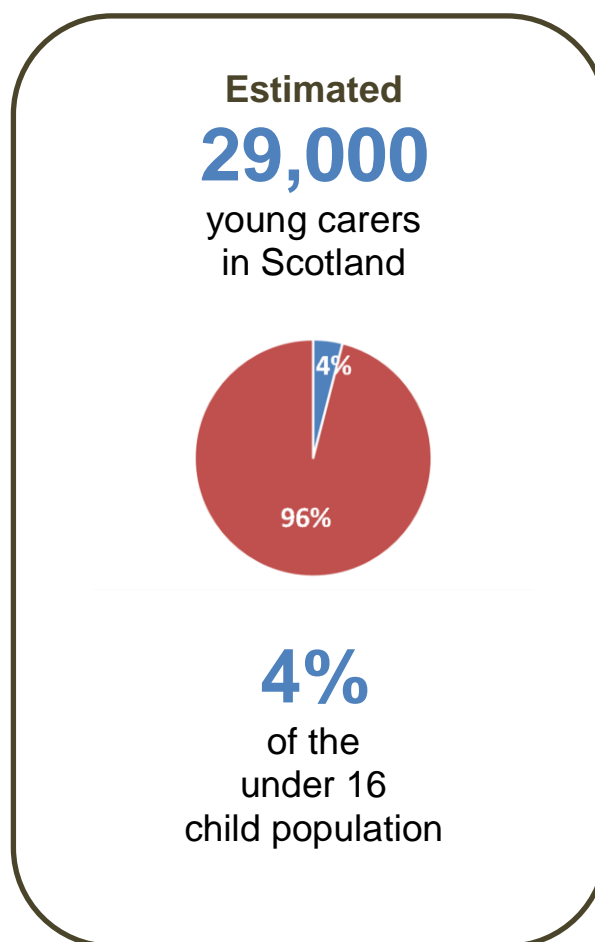
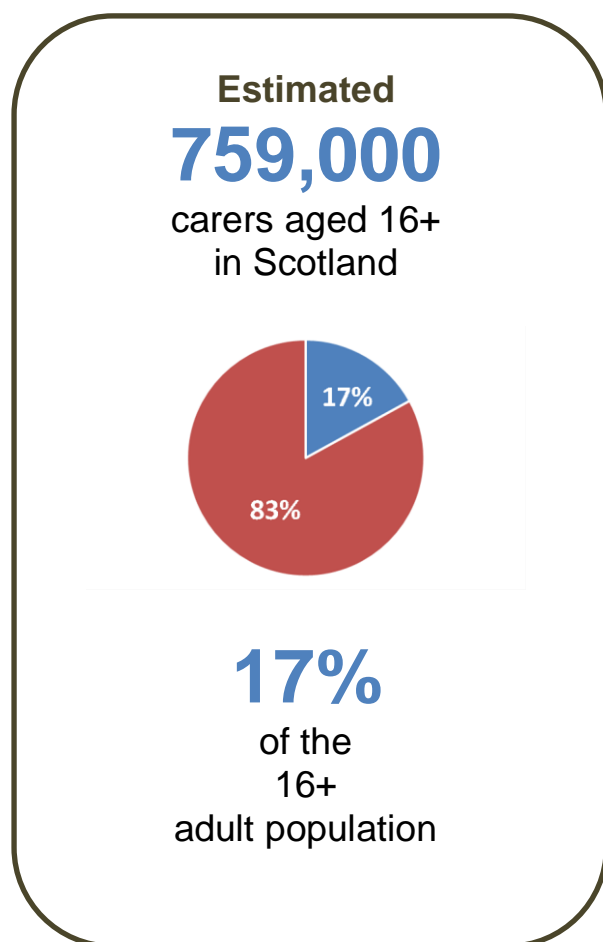


# Scotland's Carers

An Official Statistics Publication for Scotland



**Source:** Scottish Health Survey (SHeS) 2012/2013; National Records of Scotland mid-2013 population estimates

## Introduction

Unpaid carers are people who provide care and support to family members, other relatives, friends and neighbours. The people they care for may be affected by disability, physical or mental health issues (often long-term), frailty, substance misuse or some other condition. Some carers care intensively while others care for shorter periods. Some carers are life-long carers, while others may care for shorter periods of time. A carer does not need to be living with the person they care for to be considered a carer. Anybody can become a carer at any time in their life and sometimes for more than one person at a time. Carers can be any age from young children to very elderly people.

Carers are not paid workers and they are not volunteers; although some can receive payment for part of their time caring through Self-Directed Support. There may be formal paid workers and volunteers supporting the carer and the person they care for, but sole focus of this publication is unpaid carers.

## About the report

This report brings together statistical analysis and research on caring. Information is presented on who provides care in Scotland, drawing from recent population surveys such as the Scotland's 2011 Census and the Scottish Health Survey. The report considers the health and wellbeing of carers and the impact that caring can have on wellbeing as well as the nature, purpose and effectiveness of support for carers.

The report is intended to provide a useful source of information for carer's organisations, policy makers, local authorities and anyone who is a carer or knows someone who is a carer.

Chapters look at:

- 1) Who provides care in Scotland?
- 2) Carers' Health and Wellbeing
- 3) Carers' Employment, Health and Finance
- 4) Support for Carers
- 5) Where do carers live?
- 6) Conclusions

The statistics presented in this report are mainly Scotland level but much of the information from **Scotland's 2011 Census** is also available at local authority level.

An Excel spreadsheet is available to download and contains all charts included in this publication.



Charts which have this symbol next to them are available at Local Authority level in the spreadsheet which accompanies this publication.

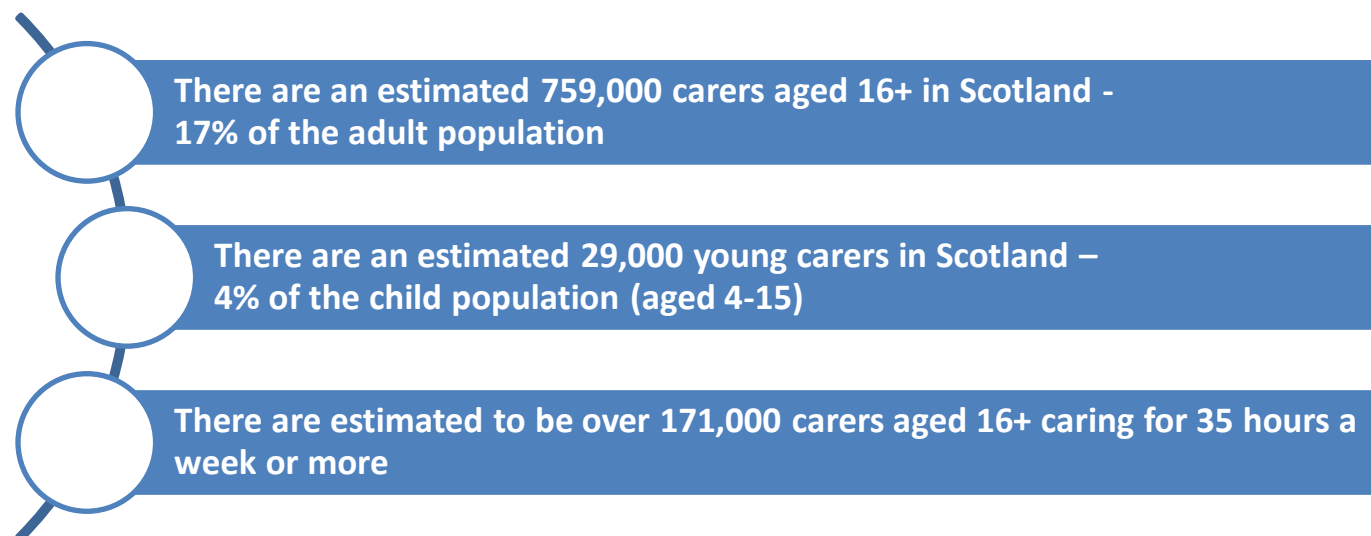
## Acknowledgements

We are extremely grateful to a number of people who assisted us in the development of this report. This includes: the Census team at National Registers of Scotland who provided secure access to data; Dr Iain Atherton, Edinburgh Napier University, who peer reviewed the publication; and Aisha MacGregor, a former graduate intern in Scottish Government, who was involved in reviewing some of the existing research on carers.

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# 1. CHAPTER 1: WHO PROVIDES CARE IN SCOTLAND?



## 1.1. Introduction

There are around 759,000 adults, 17% of the adult population aged 16 and over in Scotland, providing care to one or more people. This chapter presents the latest data from Scotland's 2011 Census and the Scottish Health Survey (SHeS) 2012/2013 (see section 1.3 for explanation of these data sources) to show the diverse profile of carers in Scotland including;

- Who are the carers, by age, gender, ethnic origin, relative deprivation, family situation and where they live.
- Hours of care provided and the length of time they have been caring.

## 1.2. Background

These figures are derived from robust survey data collected by the Scottish Government and are considered the most accurate available for the number of carers in Scotland in 2012/2013. They are derived from robust survey data collected by the Scottish Government but need to be understood in light of factors in gathering data on carers. Whilst method, design and the nature of the population can affect the data in social surveys there are known to be issues relevant, but not unique, to carers. Research has found it can be difficult to identify people who are carers. Research with carers has revealed a main reason for this to be:

- Often people providing care do not self-identify as a carer or with the term because they see their relationship is as a relative, maybe a child, or friend to which the caring activities are an integral dimension (Carduff, et al., 2014; (Smyth, et al., 2011).
- Women are more likely than men to view tasks as integral to their existing role rather than as separate “caring” (Jarvis & Worth, 2004).
- Often caring commences at a low level and can include “invisible tasks” such as giving the cared for person; “emotional support, monitoring their situation and worrying about them” (Jarvis & Worth, 2004) which are less recognised than the tangible caring tasks. More people come to identify as a carer when caring intensifies, which is common, and at key junctures such as giving up employment to care (Carduff, et al., 2014).

- Acceptance of the identity of care necessitates acknowledgement that the other person needs care which can be difficult for one or both parties to do (Carduff, et al., 2014).

### 1.3. Estimating number of carers and hours of care provided

The **Scottish Health Survey** shows that **17%** of the adult population (aged 16+) are carers. For all the reasons set out this provides our **best estimate** of the number of carers in Scotland.

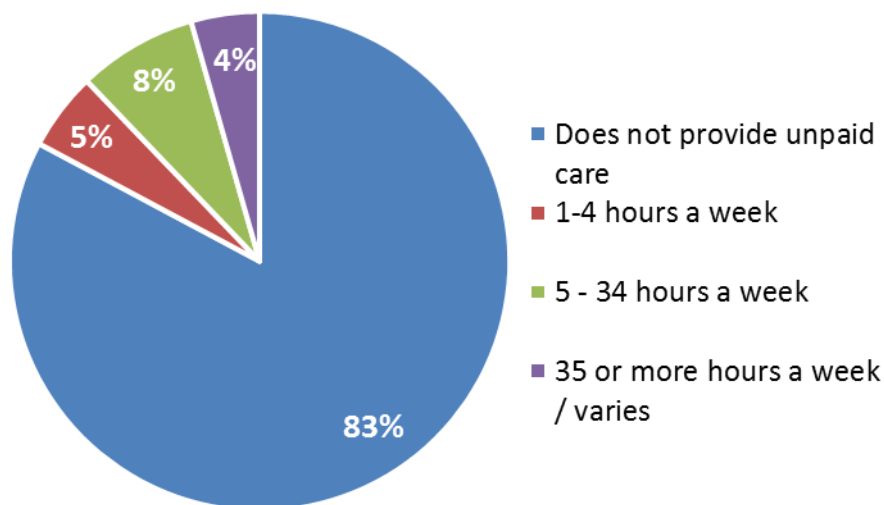
The **Scottish Health Survey (SHeS)** estimates are based on a statistically drawn sample, with survey weights applied to reflect the population age distribution across Scotland and in Scottish areas. Taking into account the stratified and clustered sample design and scaling to population estimates, 95% confidence limits around the estimated number of carers aged 16+ in Scotland are [714,000; 804,000].

**SHeS** provides what we consider to be the **best estimate** of the number of people caring in Scotland at the present time. **SHeS** asks whether anyone in the household looks after or gives any regular help or support to family members, friends, neighbours or others because of either long-term physical / mental ill-health / disability; or problems related to old age. The SHeS provides estimates for carers aged 4-15 and 16 and over and these groups are reported here. However in practice young carer are considered to be those aged up to 18 years and indeed younger adult carers are considered to be aged 18-25 (Scottish Government, 2010b).

#### For adults aged 16+, SHeS for 2012 and 2013 shows:

- 83% said that they did not provide any unpaid care
- 5% said they provided up to 4 hours of care a week
- 8% said they provided 5-34 hours of care a week
- 3% said they provided 35 or more hours care a week
- 1% said the amount of care they provided varied from week to week

**Figure 1: SHeS 2012 / 2013 – Estimated 759,000 carers aged 16+**



**Source:** Scottish Health Survey 2012/2013; NRS population estimates

**Scotland's 2011 Census** shows that

- 9.3% of the population are carers
- 11% of the adult population (aged 16+) are carers
- Over 171,000 people aged 16+ said they provided 35 or more hours care each week

**Scotland's 2011 Census** is thought to underestimate the extent of low level caring for reasons set out in this chapter but provides a good estimate of people with substantial caring responsibilities

**Scotland's 2011 Census** also provides information on the number of people in Scotland who identify themselves to be carers. In the Census, people were asked if they look after or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health or disability; or problems related to old age.

**Overall:**

- 4,803,000 people said they provided no care (90.7%); while
- over 492,000 people said that they did provide care (9.3%)

Of those that said that they provided care:

- Over 273,000 people said they provided 1-19 hours care a week (5.2% of the population)
- Over 46,000 people said they provided 20-34 hours care a week (0.9%)
- Over 172,500 people said they provided 35 or more hours care a week (3.3%)

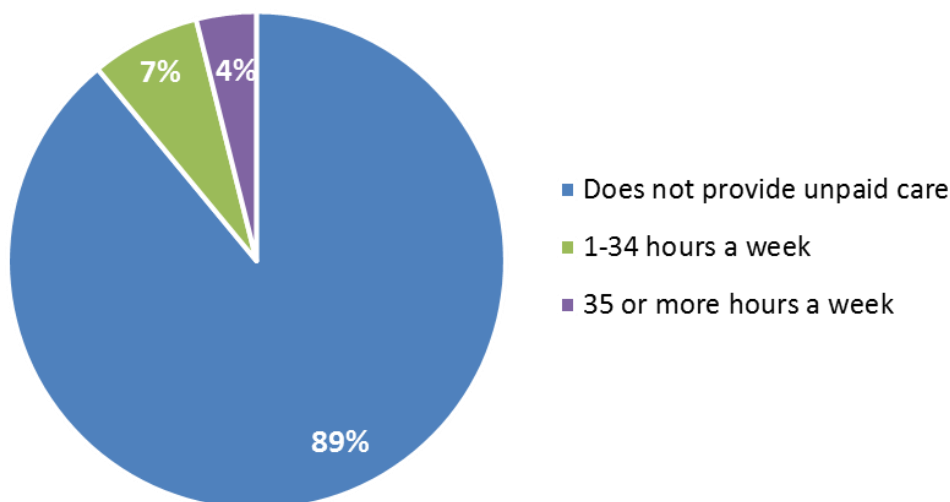
**For adults aged 16+**

- 3,897,000 people said they provided no care (89.0%)
- Over 482,000 people said that they provided care (11.0%)

Of those that said that they provided care:

- Nearly 266,000 people said they provided 1-19 hours care a week (6.1% of the population)
- Over 45,000 people said they provided 20-34 hours care a week (1.0%)
- Over 171,000 people said they provided 35 or more hours care a week (3.9%)

**Figure 2: Scotland's 2011 Census – 482,000 carers aged 16+**



**Source:** Scotland's Census 2011

In this publication some analyses will relate to the SheS 2012/2013 estimate (759,000 carers) while more detailed analyses will tend to relate to data from Scotland's 2011 Census (482,000 carers). The text and source information should make it clear which source is being used.

#### **1.4. Comparing findings from the SHeS and Census 2011**

It is useful to consider why these two sources differ so much. The main difference appears to be for carers who care for only a few hours per week. These carers are more likely to have been identified in the SHeS.

One reason that we get different answers from different surveys is because often people don't recognise themselves as a carer but simply as someone who is looking after their family and friends.

Scotland's 2011 Census and the 2012/2013 SheS ask identical questions so it might be reasonable to expect a similar response. However, the 2011 population census is a postal survey and generates a much smaller response to the caring question (492,000 carers) than the SHeS (788,000 carers) which is an interview survey.

There are a number of reasons why these differences may occur:

- In the SHeS each adult in the household is personally asked the carers' question. Therefore each adult speaks directly to the interviewer and says whether they provide care and how many hours a week.
- In Scotland's 2011 Census, it may be the case that one person will answer the questionnaire for the whole household. This person may not be aware of caring activity going on elsewhere in the household or may feel uncomfortable explaining that someone else in the household provides care for them.
- Because the SHeS is an interview survey it allows the respondent to ask for clarification if they don't understand the question. There is not this opportunity with a postal survey.
- The SHeS question is asked as part of a detailed health survey and follows a block of questions about long-term conditions which means that people will be thinking more about health and care issues when they answer the question.
- The SHeS has an additional category asking if people provide care for up to 4 hours each week whereas the first category in Scotland's 2011 census is "up to 19 hours of care" a week. It may be that the large number of hours in the census category deters people who only provide a small amount of care from answering.

For all of these reasons, the SHeS is considered to provide the best estimate of the overall number of carers in Scotland. Both sources provide similar results when looking at carers who do substantial amounts of caring each week and the Census figure of 171,000 has been used as a best estimate of adult carers who care for 35 or more hours each week.

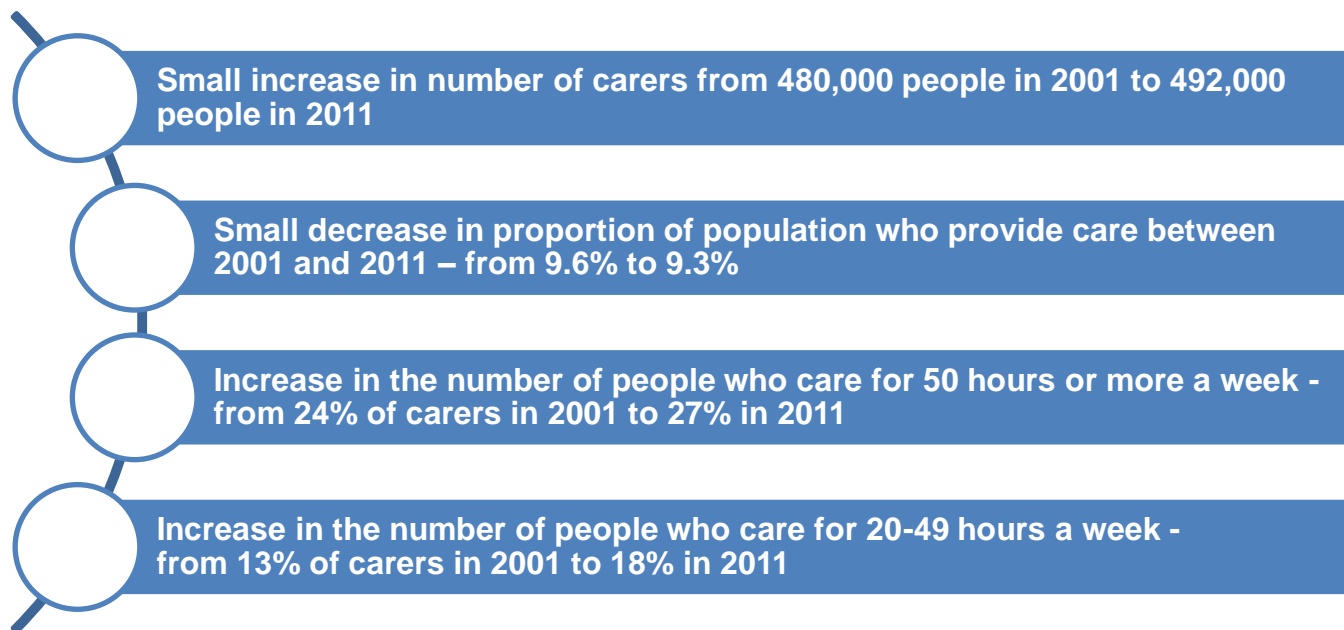
Both Scotland's 2011 Census and the 2012 and 2013 SHeS provide similar estimates of the number of carers who are caring for 35 or more hours a week. Scotland's 2011 Census shows that 4% of the population said they cared for 35 hours a week or more while the SHeS shows that around 4% of the population said that they cared for 35 hours a week or more or that their caring varied from week to week. 35 hours a week is a significant amount of time, equivalent to the number of hours in a full-time working week, so it is perhaps unsurprising that these people are more likely to identify as carers in both surveys. SHeS estimates that around 140,000 people are caring for 35 or more hours each week. In addition it is estimated that a further 54,000 people provide care that varies a lot from week to week. Taking both of these figures into account and the Census 2011 figure of 171,000 people aged 16+ caring for 35 hours a week or more leads to conclude that there are over 171,000 carers aged 16+ caring for 35 hours or more a week.



