2–3 months or less.

Breaks are crucial for carers, not a luxury. They are a key way of promoting their mental and physical health and ensuring their caring role is sustainable. Despite commitment from governments to improving support for carers, it is clear that many carers still do not get regular breaks – often because there is no high quality replacement care available which meets the needs of both the carer and the person they care for.

**Figure 19 – Frequency of breaks (% of total)**

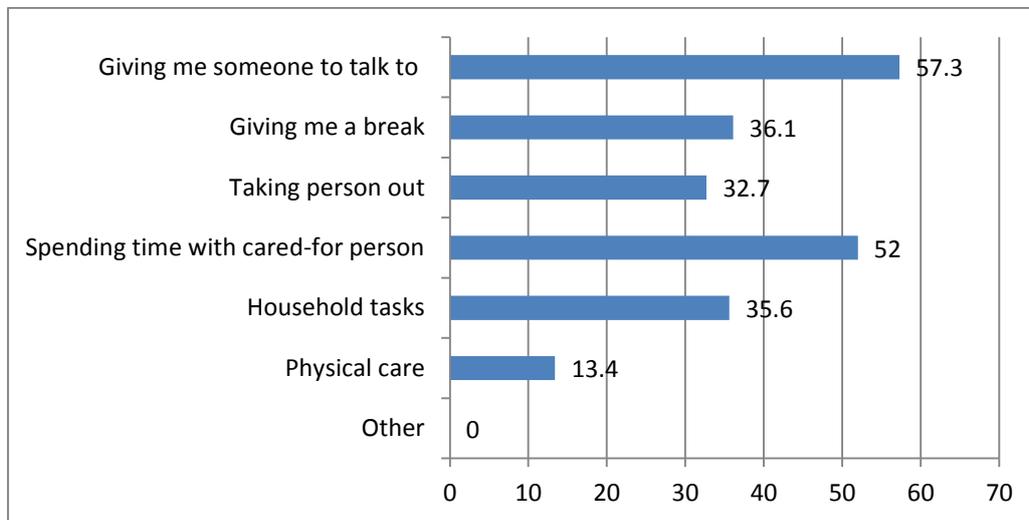


## 10.3 Help from friends, family or neighbours

Overall, 11.7% of older carers said they get lots of help from friends, family or neighbours. 57.7% said they get some help while 30.6% said they did not get any help. The type of care provided by friends, family members or neighbours was mainly around spending time with the person being cared for and giving the carer someone to talk to. This is likely to be particularly important, given the number of

carers expressing a feeling of isolation. Support from friends and family was less likely to involve physical aspects of care such as washing or dressing.

**Figure 20 – Type of help received by friends or family in the last year (% of total)**



#### **10.4 Access to a range of support and services**

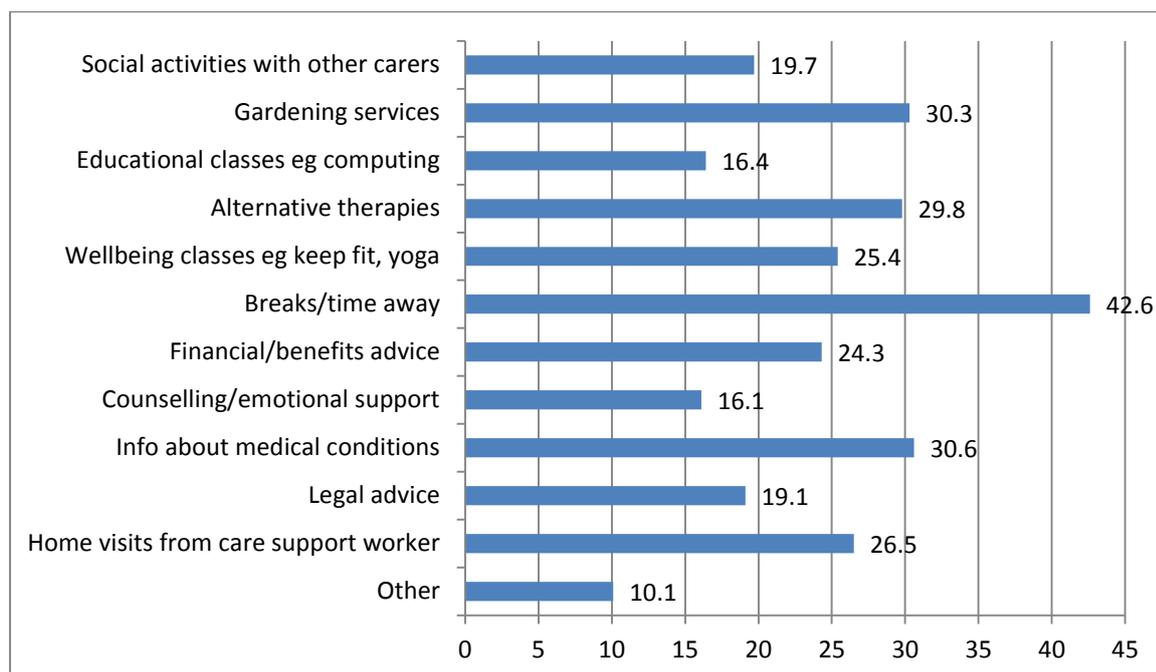
The type of support carers wanted the most which they were not able to obtain in the last year was a break. The next *most* common was information about medical conditions. However, many other common answers also related to having a break or time for themselves – for example gardening services which would ensure they could spend time relaxing in their garden, fitness or relaxation classes and alternative therapies. Breaks from the caring role, relaxation and wellbeing are therefore of key importance to this group.