Scotland's 2001 and 2011 Censuses underestimate the number of people providing small amounts of care each week and this should be borne in mind when considering any of the census analysis presented in this publication.

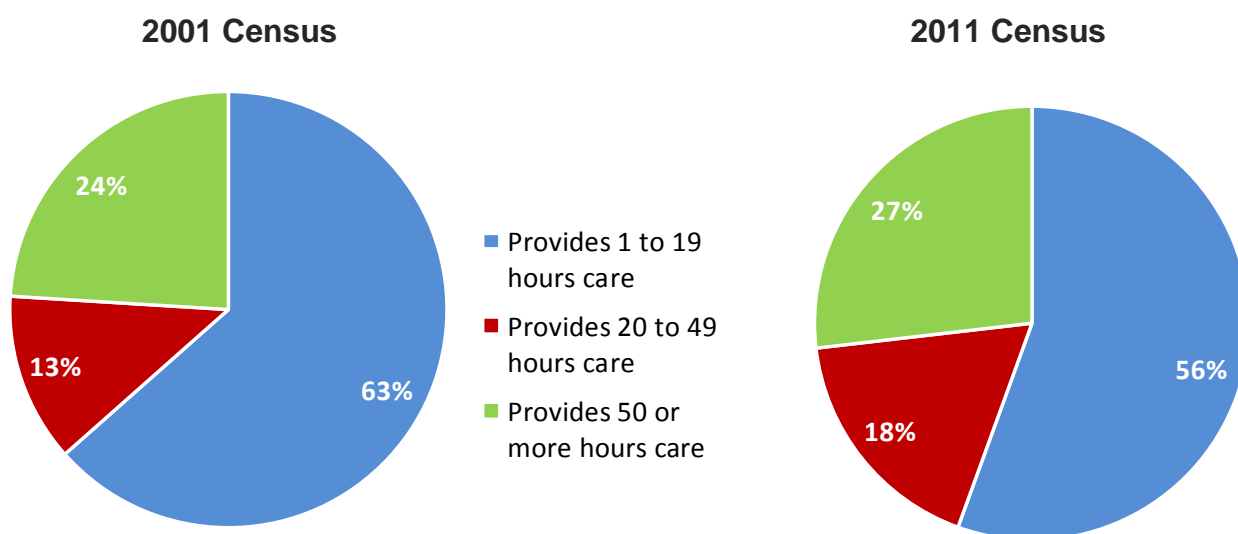
Scotland's 2001 and 2011 Censuses do however provide a good estimate of the number of carers who provide substantial levels of care and support each week. Being a full census, they also allow for more in-depth analysis of carers and allow for analysis at Local authority level.

## 1.5. Are Scotland's carers increasing or decreasing in number?



A question on caring was asked in Scotland's 2001 and 2011 population censuses and this allows comparison of how many people identified themselves as carers at each census point and how this has changed over the ten year period.

Figures 3 and 4: Intensity of Care provided, 2001 v 2011



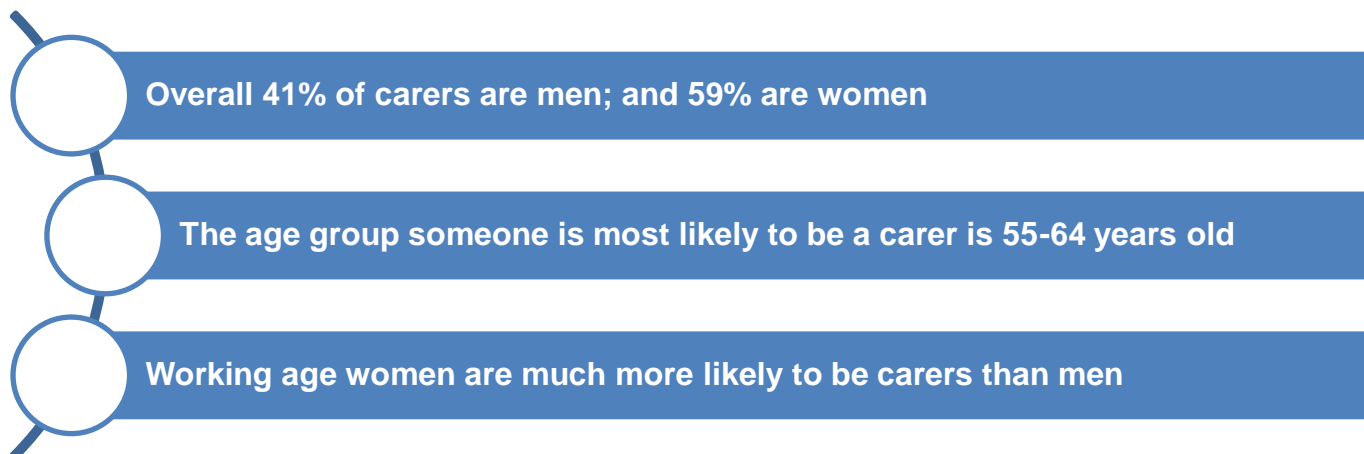
Source: Scotland's Census 2011

There has been a slight increase in the number of people identifying as carers over the 10 year period but at the same time there has been a small decrease in the proportion of the population who say that they provide care.

The main change has been in the number of hours of care provided each week.

- In 2001, there were over 115,000 people who said they provided 50 or more hours of care each week (24% of carers). By 2011, this had increased to over 132,000 (27% of carers).
- In 2001, just over 60,000 people said that they cared for 20-49 hours per week (13% of carers). In 2011 this had increased to nearly 87,000 people (18% of carers).

## 1.6. Age, gender and ethnicity of carers

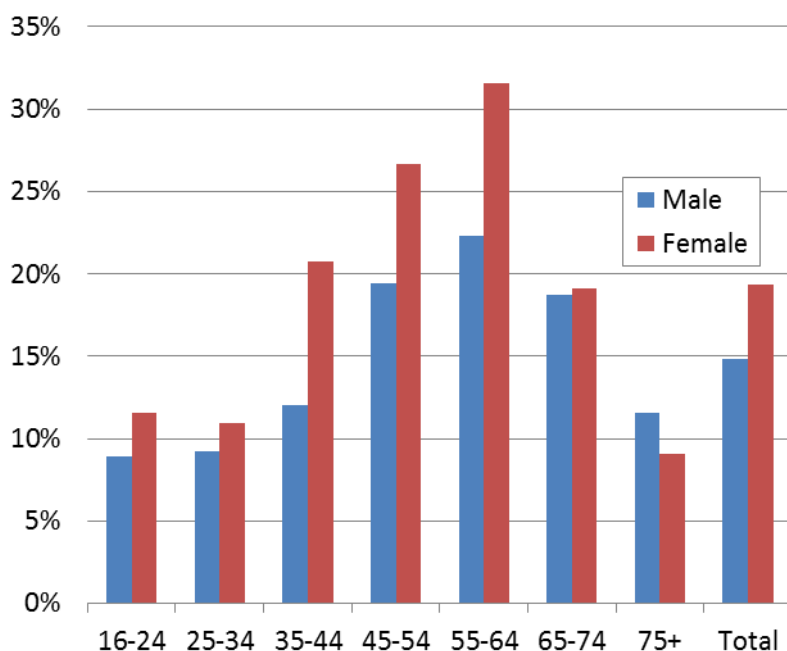


The **SHeS** shows that overall 41% of carers are male and 59% are female.

**SHeS** shows that the likelihood of being a carer increases with age, up until ages 55-64. Around 12% of women and 9% of men in their 20s and early 30s are carers but for those in their late 50s / early 60s nearly a third of women are carers as are over a fifth of men. Throughout the working years, women are more likely to be carers than men. This is particularly true for the 35-44 age group when women may also have school-age or pre-school children to look after.

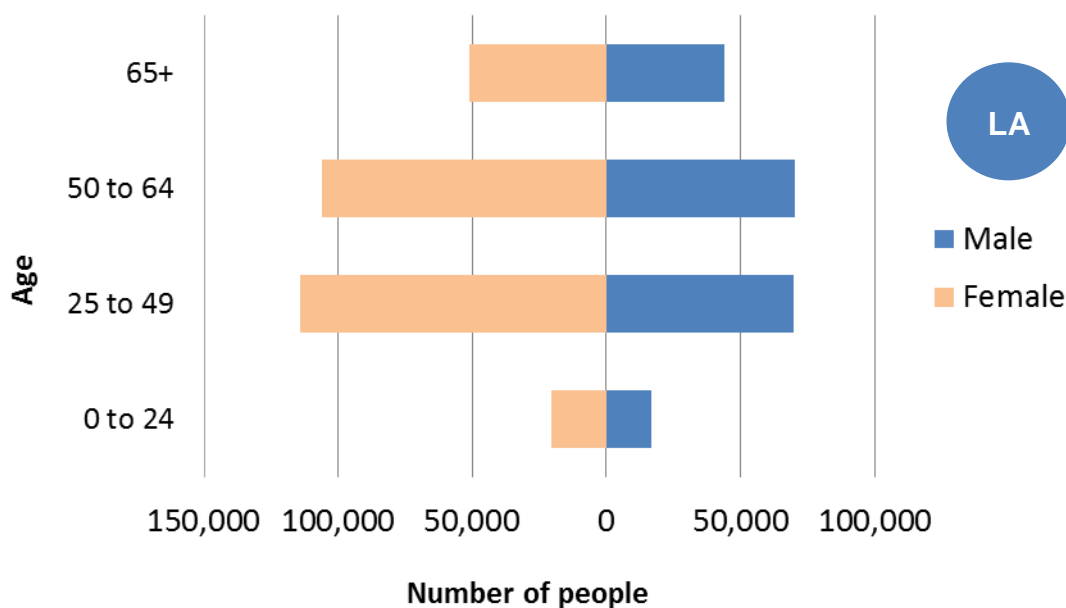
Following retirement age, the difference between men and women balances out with 19% of both men and women in the 65-74 age group providing care. Looking at the older age groups men become more likely to be carers – 12% of men aged 75+ say they are carers compared with 9% of women.

**Figure 5: Age and gender of carers, 2012/2013**



**Source:** Scottish Health Survey 2012/2013

**Figure 6: Age and gender distribution of carers in Scotland, 2011**



Source: Scotland's Census 2011

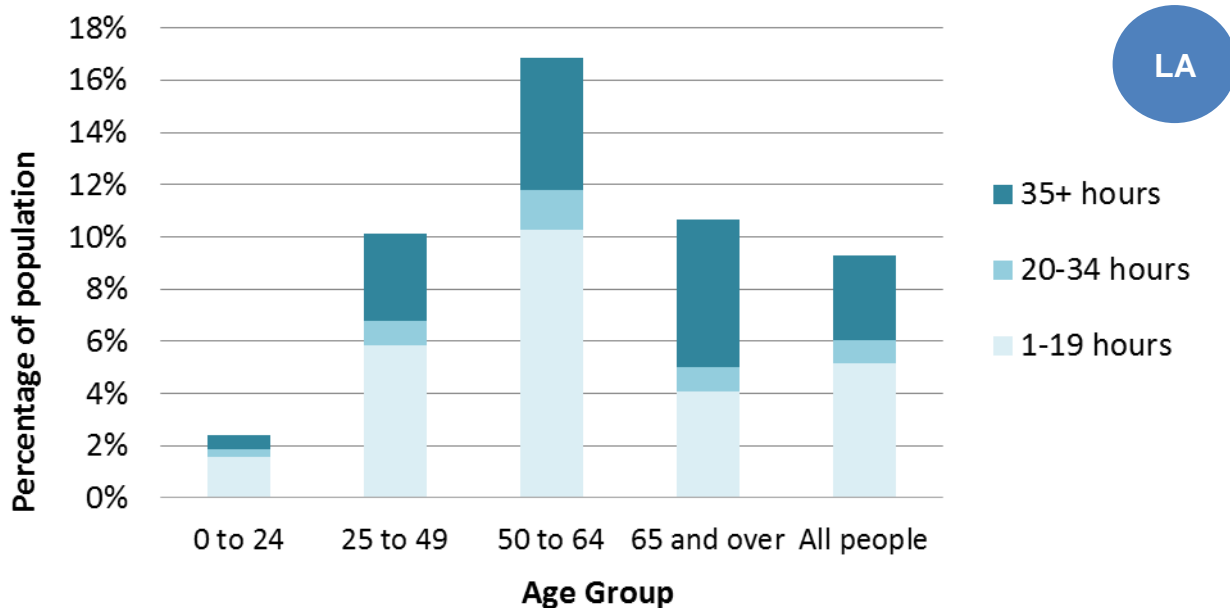
**Scotland's 2011 Census** shows the same picture, that overall 41% of carers are male and 59% are female. This varies for different life stages:

Aged under 25 years	Aged 25-49 years	Aged 50-64 years	Aged 65 and over
<ul style="list-style-type: none"> <li>• 2% of under 25s are carers</li> <li>• 45% of carers are male : 55% female</li> </ul>	<ul style="list-style-type: none"> <li>• 10% of this age group are carers</li> <li>• 38% of carers are male : 62% female</li> </ul>	<ul style="list-style-type: none"> <li>• 17% are carers</li> <li>• 40% of carers are male : 60% female</li> </ul>	<ul style="list-style-type: none"> <li>• 11% are carers</li> <li>• 46% of carers are male : 54% female</li> </ul>

**Scotland's 2011 Census**, allows us to look in more detail at the amount of caring that different age groups provide.

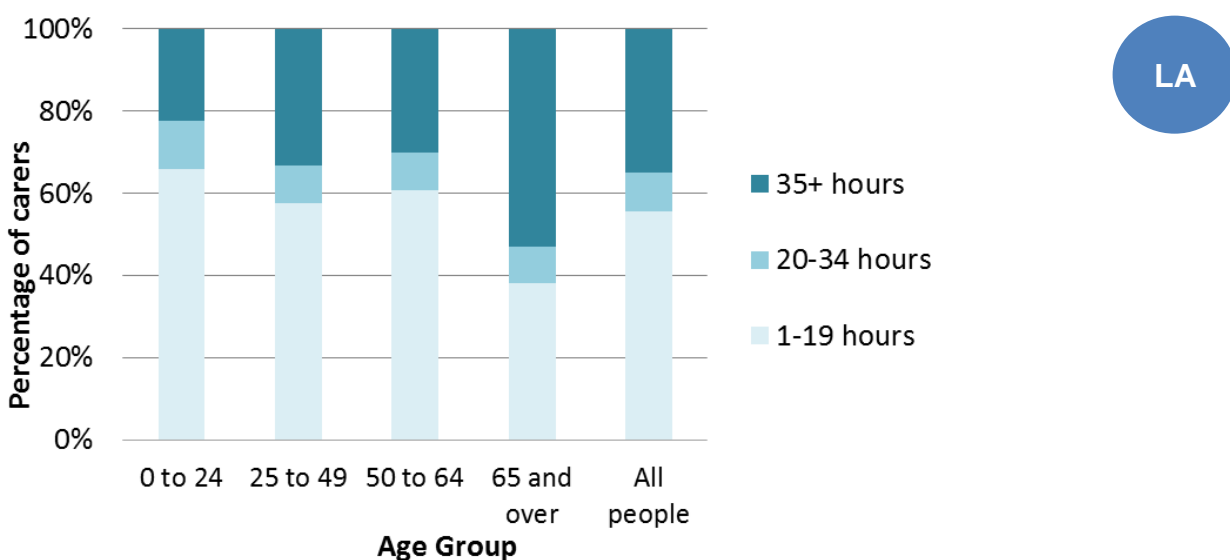
- The 50-64 age group is the most likely to provide care: nearly 17% of people in this age group said they provided care
- Over half of older carers (aged 65 and over) provide 35 hours of care a week or more compared with just over a fifth of young carers aged under 24.

**Figure 7: Level of care per week, by age group (all people), 2011**



Source: Scotland's Census 2011

**Figure 8: Level of care per week, by age group (all carers), 2011**



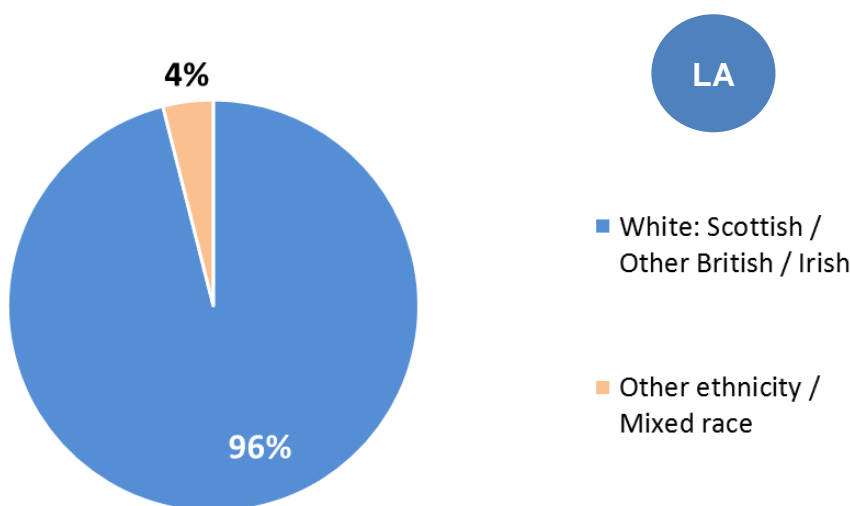
Source: Scotland's Census 2011

**Scotland's 2011 Census** tells us about carers' ethnicity. Overall 9% of the white Scottish / British / Irish population are carers compared to 5% of other ethnicities. Further work is needed to look at the age structure and health of different ethnic populations to see if that explains some or all of this difference.

Further information on carers and ethnicity is also available from "Analysis of Equality Results from the 2011 Census" published by the Scottish Government in 2014. Chapter 1 considers ethnicity in more detail: <http://www.gov.scot/Publications/2014/10/8378/3> and shows that:

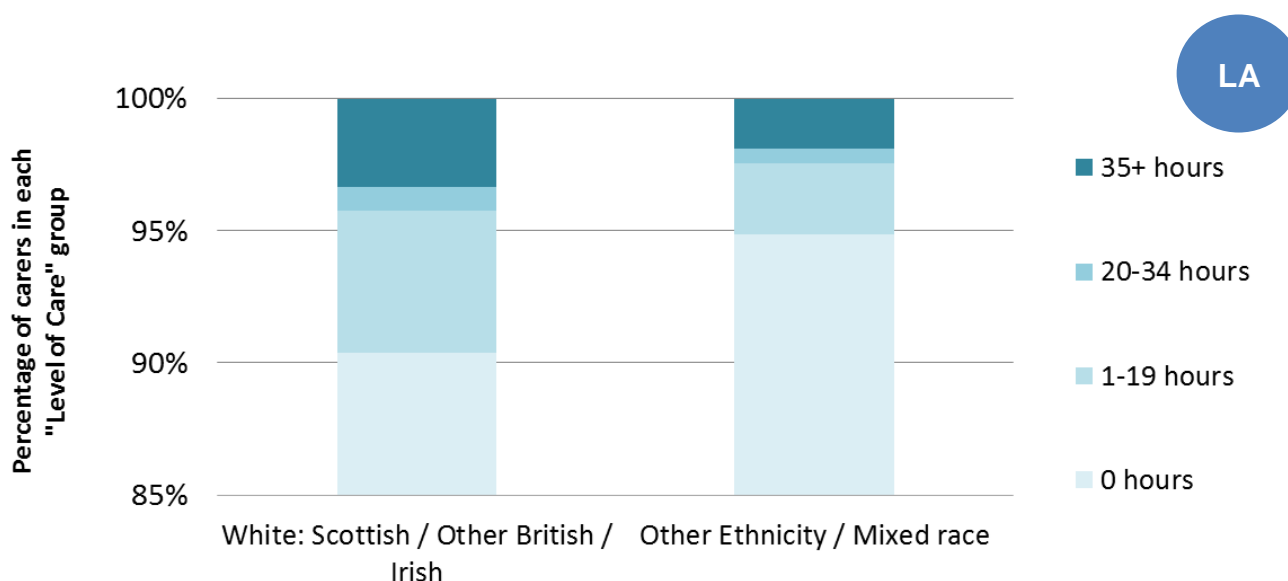
- People from older ethnic groups such as 'White: Scottish' and 'White: Other British' were the most likely to provide unpaid care.
- People from ethnic groups with younger age profiles (such as the 'Arab' and 'White: Polish' groups) were least likely to provide unpaid care.

**Figure 9: Percentage of all carers who are from an ethnic minority background, 2011**



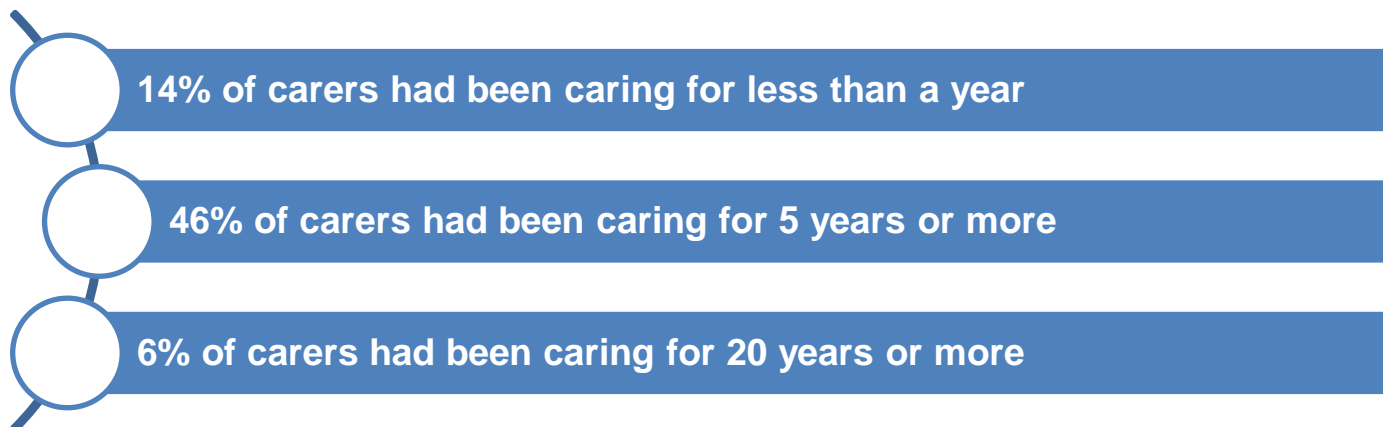
Source: Scotland's Census 2011

**Figure 10: Ethnic group and level of care per week provided by carers, 2011**



Source: Scotland's Census 2011

## 1.7.Length of time spent caring

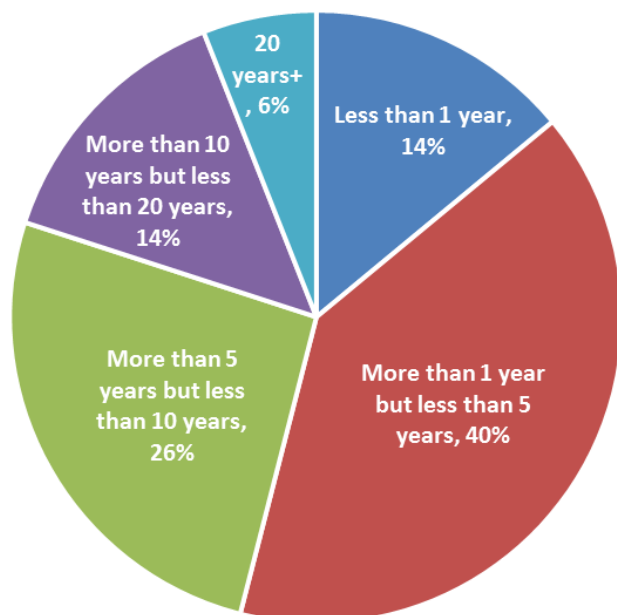


The **SHeS 2012/2013** asks people how long they have been caring.

Overall:

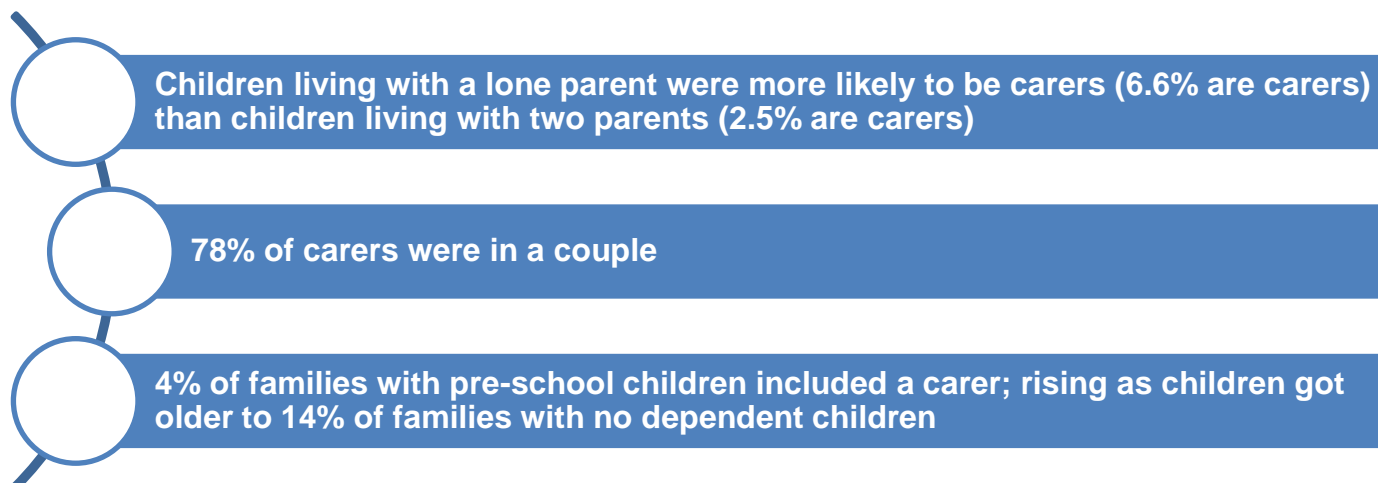
- 14% of people had been caring for less than 1 year;
- 40% had been caring for between 1 and 5 years;
- 26% had been caring for between 5 and 10 years;
- 14% had been caring for between 10 and 20 years; and
- 6% had been caring for more than 20 years.

**Figure 11: Length of time spent caring, 2012/2013**



**Source:** Scottish Health Survey 2012/2013

## 1.8. Caring relationships



Unfortunately **Scotland's 2011 Census** cannot tell us who each carer cares for. Carers may care for more than one person and people may have more than one carer so the relationships can be very complex.

People may care for someone within their household and the Census 2011 disability questions allows us to identify people in households who may require care. It could be assumed that other members of the household who say that they provide care are caring for this person, though caution should be exercised in this interpretation. Where this is most likely to be true is in the case of child carers who are more likely to be caring for someone in the same household.

**Scotland's 2011 Census** shows that children who live with a lone parent are much more likely to be a carer (6.6% are carers) than a child who lives with two parents (2.5% are carers).

Children who live with a lone parent are also much more likely to have substantial caring responsibilities (35 hours or more a week) than children living with two parents. **Scotland's 2011 Census** shows that nearly 3% of children living with a lone parent are caring for 35 hours a week or more while only 0.5% of children living with two parents provide this level of care.

Over 429,000 carers live with family rather than on their own or with people they are not related to (e.g. student household). **Scotland's 2011 Census** provides information on the different type of family situations that exist and the likelihood of being a carer for each of these.

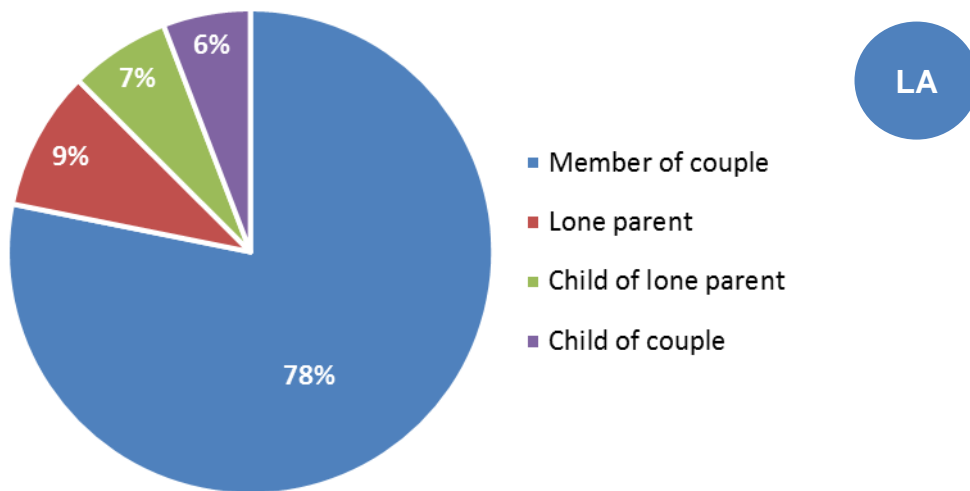
In **Scotland's 2011 Census**,

- 78% or nearly 336,000 carers were in a couple this includes couples with or without children
- 9% or nearly 40,000 carers were a lone parent
- 7% or nearly 29,000 carers were the child of a lone parent; this can include adult children who live with a parent
- 6% or 25,000 carers were the child of a couple; including adult children who live with their parents

These figures explain the relationship within the household that the carer lives but that does not necessarily infer the caring relationship that they do. For example, a member of a couple does not necessarily care for their partner. Also a member of a couple could be living with one or more children or other relatives who they may or may not care for.



**Figure 12: Family status of carer (people in families only), 2011**

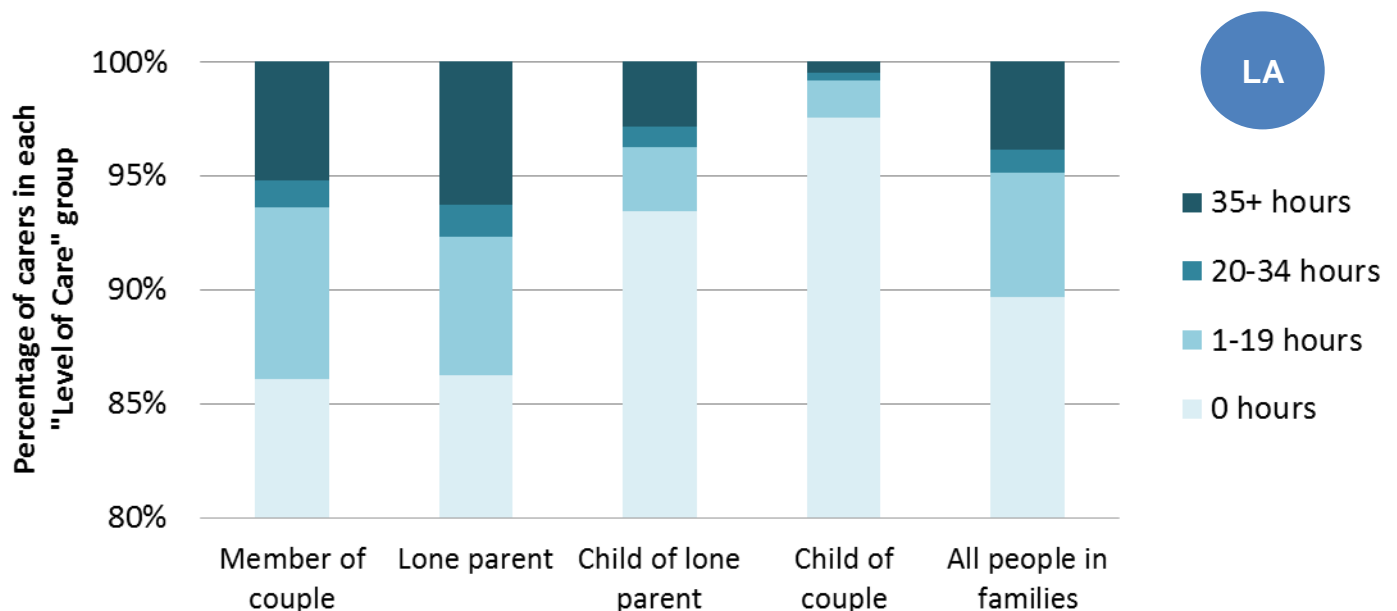


Source: Scotland's Census 2011

Data from **Scotland's 2011 Census** shows that couples and lone parents are equally likely to be carers but lone parents are more likely to care for 20 hours a week or more. This makes sense as couples are more likely to be able to share the caring role.

Also a child living with a lone parent is much more likely to be a carer than a child living with a couple (note that this will include adult children who still live with their parents). Again this is not surprising as a child living with a couple is more likely to have support to provide care.

**Figure 13: Family status of carer and level of care per week, 2011**

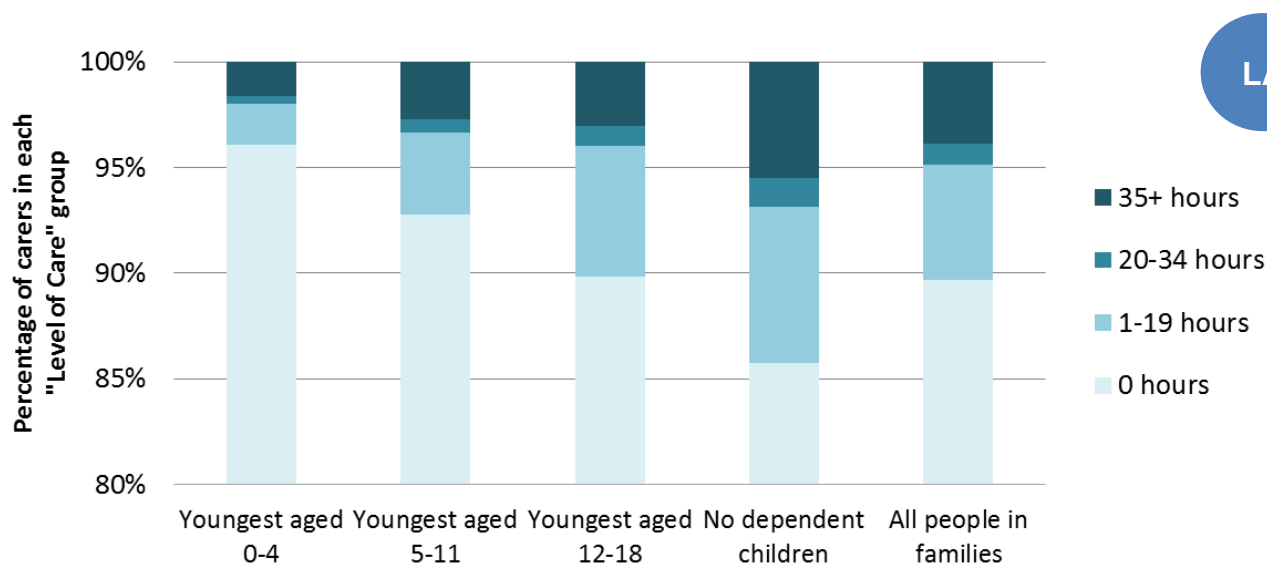


Source: Scotland's 2011 Census – 429,330 carers (excludes carers who live alone)

**Scotland's 2011 Census** tells us about the family situation of carers and whether there are any children living in the family. Families with pre-school children are the least likely to include a carer in the family – only 3.9% say that they are carers. However the likelihood of being a carer increases as children get older and is most likely for family situations where there are no dependent children. This could be older couples caring for parents or older couples caring for each other.

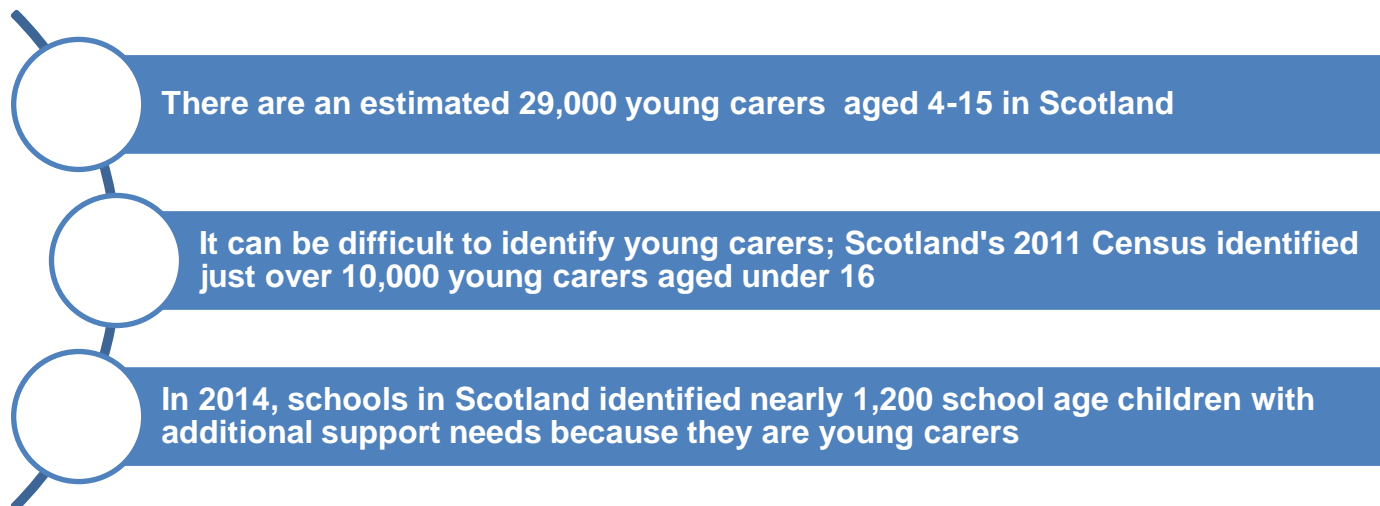
- 4% of families with pre-school children included a carer in the household;
- 7% of families with primary school age children;
- 10% of families with secondary school age children;
- 14% of families with no dependent children;

**Figure 14: Carers who have dependent children, by level of care per week, 2011**



**Source:** Scotland's 2011 Census– 429,330 carers (excludes carers who live alone)

## 1.9. Young carers



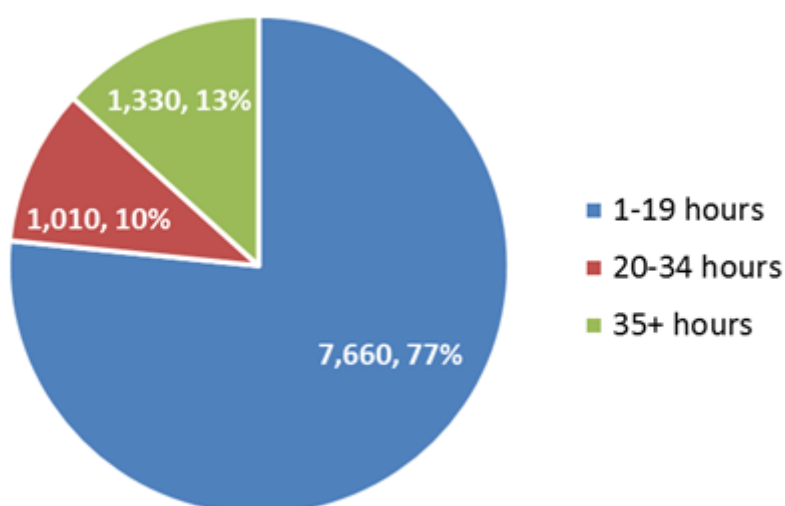
The **SHeS** estimates that 4% of children aged 4-15 are carers. Taking into account the sample design and scaling to population estimates, 95% confidence limits around that estimate are [22,000; 36,000].