“I would love for my wife, who is very intelligent, to be able to use rewarding services which give me a break. We have consulted social services etc and researched locally but there is nothing.”

“I would like back-up support to enable me to have a break without the guilt and worry of the person [being] cared for.”

“I would really benefit from a long break [rather] than the three hour slots available to me at the moment – 2–3 days would help to re-energise and catch up.”

**Figure 21 – Type of help carers would have liked but couldn't get in last year (% of total)**



## Recommendations

Access to carers' breaks should be increased. Carers should be offered activities which support all aspects of their health and wellbeing and which give them the opportunity to pursue their own interests. Support for carers' breaks should include access to high quality alternative care.

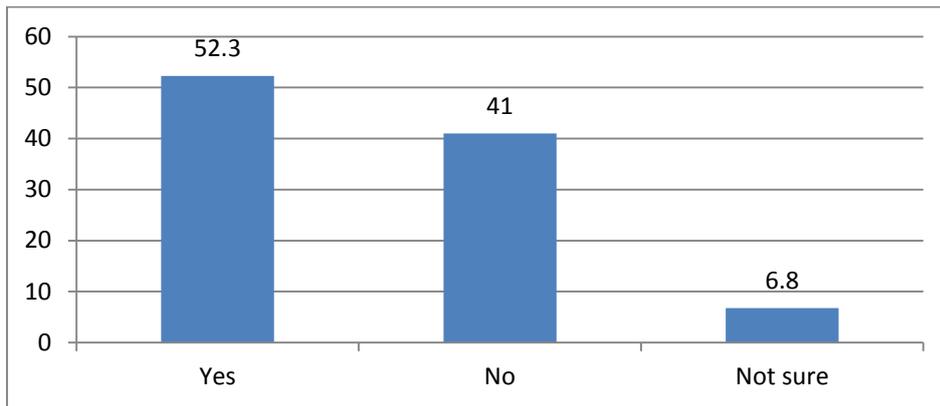
Develop ways to promote carers' wellbeing in the way most useful to them – such as gardening schemes to make their home environment more manageable.

## 10.5 Support from local carers' organisations

### Use of Carers' Centres

Over half of carers in this survey used a local Carers' Centre. Of those who did, satisfaction was very high. 75.4% of carers who had used a Carers' Centre and expressed an opinion stated that the Carers' Centre was excellent or very useful. Only 6.9% had found it not very useful. A number of other organisations were also mentioned as being helpful – including hospices, respite services and condition-specific organisations.

**Figure 22 – Carers using a local Carers' Centre (% of total)**



“Some of the time I feel like walking away and I feel the carers’ meeting lets one let off steam, I’m sure we all feel the same as we are in similar situations.”

“The [local] Carers’ Centre is a most welcome break for carers and gives them the chance to meet other in similar circumstances and share experiences.”

“All my thanks go to the staff at [local] Carers’ [Centre]. They I feel are the only people that do care!”

## 11. Conclusions

The older carers who responded to our survey were clear, articulate and frank. They have put their own life on hold in order to care for their family member or friend, often at the expense of their own health and mental wellbeing.

Few expressed resentment at this, most simply wished for the recognition and involvement from the Government and professionals that they deserve, and a chance to live their own lives, even to some limited extent.

The most striking finding was that they were overwhelmingly exhausted and worried. Carers in the 60–69 age group were also in a particular predicament – being caught in a sandwich of caring for multiple generations, which they often had to balance with work and financial anxiety.

Our society depends on older carers. With an ageing population ever more people will take on a caring role in their retirement. Older carers deserve to enjoy their retirement in good physical and mental health and the chance to live their lives to the full. Being a carer means they should not be expected to give up their health, wellbeing or aspirations. Government, health and care services, professionals, and wider society as a whole needs to recognise the role older carers play and offer greater support.

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