While the **SHeS** provides the best estimate of overall numbers of young carers aged under 16, the sample size does not allow for analysis of these young carers in any more detail. Scotland's 2011 census, while underestimating what we understand to be the true level of young caring does allow for more detailed analysis of the young carers who self-identified.

Just over 10,000 young people aged under 16 identified themselves as carers in **Scotland's 2011 census**:

- Over three-quarters, 7,660 children said that they provided care for up to 20 hours a week
- 10% said that they provided care for 20-34 hours per week (just over 1,000 children)
- 13% said that they provided more than 35 hours of care a week (over 1,300 children)

**Figure 15: Young carers aged under 16; by intensity of care provided, 2011**



**Source:** Scotland's Census 2011

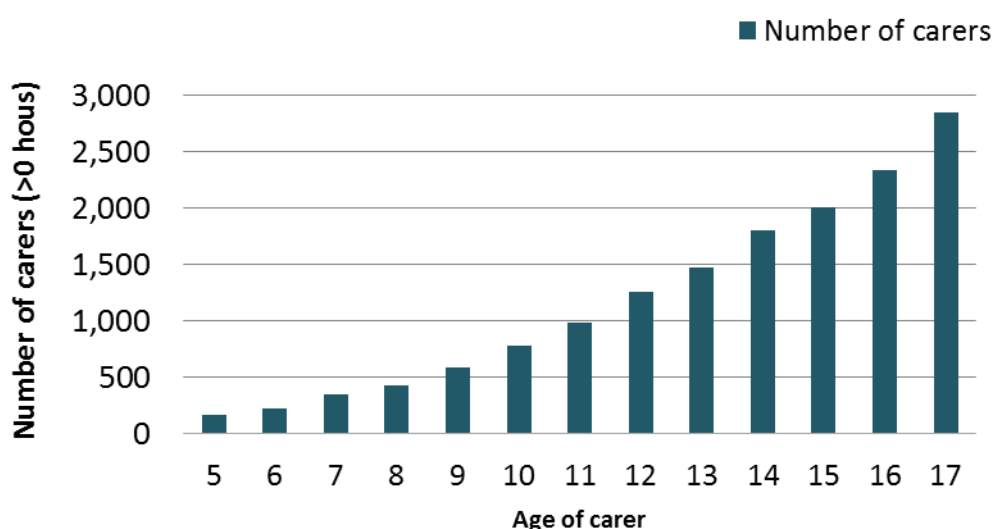
Young carers are difficult to identify in the census, particularly because the census form will often be completed by the main householder who is likely to be an adult and may also be the person that the child provides care to.

The census is likely to pick up carers who are already known to carers' centres and to schools and those who are doing substantial amounts of care but may not give a good indication of the level of caring which is not known to local authorities or schools.

The **Scottish Health Survey (SHeS)** estimates that there are around 29,000 young carers aged under 16 in Scotland. This is three times the number who are identified as carers in the Census. Section 1.4 explains why the SHeS provides a better estimate of the number of carers.

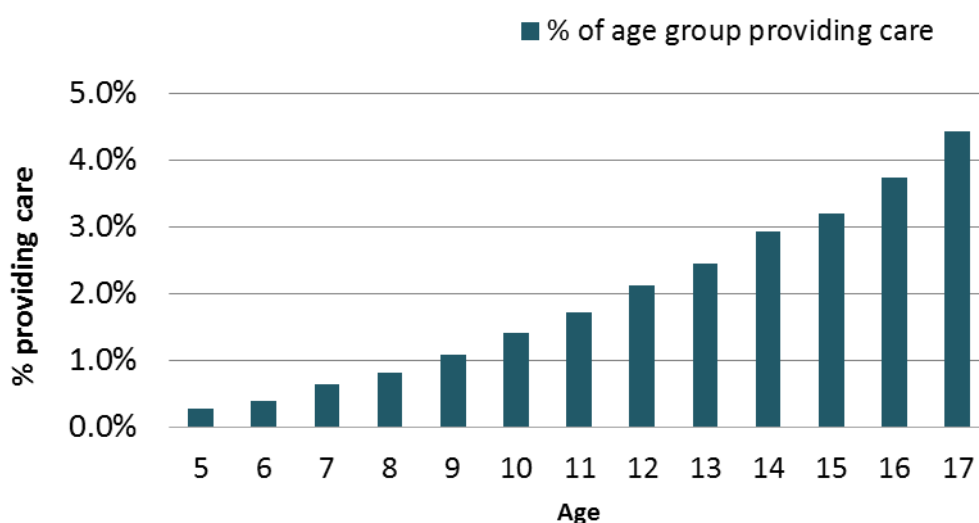
**Scotland's 2011 Census** shows that the both the number and proportion of children who say they provide care rises with each year of age. Only 160 (0.3% of) 5 year olds are identified as providing care and this increases with each year of age up to 2,840 (4.4% of) 17 year olds.

**Figure 16: Number of young carers (aged 5-17), 2011**



Source: Scotland's Census 2011

**Figure 17: % of young people (aged 5-17) providing care, 2011**

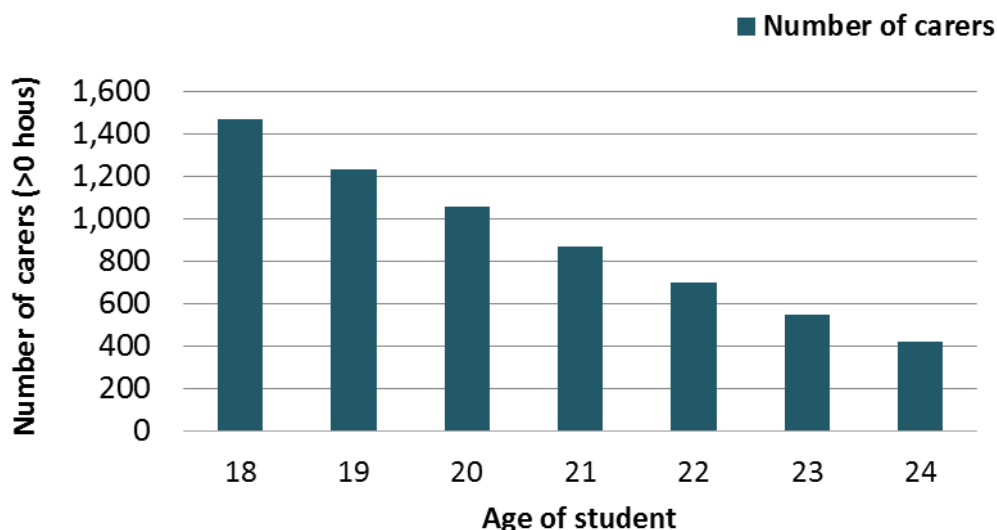


Source: Scotland's Census 2011

**Scotland's 2011 Census** shows that the number of students who say that they are carers, declines with each year of age. There were 1,470 18 year old students who said that they provided care and this is nearly 4% of the 18 year old student population. Students aged 21 were the least likely to be providing care: just under 3% of 21 year old students provided care. Further research would be needed to determine the reasons for this and whether young people are giving up caring in order to study or giving up their study in order to care.

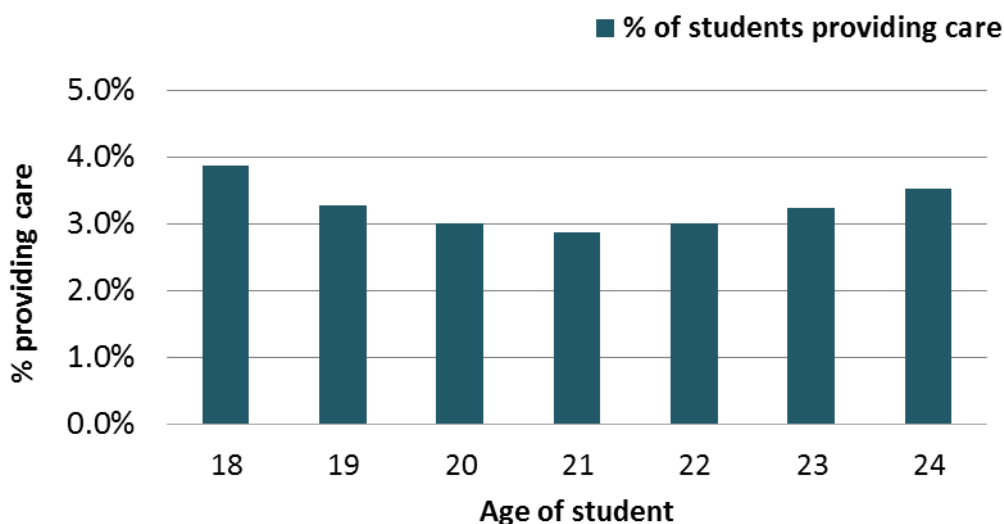
There are a larger proportion of student carers with each year of age from 21 onwards. Further research could be done to see if student carers take longer to get their degree or switch to part-time courses to accommodate their caring responsibilities.

**Figure 18: Number of students aged 18-24 providing care, 2011**



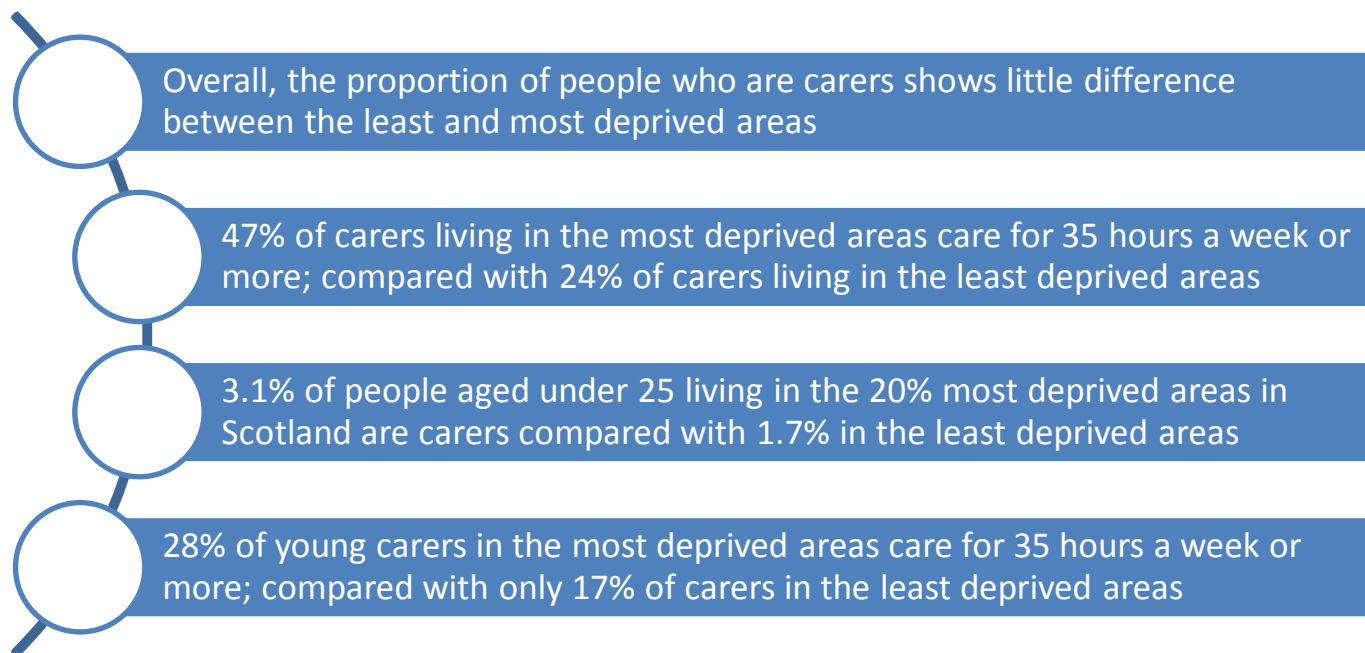
Source: Scotland's Census 2011

**Figure 19: % of students aged 18-24 providing care, 2011**



Source: Scotland's Census 2011

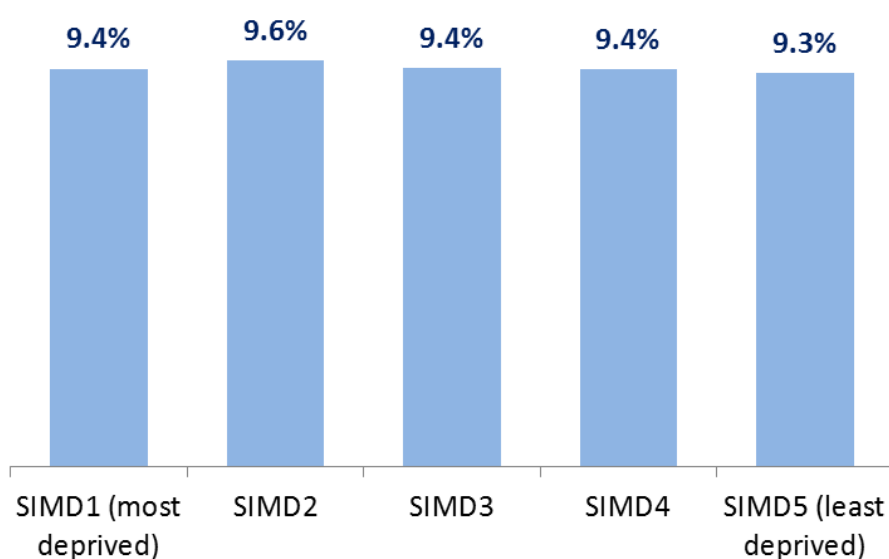
## 1.10. Scottish Index of Multiple Deprivation



**Scotland's 2011 Census** allows us to look at carers and where they live in Scotland categorised according to the **Scottish Index of Multiple Deprivation (SIMD)**. The **SIMD** ranks the 6,505 datazones that cover Scotland from most deprived (ranked 1) to least deprived (ranked 6,505). These datazones can then be split into five quintiles with SIMD1 including the 20% of datazones that are most deprived up to SIMD5 which contains the 20% of datazones that are least deprived.

The proportion of people who say they are carers varies very little between the most deprived datazones and the least deprived datazones. Variation ranges from 9.3% in the least deprived datazones (SIMD5) to 9.6% in SIMD2.

**Figure 20: Proportion of carers in each deprivation quintile, 2011**

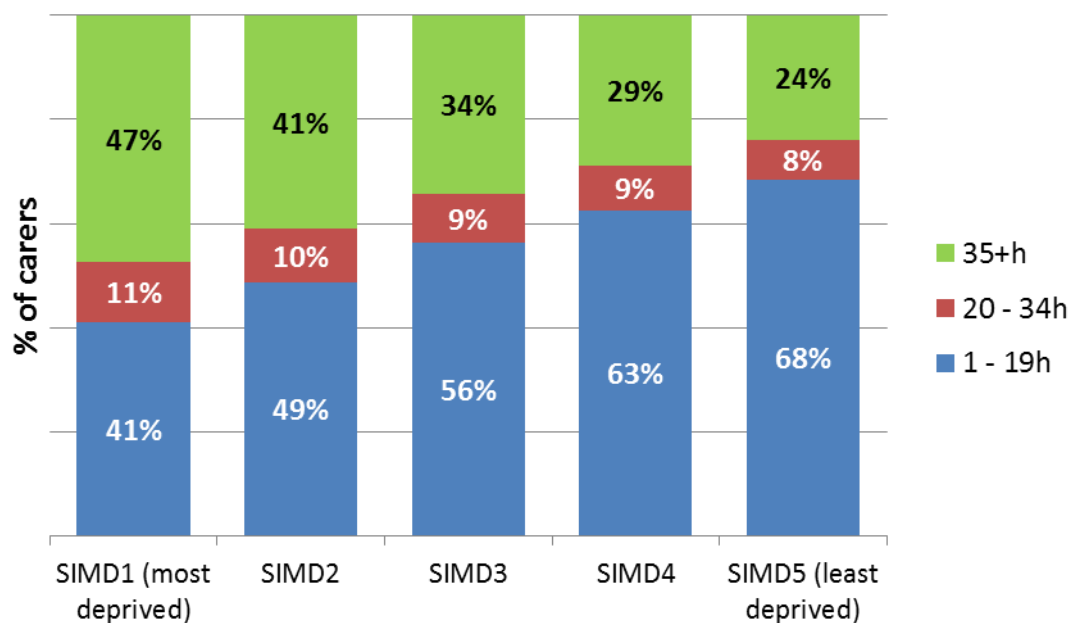


**Source:** Scotland's Census 2011

**Scotland's 2011 Census** shows the intensity of care that carers provide each week. This does vary with deprivation:

- 47% of carers in the most deprived areas care for 35 hours a week or more. This is almost double the level in the least deprived areas where only 24% of carers care for 35 hours a week or more. The chart shows a linear increase in the percentage caring for 35 hours or more with increasing deprivation.
- 41% of carers in the most deprived areas care for under 20 hours a week. This compares with 68% of carers in the least deprived areas.

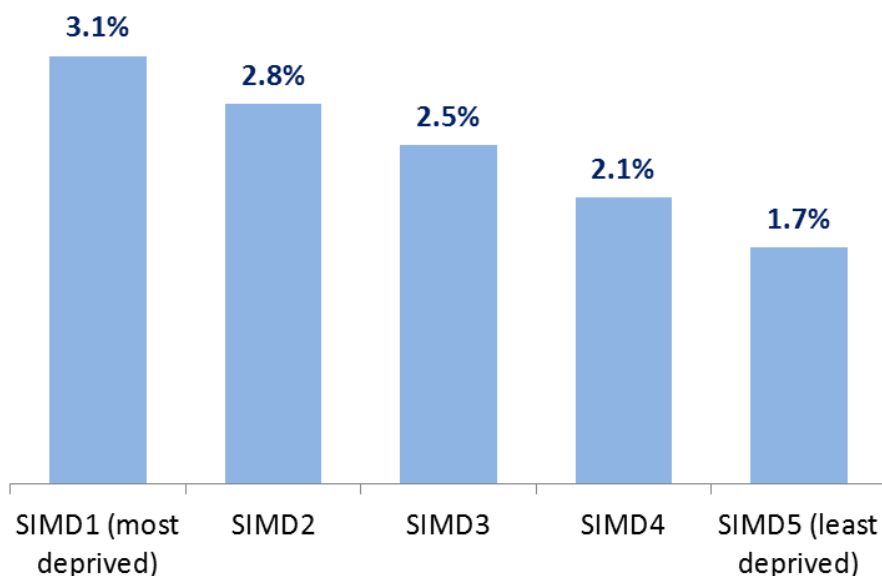
**Figure 21: Intensity of caring in each deprivation quintile, 2011**



Source: Scotland's Census 2011

Scotland's 2011 Census shows that 3.1% of younger people (aged under 25) living in the 20% most deprived areas in Scotland are carers compared with 1.7% of younger people in the least deprived areas.

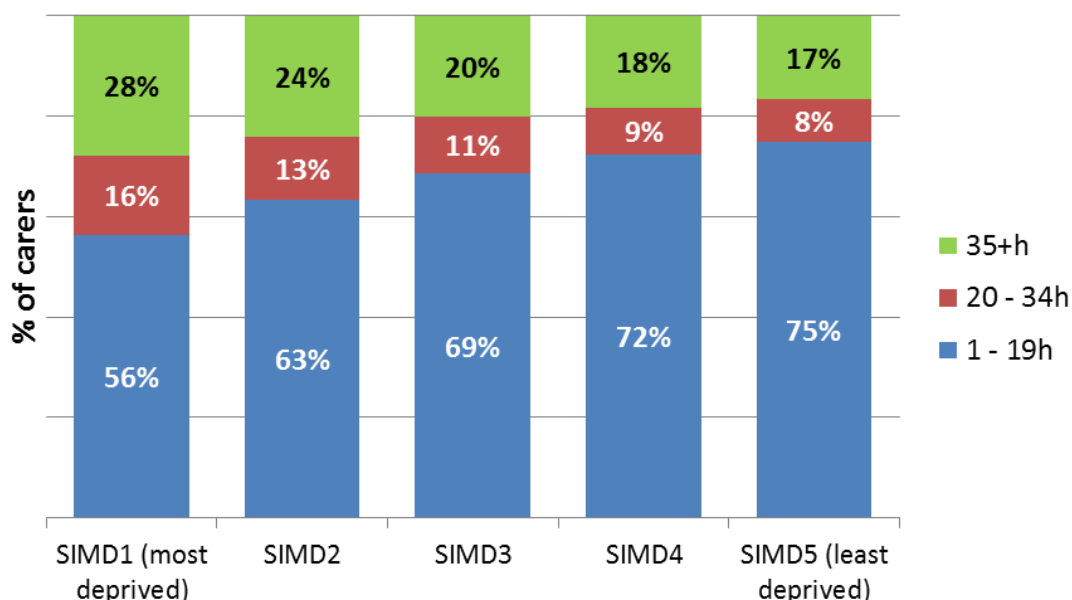
Figure 22: Percentage of population aged under 25 who are carers, 2011



Scotland's 2011 Census shows the intensity of care that these younger carers (aged under 25) provide:

- 28% of younger carers in the most deprived areas care for 35 or more hours each week; this compares with only 17% of carers in the least deprived areas.

Figure 23: Younger carers aged under 25: Intensity of caring each week, 2011

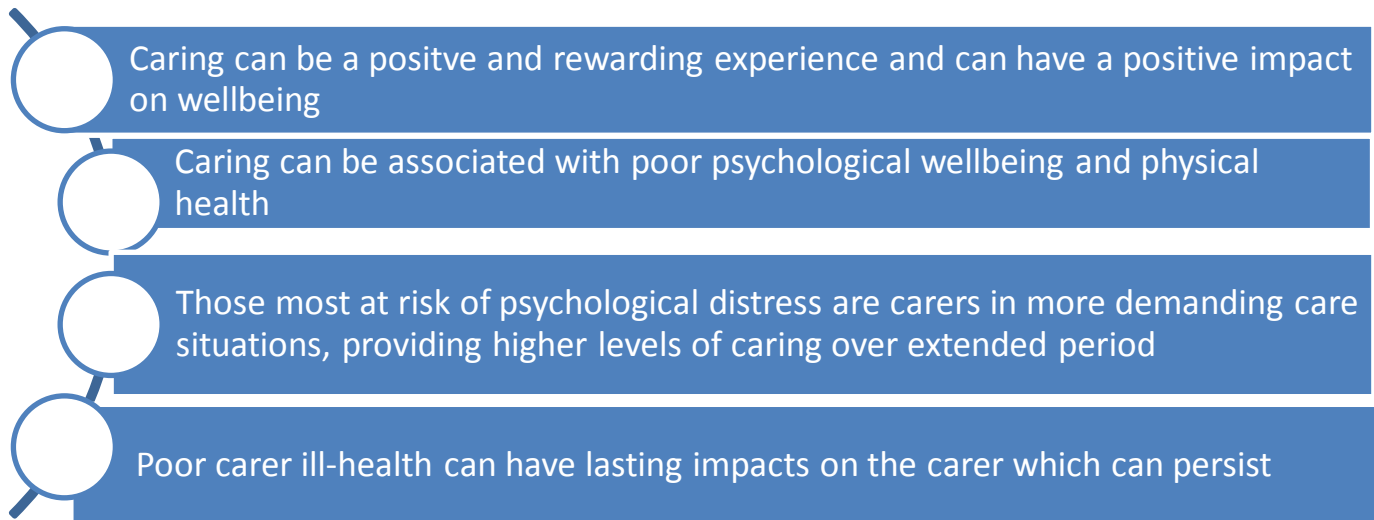




## **1.11. Conclusion**

Here we see the diversity of carers and their circumstances. Whilst a snapshot has found that 17% of the population in Scotland are caring, the number of us that will do so in a lifetime will be far higher. Caring intensity is on a spectrum; with most carers providing up to 20 hours; a quarter 20-49 hours and almost 20% over 50 hours. Most carers are women, but so too are many men; people of all ethnicities and ages contribute to caring. Carers are in all social groups but it is those in the most deprived areas that provide the most hours of caring. Young carers are more common in lone parent families and also contribute the most hours. The remainder of this report looks closer at carers, their welfare and needs and how they can be supported.

## 2. CHAPTER 2: CARERS' HEALTH AND WELLBEING



### 2.1. Introduction

This chapter explores the health and wellbeing of carers and outlines the impact that caring can have on wellbeing, drawing from a range of research and statistical surveys. It also explores how carers respond to their caring situation and role and draws out the implications for policy and practice.

It's important to understand the impact that caring can have on wellbeing to ensure that appropriate supports are put in place to maintain the health and wellbeing of the carer. It is also important to consider the influence on wellbeing arising from other individual characteristics and circumstances as caring may interact with and exacerbate existing inequalities. For example the last section identified that carers are over-represented in middle and older age groups. These carers may have age-related health problems which they have to manage alongside their caring responsibilities. Similarly the differences between men and women in psychological and mental wellbeing seen in the general population are heightened in the carer population (Hirst 2004). As in other similar studies, our analysis also shows that carers with more significant caring responsibilities are drawn disproportionately from more deprived areas. Caring may therefore stem from lack of choice and unfair circumstances and may be exacerbated by these existing inequalities (Hirst, 2004).

Poor carer health and wellbeing is concerning for both the carer and the cared for person. It can result in greater use of health and care services by the cared for person, particularly older people for example through admission to, and delayed discharge from, hospital; referral to a day hospital or geriatric unit; and admission to institutional care (Pearson et al., 2002; Armstrong, 2000; Williams and Fitton, 1991). Carer ill-health has therefore important implications for formal health and care sectors.

Coping with the stresses and demands, and a willingness to continue caring, are both associated with lower levels of stress in carers (McKee et al., 1999). Therefore it is widely recognised that it is important to maintain the health and wellbeing of carers to enable them to support the people they care for and maintain the quality of their relationships (Hirst 2004).

## 2.2. Caring can be a positive and rewarding experience

While much attention is focused on the negative aspects of caring, it is important to consider the positive aspects to understand the range of factors that can sustain carers in their role (Hirst, 2004). Caring can be a positive and rewarding experience for both carers and cared for person(s). It can also have a positive effect on wellbeing including hobbies, family life and friendships as well as mental health through the development of self-esteem and confidence (IRISS, Shared Care & Coalition of Carers in Scotland, 2012).

A recent Scottish survey of GP practice patients found that 70% (n= 16,107) of carers surveyed felt that they had a good balance between caring and other things in life (Scottish Government, 2014a). There is also evidence to suggest that there are wellbeing gains for some carers who provide a small amount of care. As discussed later in this chapter, recent analysis of SHeS found that those who provide up to 4 hours per week have higher mean mental wellbeing scores than non-carers (Scottish Government, 2015). Caring can therefore be a positive contributing factor towards wellbeing, providing that it is balanced with other activities.

Some argue that caring can't be seen as a one-dimensional experience, with either positive or negative attitudes: caring satisfaction can co-exist with stressful aspects of the care giving role (Lopez et al., 2005). This implies that interventions to support carers should not just focus on reducing the negative aspects of caring but also find ways to enhance the positive aspects (Bulducci et al., 2008).

Understanding how carers cope with their role is important for policy responses. There is no clear, linear explanation as to why some people experience mental distress while others faced with similar circumstances do not. Factors directly related to the caring situation can have an influence on broader aspects of an individual's life, such as employment and wider family relationships (Sörensen *et al*, 2006). A carer's subjective view of their ability to cope, can also influence mental health including the presence of depressive symptoms (Pinquart and Sörensen, 2003).

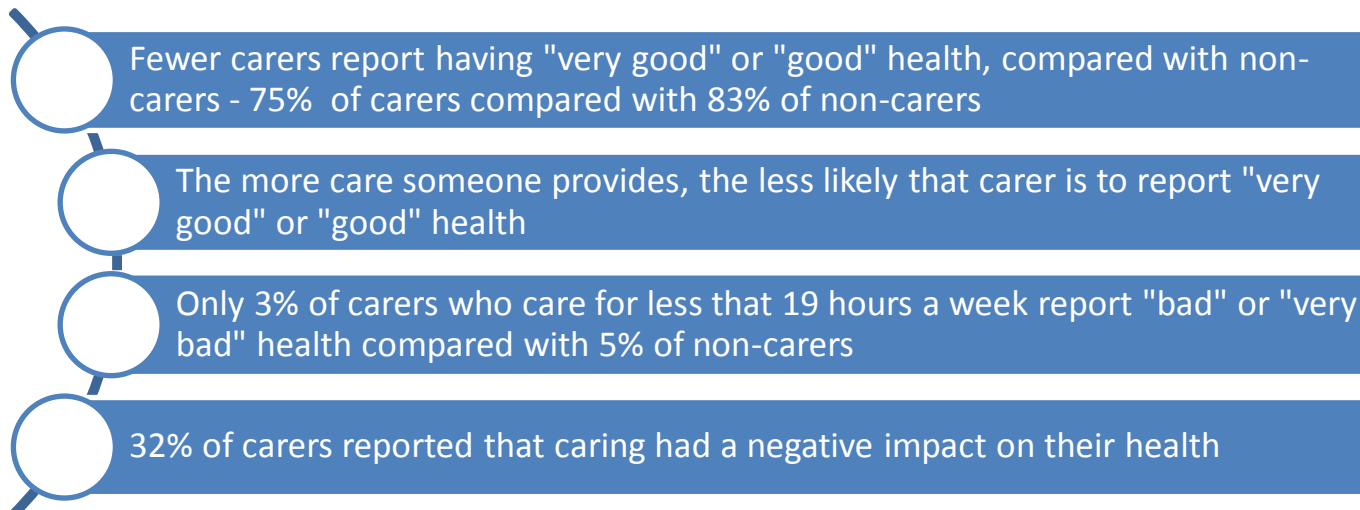
However, certain factors can 'moderate or mediate' the impact of stress on carers (Sörensen et al., 2006). In a study looking at carers of people with dementia, these factors included larger social networks, frequent social contact and the ability to arrange for assistance from friends (Sörensen et al., 2006). Carer enrichment can be experienced through closer familial and wider relationships as well as increased inner strength, confidence and self-esteem (Gelkopf and Roe, 2014; Green, 2007; Deeken, 2003).

Although caring be hugely rewarding, there is a large body of research which highlights carer burden and/or stress with negative consequences for carer health and wellbeing. The section which follows considers such research and discusses which groups of carers are most at risk.

## 2.3. A note about research

It's worth noting that research on carer wellbeing is vast and varied, ranging from subjective carer assessments largely derived from convenience sample surveys to studies comparing the health of carers with non-carers using probability population surveys and in some cases controlling for other potentially influential variables. The latter identify the factors associated with carer ill-health and provide useful insights into those most at risk from poor carer wellbeing. The former tend to comprise those with heavier caring responsibilities, however, they nonetheless provide useful insights into the demands of care giving from the perspective of carers themselves.

## 2.4. What do carers say about their health?

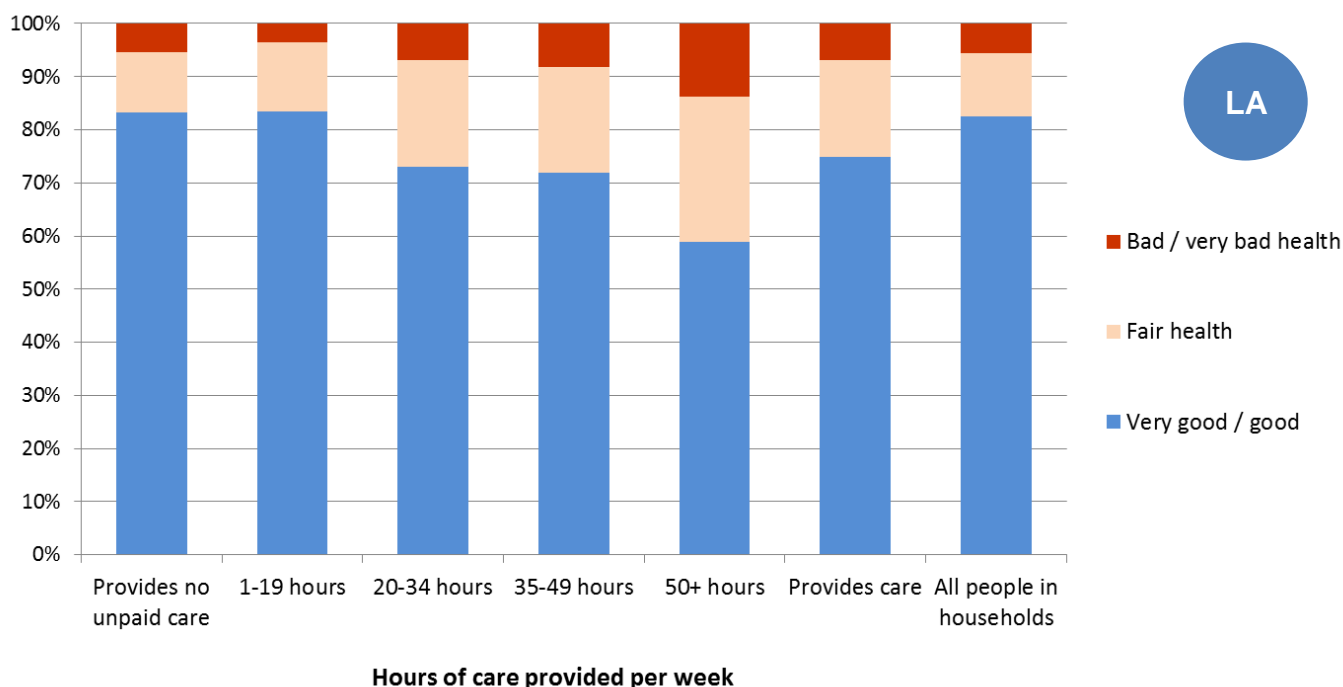


This section discusses findings from population and carer-specific surveys on carers' self-reported health.

Population surveys, such as Scotland's 2011 Census, provide useful evidence of the self-reported health of carers compared to non-carers. Scotland's 2011 Census shows that around 5% of the household population claim to have "bad" or "very bad" health. Overall, this percentage is higher for carers at 7%. However only 3% of those caring less than 19 hours a week claim to have "bad" or "very bad" health, while 14% of those who care for 50 or more hours a week report "bad" or "very bad" health.

Carers are less likely to report "very good" or "good" health – overall 83% of non-carers reported "very good" or "good" health compared to 75% of carers. This may partly reflect the fact that carers are likely to be older and may have age-related health problems.

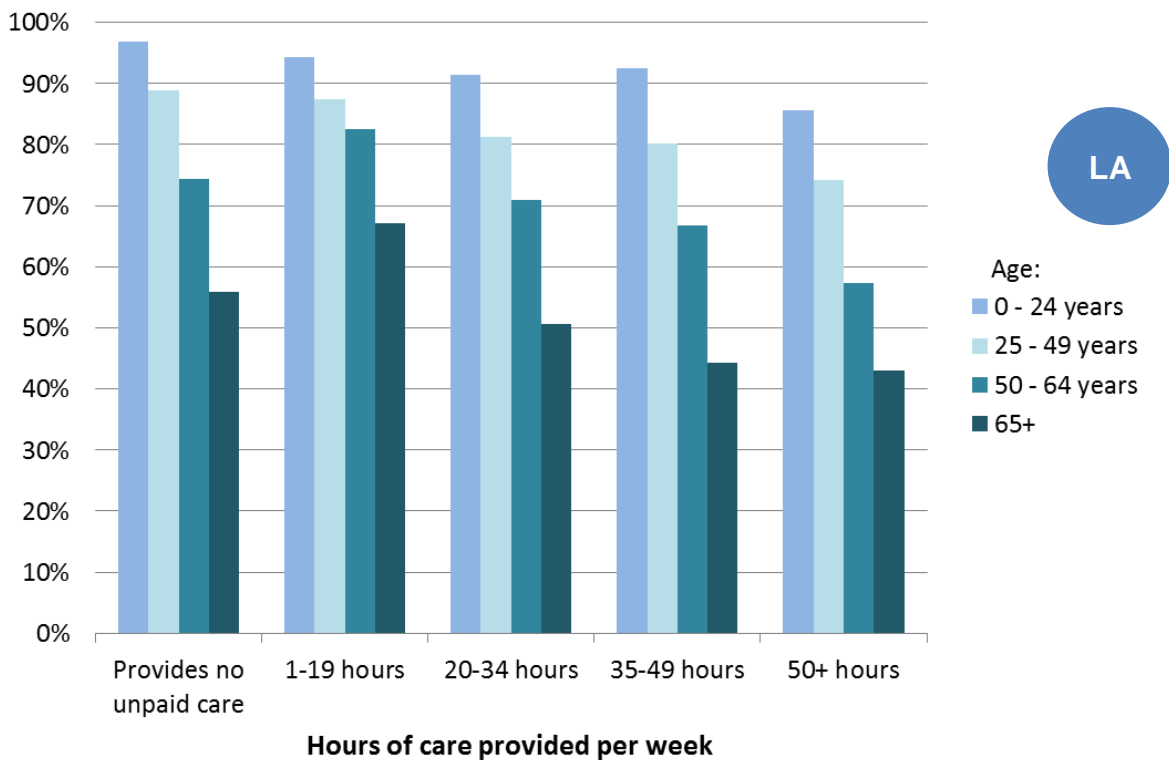
**Figure 24: Self-reported health of carers, by hours of care, 2011**



Source: Scotland's Census 2011

**Scotland's 2011 Census** also shows that the more care someone provides, the less likely they are to report having “very good” or “good” health and this is true for different age groups. For example, 97% of people aged under 25 who provided no care said that their health was “very good” or “good”. This compares with 94% of people who provide 1-19 hours of care a week and 86% of people who provide 50 or more hours of care each week. Interestingly, there was very little difference between the group caring for 20-34 hours per week and 35-49 hours per week for this age group.

**Figure 25: Percentage of carers who say their health is either “very good” or “good” by age and intensity of care, 2011**

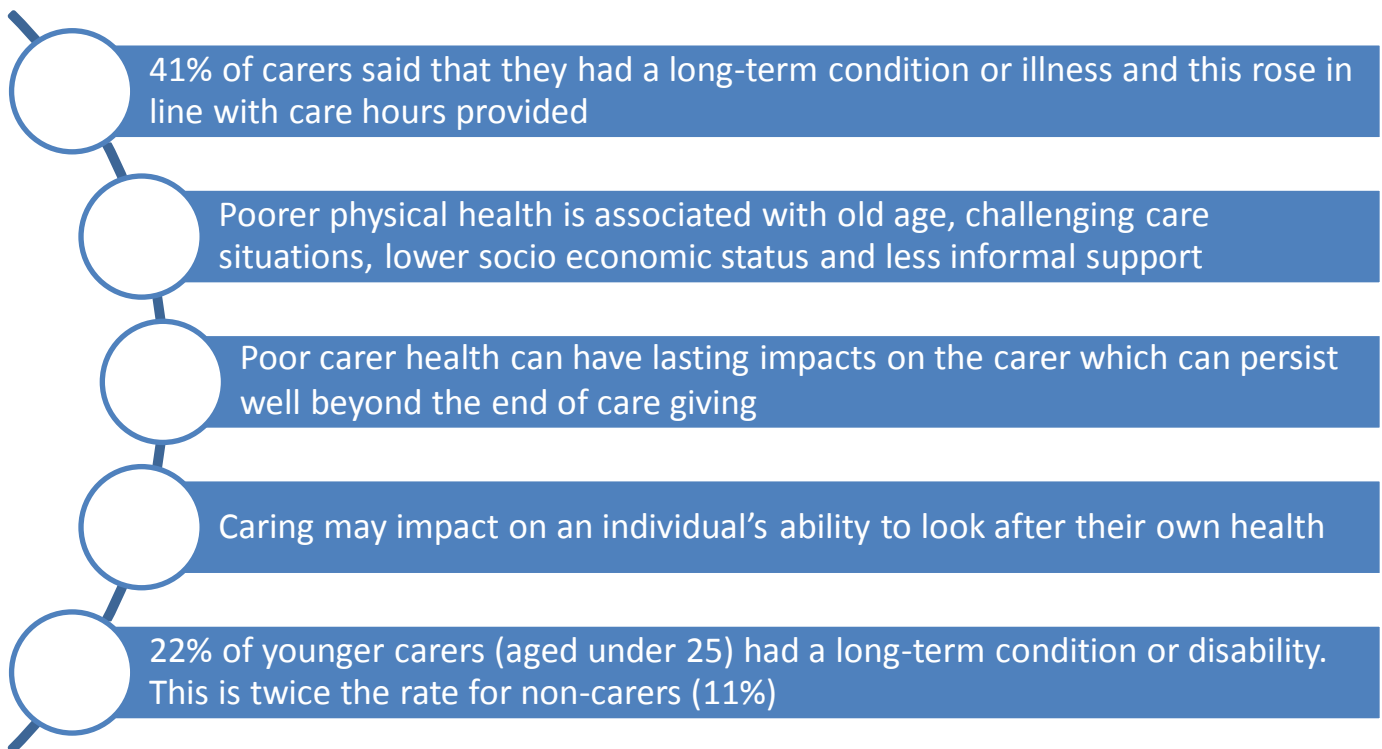


**Source:** Scotland's Census 2011

The figures presented here represent each person’s perception of their health. In some cases the Census may be completed by one person on behalf of the household and in this case it may be that person’s perception of the health of each member of the household. In addition it should be noted that people who require care may be more likely to be included in the non-carers category though this is not the case for everyone. Carers’ self-reported health deteriorates with age across all levels of caring intensity.

Carers often report poor health as a result of caring in surveys. For example in the recent Health and Care Experience Survey (HACE) of Scottish GP practice patients, 32% (n=4,903) of carers indicated that their health was negatively impacted by their caring role (Scottish Government, 2014a:69) and this rose to 41% in those providing 50+ hours of care.

## 2.5. Physical wellbeing of carers



This section considers the physical wellbeing of carers. Drawing on analysis of population surveys, it highlights the difference in health conditions between carers and non-carers. In addition, it explores the potential effects of caregiving on physical health. While considerable research has been conducted on the effects of care giving on psychological health, there has been less attention focused on the physical impacts of caring (Piquart and Sorensen, 2007). This may be because the evidence around negative impacts of caring on physical health is inconsistent. Studies examining physical associations with caring using objective health measures such as chronic illness, number of hospitalisations etc tend to show smaller associations than those using other physical and subjective indicators which may be because diseases examined are unlikely to be influenced by caregiving (Piquart and Sorensen, 2007).

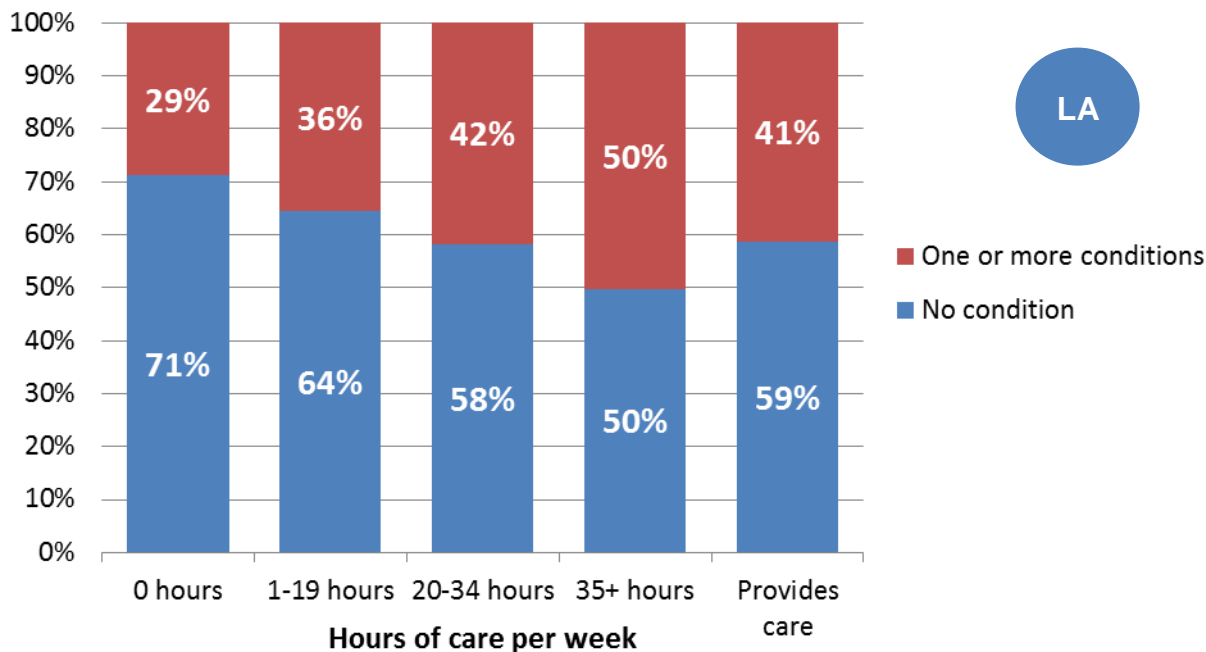
The **2011 Census** analysis shows that carers are more likely to have a long-term condition or illness than non-carers. Overall:

- 41% of carers had a long-term condition or illness; while only
- 29% of non-carers had a long-term condition or illness

As discussed earlier around carers' self-reported health, the reason for the difference could be partly explained by the fact that carers tend to be older and the likelihood of developing a long-term illness or disability increases with age. However this also raises the question of whether caring has an effect on health or whether people who have poor health are more likely to become carers (Parker and Lawton, 1994).

**Scotland's 2011 Census** shows that 41% (over 203,000 people) of the 492,000 carers said that they had a long term condition or illness.

**Figure 26: Percentage of carers who have one or more condition, by level of care, 2011**



Source: Scotland's Census 2011

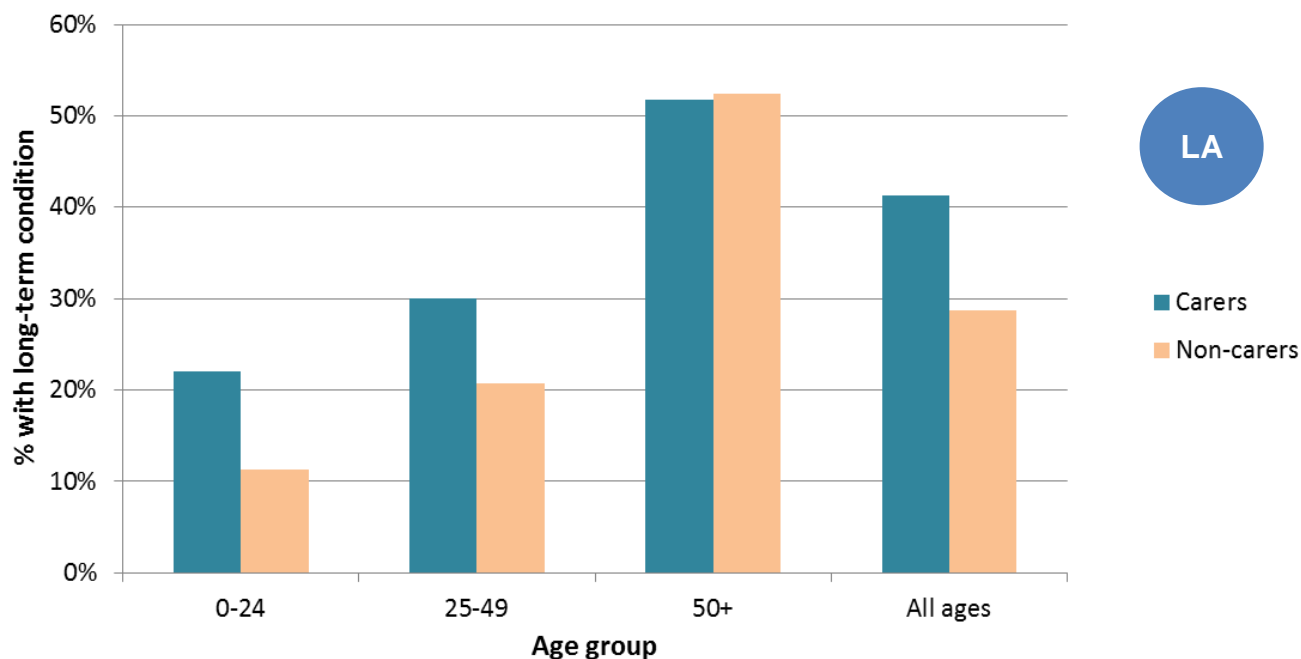
**Scotland's 2011 Census** shows that carers providing more hours of care each week are more likely to have a long-term illness or disability:

- 36% of carers who care for 1-19 hours a week have a long-term condition or disability;
- 42% of carers who care for 20-34 hours a week have a long-term condition or disability;
- Half of carers who care for 35 hours of more each week have a long-term conditions or disability.

It shows that when the proportion of people with long-term conditions is presented for different age groups, younger people are more likely to say they have a long-term condition or disability if they are a carer.

- 22% of young carers (aged under 25) had a long-term condition or disability. This is twice the rate for non-carers (11%).
- 30% of carers aged 25-49 had a long-term condition or disability compared to 21% of non-carers.
- For the 50+ age group there was very little difference between carers and non-carers; just over half had a long-term condition or disability.

**Figure 27: Percentage of carers and non-carers who have long-term conditions, by age, 2011**

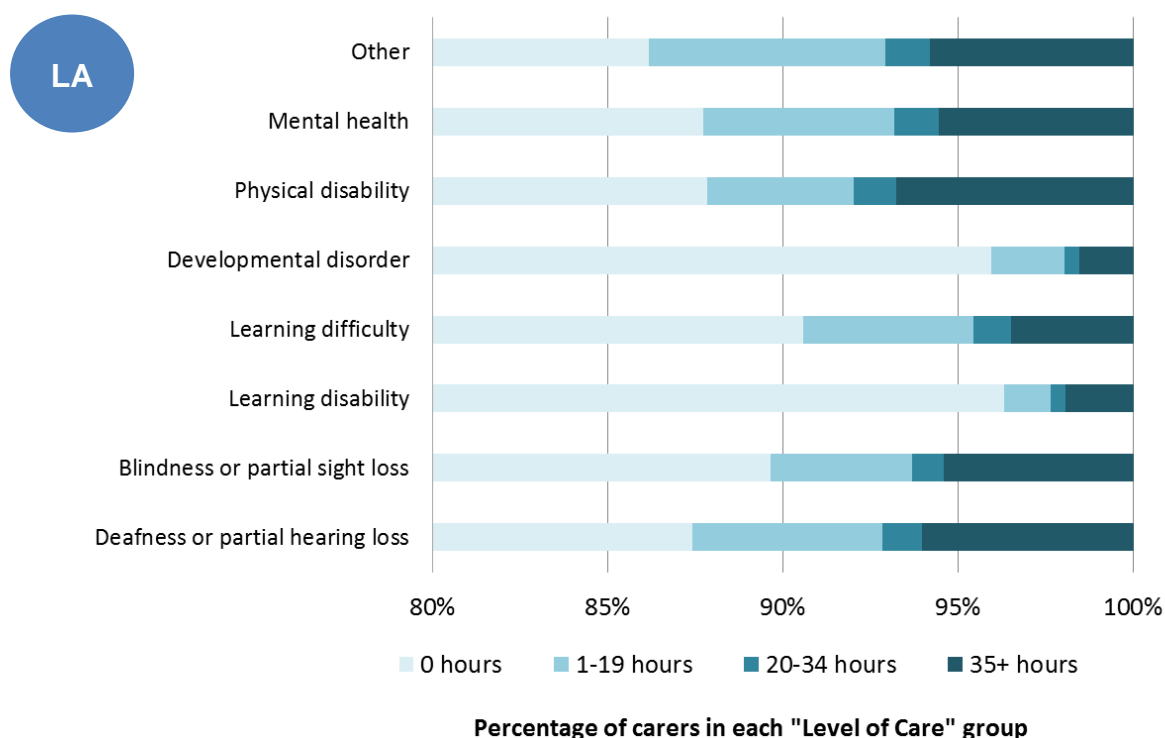


Source: Scotland's Census 2011

**Scotland's 2011 Census** shows the types of long-term conditions and disabilities experienced by carers and the amount of caring they do. For those carers who said that they had one or more long-term conditions:

- 16% were deaf or had partial hearing loss
- 16% had a physical disability
- 11% had a mental health condition
- 44% had some other condition not listed in the question categories

**Figure 28: Long-term conditions of carers, and level of care per week, 2011**



Source: Scotland's Census 2011



## 2.6. Findings from review of research on physical wellbeing of carers

Carers themselves report poor physical health in carer specific surveys and this rises the more hours spent caring. While these surveys are often based on convenience samples, comprising those with heavier caring responsibilities, they nonetheless provide insight into the demands of care giving from the perspective of carers themselves. For example a recent Scottish carers' survey found that 44 per cent of carers reported that caring had a negative impact on their physical health (IRISS Shared Care & Coalition of Carers, 2012). In the qualitative research which followed the survey, exhaustion and lack of sleep were widely reported among carers.

Studies examining the association between caring and other physiological 'non disease' indicators show differences between carer and non-carer populations. For example Vitaliano et al., (2003) meta-analysis found that carers took more medication for physical illness, had 23% higher levels of stress hormones and 15% lower antibody responses compared with non-carers (Vitaliano et al., 2003). Although this study did not analyse predictors of impaired physical health among carers, it is important given that prolonged stress hormones can increase the risk of hypertension and diabetes, and lower levels of antibodies can reduce resistance to viruses (Vitaliano et al., 2004).

There are many reasons why caring can have an impact on physical health. Some carers encounter particular risks of injury related to their caring activities, and emotional distress associated with care giving may increase susceptibility to physical illness (Brown and Mulley, 1997 and Dyck et al., 1999 cited in Hirst 2004). Increased stress can reduce antibodies and increase the likelihood of infection, and caring situations may lead to health behaviours such as poor diet and lack of exercise (Pinquart and Sorensen, 2007; Glaser and Kiecolt-Glaser, 2005).

Particular groups of carers are more at risk from poor physical health. In a meta-analysis of 176 studies on indicators of physical health, higher levels of care recipient behaviour problems were more consistently related to poor carer health than were care recipient impairment and intensity of care giving (Piquart and Sorensen 2007). Older age, lower socio economic status and lower levels of informal support were related to poorer health. Associations of caregiving stressors with health were stronger among older samples, dementia caregivers and men. The researchers concluded that "the negative effects of caregiving are mostly likely to be found in psychologically distressed caregivers facing dementia related distressors" (Piquart and Sorensen 2007: 132).

In the above meta-analysis, co-resident carers were more likely to experience stronger impacts on physical than on mental health (Pinquart and Sorensen, 2007). Living with the cared for person is likely to mean heavier caring responsibilities and fewer opportunities to take a break from caring (Zarit and Talley, 2013). Having a life alongside caring and being able to take a break is important to carer wellbeing. The absence of such can result in stress and the lack of ability for individuals to look after their own needs (Vitaliano et al, 2003). Co-resident care giving may also be detrimental to health-related habits such as getting sufficient sleep and engaging in healthy eating (Pinquart and Sorensen, 2007).

Studies which have examined the influence of spousal caring on health are mixed. The meta-analysis described above suggested that after controlling for age (since spousal carers are on average older) spousal effects on carer health are generally weaker. This may be because spousal caring is more typical than providing care for other people and because there are less likely to be conflicts between the caring role and other family roles (Pinquart and Sorensen, 2007).

However a number of other studies have shown that caring for a spouse is related to poor physical health. A US longitudinal study of a large sample of adults which modelled the chronicity of caregiving with respect to risk of Cardio Vascular Disease (CVD) onset, found that spousal caring

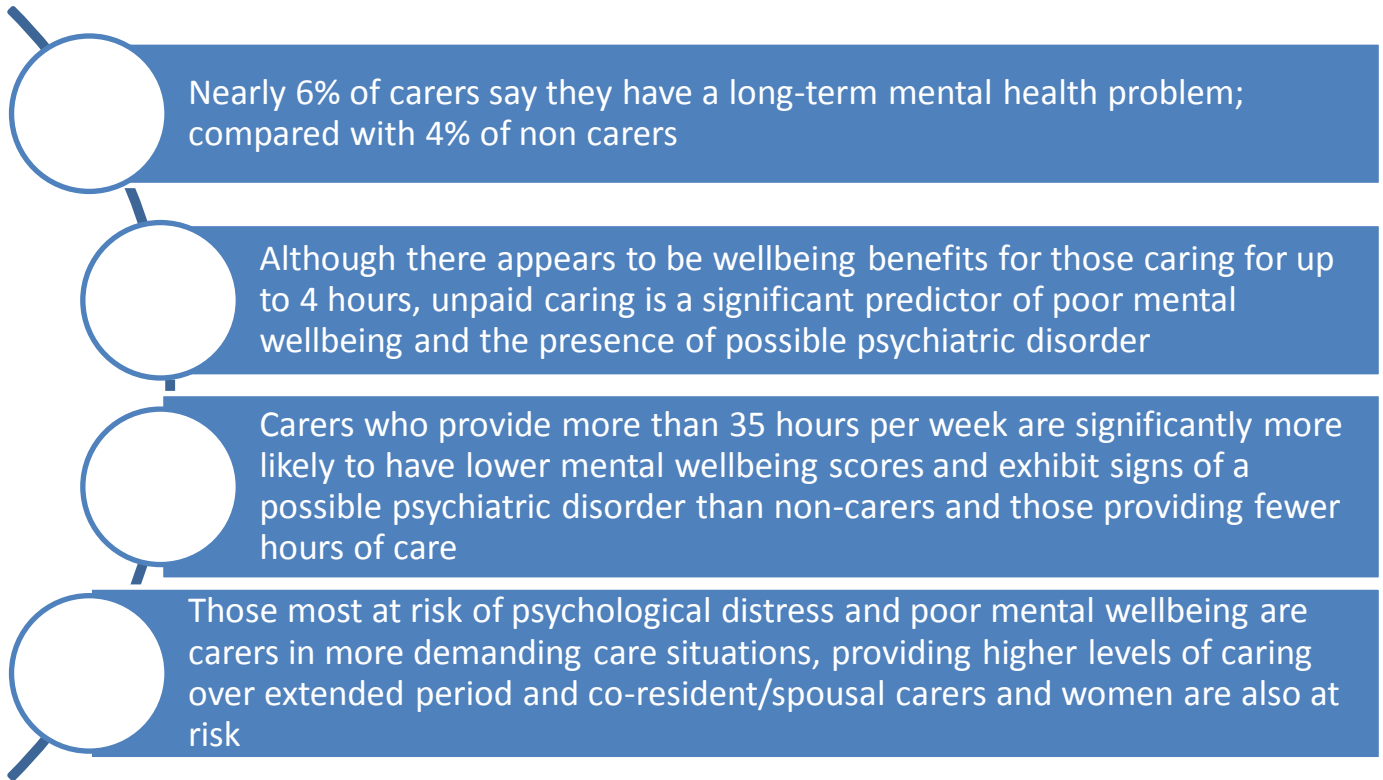
independently predicted risk of CVD. Care giving was associated with a modest, significant elevation in risk of CVD onset among spousal caregivers overall and a near-doubling of risk of CVD onset among spousal caregivers with high intensity caregiving (Capistrant et al., 2012: 3). It's not clear from the study whether this was a direct result of caring or indirectly from health behaviours.

## **2.7. Carers may find it difficult to look after their own health**

Carers may be unable to look after their own health to ensure the wellbeing of the cared for person. Arskey and Hirst (2005) found that women with heavy caring responsibilities were less likely to visit their GP than non-carers. It appears that some carers may treat their own health as secondary to the care recipients. Indeed carers themselves report that it's difficult to look after their own health – 58% of carers responding to the Carers UK survey indicated that they do less exercise since starting caring and 45% find it hard to maintain a balanced diet as a result of caring (Carers UK 2014).

Given that caring may impact on carers' physical health, albeit to a lesser degree than psychological wellbeing, interventions to support carers should also focus on physical health promotion such as providing opportunities for exercise, healthy eating, and preventative care visits (Pinquart and Sorensen, 2007; Patterson and Grant 2003 cited in Pinquart and Sorensen, 2007:132)

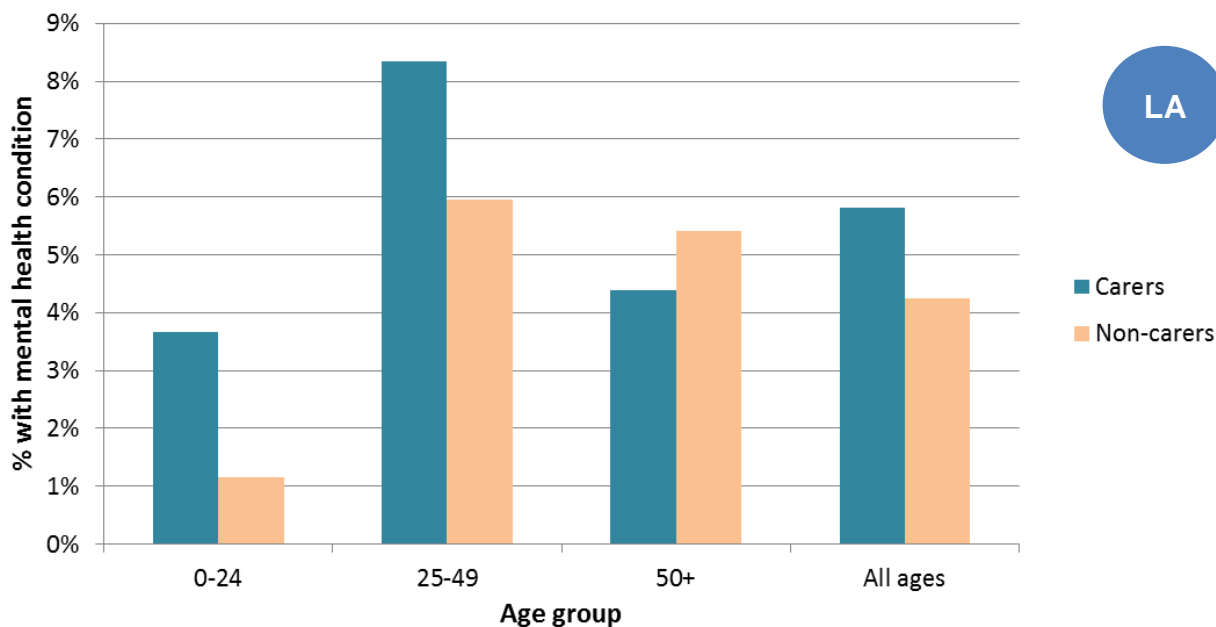
## 2.8. Carers and mental wellbeing



This section considers caring and mental wellbeing drawing on objective assessments of mental wellbeing status from population surveys as well as subjective assessment through carer focused studies.

**Scotland's 2011 Census** allows for analysis of specific long-term conditions or illnesses. Each person is asked whether they have any conditions which have lasted, or are expected to last, at least 12 months. One of the conditions listed is "Mental Health condition". Overall 4% of the population said that they had a mental health condition that had lasted or was expected to last at least 12 months but this was the case for nearly 6% of carers.

**Figure 29: Percentage of people with mental health condition, 2011**



**Source:** Scotland's Census 2011

Nearly 4% of young carers (aged under 25) said that they had a mental health condition compared with just over 1% of people in this age group who were not carers.

Over 8% of carers aged 25-49 said that they had a long-term mental health condition, compared with 6% of people in this age group who were not carers.

For the age 50 and over age group, the picture is different with 4% of carers saying they had a long term mental health condition (similar to the overall population rate) and over 5% of those not caring having a long-term mental health problem.

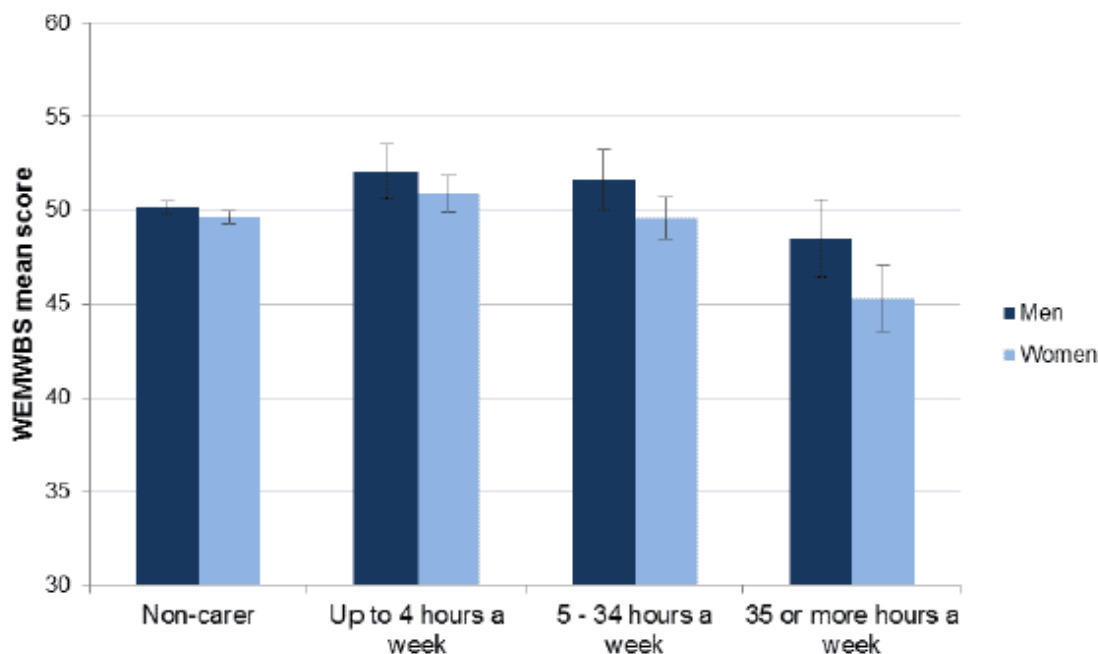
## 2.9. Mental wellbeing and psychiatric disorders

A recent published analysis of SHeS found that mental wellbeing scores were lower among adults who provide unpaid care indicating a lower level of mental wellbeing. SHeS uses the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) to measure mental wellbeing and the General Health Questionnaire (GHQ) to identify individuals showing signs of the presence of a possible psychiatric disorder; GHQ12 scores of 4 or higher indicate the signs of the presence of a possible psychiatric disorder. However those who provide a small amount of care (0-4 hours) per week scored more positively on both measures of mental health and wellbeing than non-carers. Those caring 35+ hours per week were significantly more likely to have lower wellbeing scores and exhibit signs of the presence of a possible psychiatric disorder than other groups of carers and non carers (Scottish Government, 2015). More detailed findings from this analysis are outlined below.

The mean score on the WEMWBS scale in 2012/2013 was 50.3 for men and 49.6 for women. Mental Wellbeing is significantly associated with age, with mean scores high in the youngest adults age groups, dropping among adults aged 45-54 (48.9), rising to a peak between aged 65 and 74 (51.1) and then dropping off again among the over 75s (49.5). The analysis comparing carers and non-carers controlled for age to take account of the age profile of carers.

Among carers who provide support for more than 35 hours per week, WEMWBS scores (46.4) were considerably lower than among non-carers (49.9). However, carers who provide a small amount of care, in particular those who provide up to 4 hours per week, showed a higher mean WEMWBS score (51.5) than non-carers, indicating a higher level of mental wellbeing.

**Figure 30: WEMWBS mean scores, by sex and hours of unpaid care, 2012/2013**

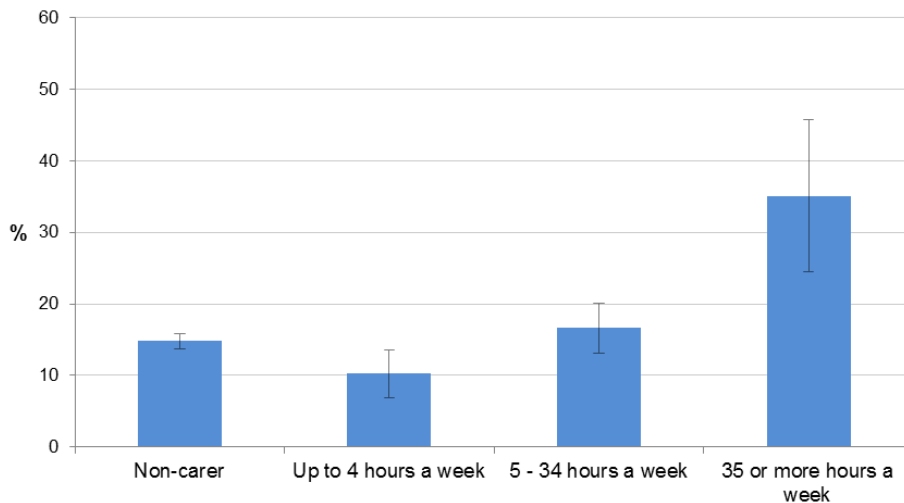


**Source:** Scottish Health Survey 2012/2013

SHeS also uses the General Health Questionnaire (GHQ) to identify individuals showing signs of the presence of a possible psychiatric disorder. Carers who provide more than 35 hours per week (35%) were significantly more likely to exhibit signs of the presence of a possible psychiatric disorder than non-carers (15%), carers who provide 0-4 hours (10%) or carers who provide 5-34 hours (17%) of care per week. The difference in the proportion exhibiting signs of the presence of a possible

psychiatric disorder, comparing carers providing up to 4 hours per week compared to non-carers, was also statistically significant (Scottish Government 2015)

**Figure 31: Proportion of adults with GHQ12 scores of four or higher, by hours of unpaid care, 2012/2013**



**Source:** Scottish Health Survey 2012/2013

The above SHeS analysis shows that although there appears to be wellbeing benefits for those caring for a small number of hours each week, unpaid caring is a significant predictor of low mental wellbeing and the presence of possible psychiatric disorders after controlling for other related factors. In addition women who are heavy carers are at risk of poor mental wellbeing. Specifically, women who carry out 35 or more hours of unpaid care were more likely to have a low WEMWBS score compared to those who do not provide any unpaid care. Although the same results were not significant for male carers, in GHQ12, men and women in an unpaid caring role for more than 35 hours per week had greater odds, compared to non-carers, of having a score of four or higher, indicating the presence of a possible psychiatric disorder. GHQ12 results are also marginally significant among women in a caring role for 5-34 hours per week.

Furthermore, women who provide 35 hours or care or more per week were significantly more likely than non-carers to respond negatively for nine of the fourteen WEMWBS component questions. However this was most notably significant for the component 'feeling relaxed' (Scottish Government 2015).

These SHeS findings replicate other similar studies. For example Hirst (2004) found that after taking account of other health determinants, those providing at least 20 hours of care per week were twice as likely to experience psychological distress compared with non-caregivers (Hirst 2004). The study also found that carers' participation in caregiving over time, the number of care episodes, and significant increases in the intensity of caring activities were also associated with a raised risk of emotional and mental health problems in carers.

These findings are reinforced in qualitative studies and surveys of carers involving subjective assessments of impacts. 50% of carers responding to a recent Scottish carers' survey indicated that caring had impacted on their mental wellbeing (IRISS Shared Care & Coalition of Carers in Scotland, 2012).

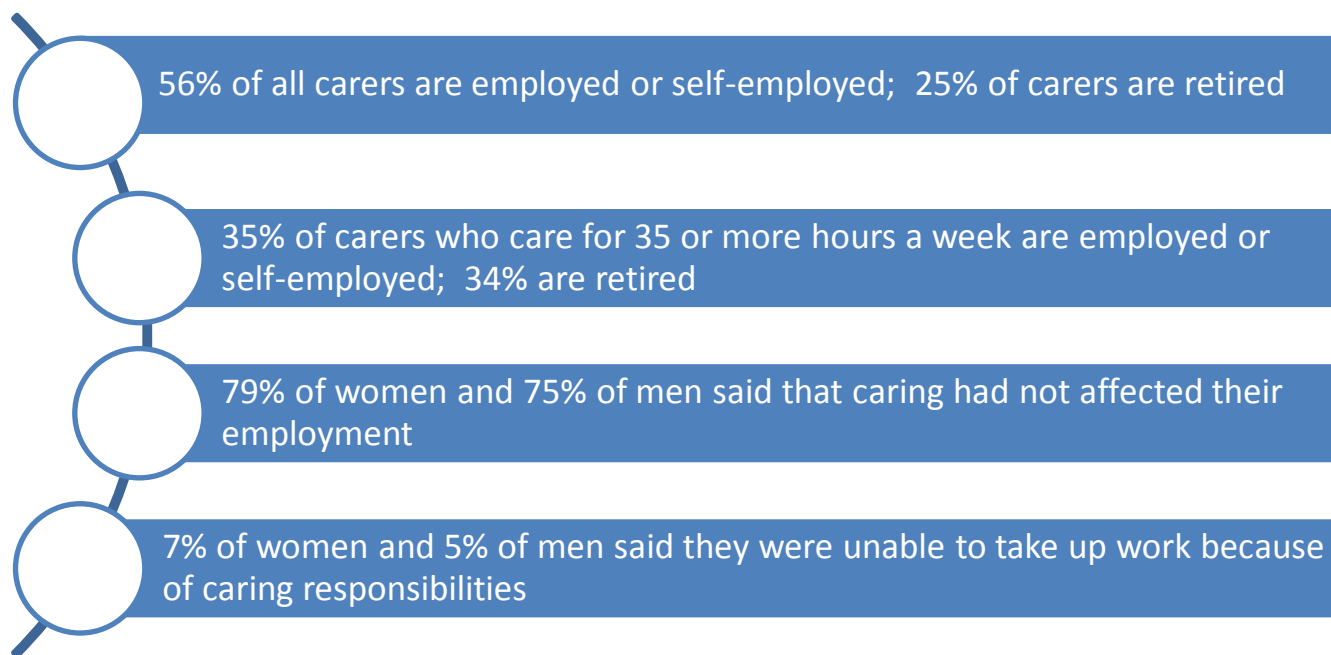
Co-resident carers are particularly associated with additional health problems (Hirst, 2004). As described earlier, such carers tend to provide more demanding physical and personal care and to be sole carers and least likely to be receiving any support (Parker, 1992 cited in Hirst, 2004). In contrast out-of-household care tends to be less intensive focused more on practical support such as shopping, housework etc (Parker and Lawton, 1994). Indeed non-resident carers who support a friend or neighbour often present better health than non-carers.

Taken together these findings suggests that those most at risk of psychological distress are carers in more demanding care situations, providing higher levels of caring over an extended period.

## **2.10. Conclusion**

Caring can be an extremely rewarding experience. However the evidence suggests that while there appears to be wellbeing gains for some carers, these diminish as caring responsibilities increase. In such circumstances, carers often experience additional health needs which can persist beyond the care giving role. Carers in more complex and demanding caring situations are most at risk of experiencing poor mental and physical health than other carers and the wider population. Although these carers may represent a minority of the carer population, they nonetheless provide the bulk of unpaid care. Taken together the evidence suggests the need to provide adequate support for carers, particularly those most at risk of poorer health to ensure their wellbeing and sustain them in their role. Chapter 4 considers the nature, purpose and effectiveness of support for carers.

### 3. CHAPTER 3: CARERS' EMPLOYMENT, HEALTH AND FINANCE



#### 3.1. Introduction

In this section we consider the survey findings on carers' employment status and their health.

We know from research that many working age carers are in employment, primarily as an economic necessity (Yeandle, et al., 2007b). Economically, carers continuing in employment can be important for their current income and their longer term finances due to the impact on pension contributions of stopping work. As expected there is an inverse relationship between caring and employment and one can impact on the other, for example those providing fewer hours care are more likely to be in employment, in some cases because work is used as a way to resist being drawn into more time on caring (King & Pickard, 2013).

Many carers leave employment to meet the demands from caring. It is recognised that employment falls when caring is for over 20 hours per week (Carmichael, et al., 2010) and recent research indicates that this is case when carers aged 50 plus provide 10 hours plus care (King & Pickard, 2013). This is not distributed evenly and socio-economic factors play a role i.e. less well-educated, older carers and those in poorer health are at increased likelihood of exiting the labour market (King & Pickard, 2013). It should also be noted that carers themselves can have health problems that affect their ability to sustain employment (Yeandle, et al., 2007a).

Whilst paid work can be important it is not a guarantee of freedom from financial difficulties. One third of carers in employment in a recent study reported they are struggling financially (Yeandle, et al., 2007b). People providing the most intensive care (20 hours and more) are more likely to be in lower level occupations (King & Pickard, 2013).

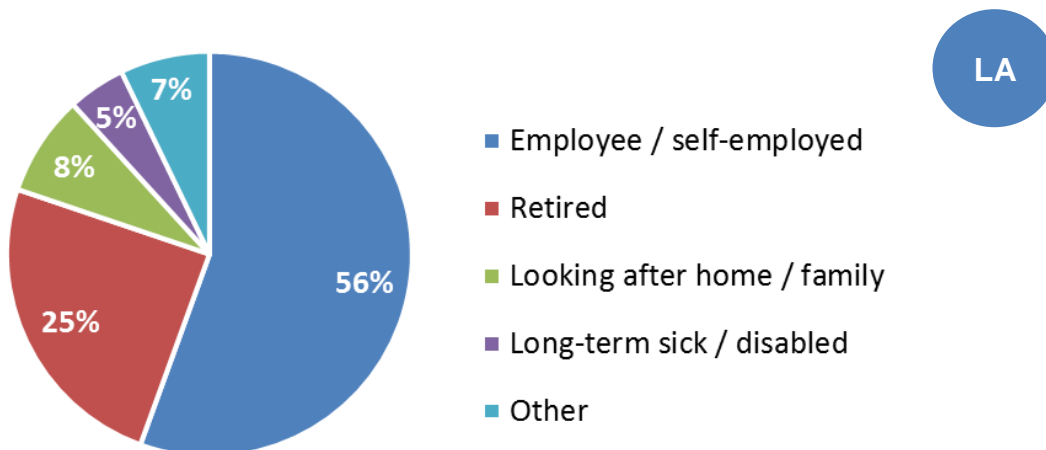


### 3.2. Economic status of carers

Scotland's 2011 census shows that overall 11% of people aged 16 and over are carers (over 482,000 people in Scotland).

- 56% of these carers are employed or self-employed;
- 25% are retired;
- 8% are looking after home or family;
- 5% are long-term sick or disabled themselves; and
- 7% are doing other things, most of which are students or unemployed.

Figure 32: Employment status of carers (482,000 people aged 16+), 2011

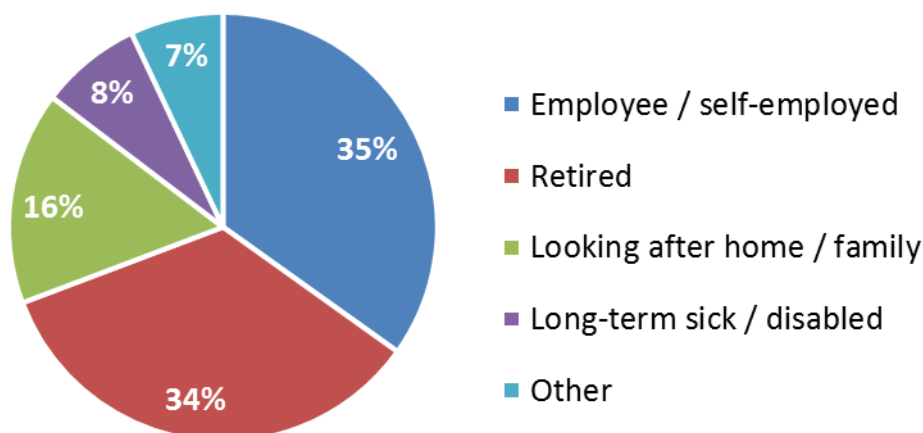


Source: Scotland's Census 2011

Scotland's 2011 census shows that nearly 4% of the population (over 171,000 people) provide 35 hours or more a week of care, equivalent to working full-time.

- Over a third of these "full-time" carers (who care for 35 hours or more a week) are also employed or self-employed;
- A third are retired;
- 16% look after home and family;
- 8% have themselves a long-term illness or disability; and
- 7% are students, unemployed, or doing other things.

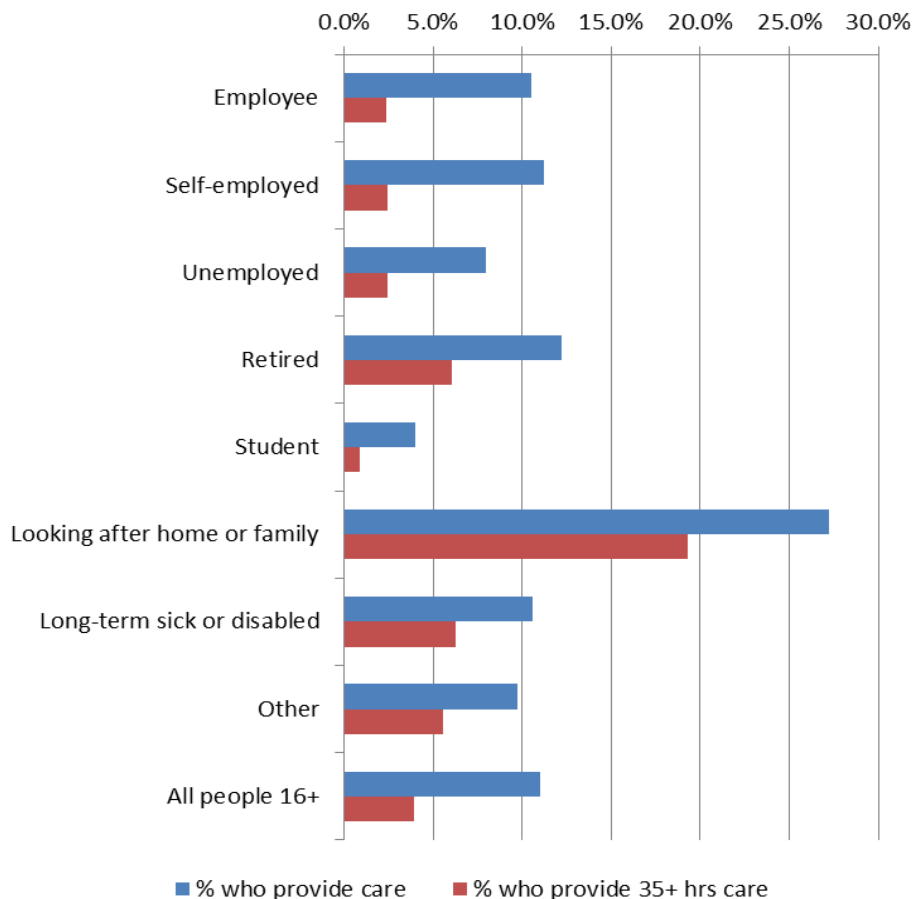
**Figure 33: Employment situation of 171,000 people who provide 35 hours or more care each week, 2011**



Source: Scotland's Census 2011

Perhaps not surprisingly, people who said they are looking after home and family in **Scotland's 2011 Census** are the most likely to be a carer: Over 27% are carers and over 19% care for 35 hours or more a week. Retired people are also more likely to provide care: Over 12% are carers and 6% provide 35 hours or more each week. Students are the least likely to be carers: only 4% of students are carers, similar to the child rate of caring and less than 1% care for 35 or more hours per week.

**Figure 34: Proportion of working age population who provide care, by employment status**

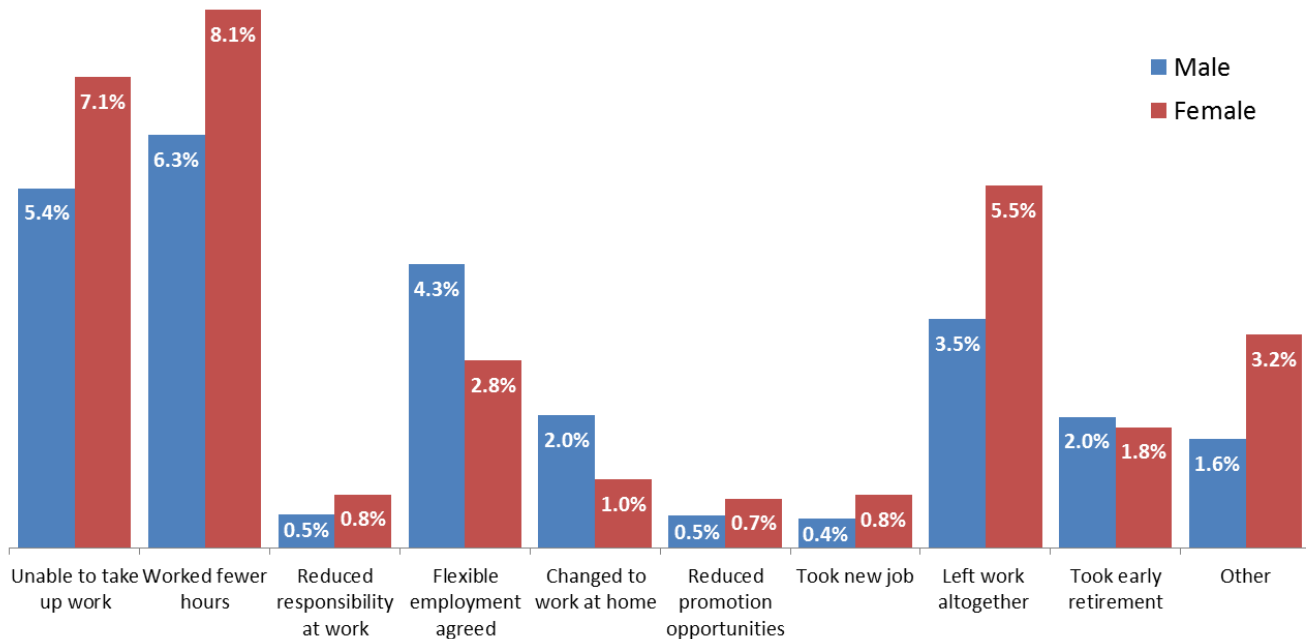


Source: Scotland's Census 2011

### 3.3. Caring impact on employment

**SHeS** asks people whether caring has had any impact on their employment. Overall 79% of women and 75% of men said that caring had not affected their employment. Over 65s and 16-24 year olds were most likely to say that caring had not impacted on employment so this may be because they had retired from work or because they had never had a job.

**Figure 35: Percentage of people aged 16+ who said that caring had an impact on their employment, 2012/2013**



**Source:** Scottish Health Survey 2012/2013

Where people did say that it had had an impact on their employment, in most cases a larger proportion of women rather than men were affected. This in part explains the higher proportion of women carers of working age not in employment.

- 7% of women and 5% of men said they were unable to take up work because of caring responsibilities
- 8% of women and 6% of men said they worked fewer hours in order to balance their caring with work commitments
- 5% of women and 3% of men said they had left work altogether because of caring responsibilities
- A small percentage (less than 1% in all cases) said that they had reduced their responsibilities at work, caring had reduced their promotion opportunities or caring had resulted in them taking a new job.

Areas where men were more likely than women to feel the impact of caring were:


- 4% of men and 3% of women agreed more flexible employment terms with their employer to enable them to continue with caring
- 2% of men and 1% of women changed to working at home because of caring commitments
- 2% of men and just under 2% of women took early retirement because of caring responsibilities.

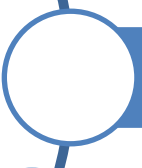
Research indicates that carers, who want to, should be supported better to remain in employment (King & Pickard, 2013). Currently much of this support is by family and friends, although finding time to spend with them can be difficult for carers in employment (Yeandle, et al., 2007a).


Formal services can enable carers to continue working (Yeandle & Wigfield, 2011) but carers experience difficulty in obtaining the appropriate, timely services, even when skilled and helpful staff are involved (Yeandle, et al., 2007a).

How employers treat staff with caring responsibilities can make a difference. Some carers report that employers are supportive, accepting of emergency absences and planned changes in working patterns, although others have a very different experience (Yeandle, et al., 2007a).

### 3.4. Carers, health and employment

- 

Carers who are economically active report better health than those who are not
- 

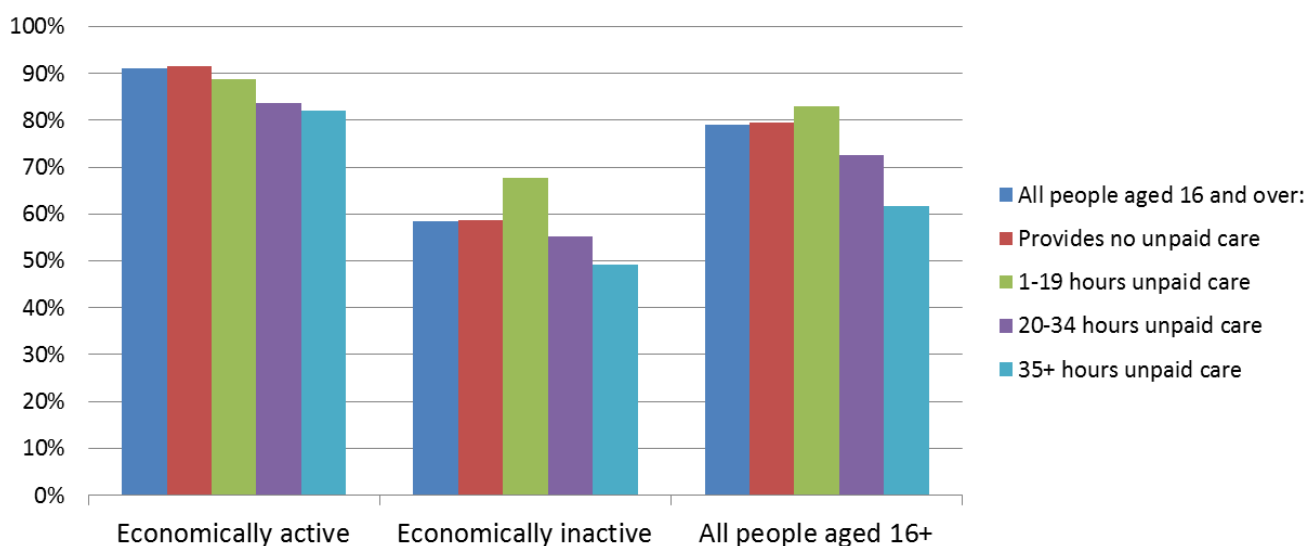
People who care for 35 hours a week or more are least likely to say their health is 'good' or 'very good'
- 

People aged 65+ who care for up to 19 hours a week report by far the best health for that age group

People who are economically active (this includes people in work, self-employed, looking for work) are much more likely to say their health is “good” or “very good” than people who are economically inactive (this includes people who are retired, looking after home and family, long-term sick or disabled and students).

92% of people who are economically active and don't provide care say that they have good or very good health. This percentage reduces as people provide more care and only 82% of those who provide 50 or more hours of care say that they have “good” or “very good” health.

**Figure 36: Percentage of people who say their health is very good or good, by economic status, 2011**

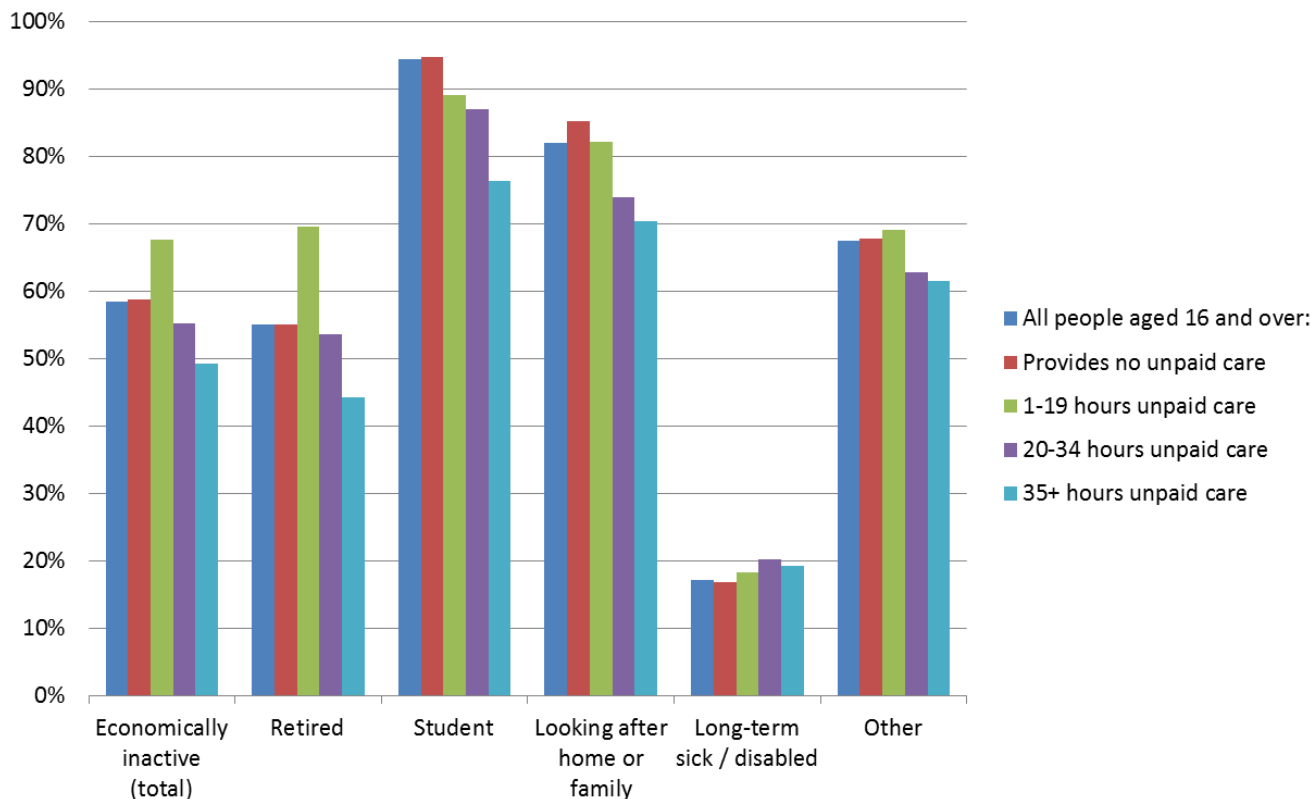


Source: Scotland's Census 2011

When looking at people who are economically inactive the picture is slightly different with those who provide up to 19 hours of care a week having the best health – 68% say their health is “good” or “very good”.

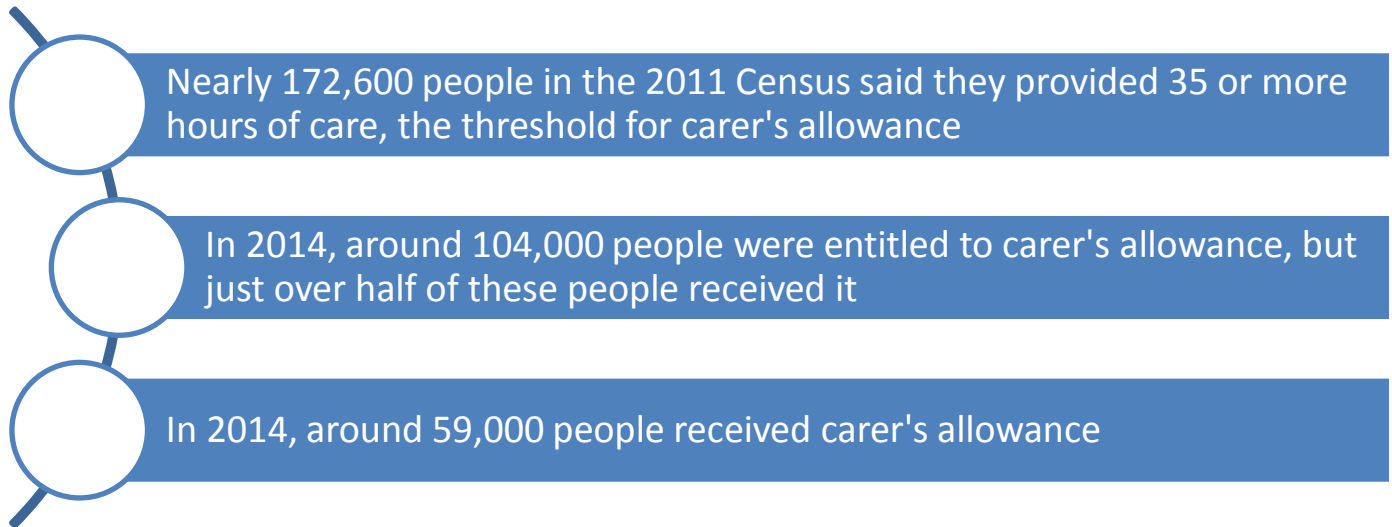
Looking at chart 37, it is clear that this is true mainly for retired people who provide care. Interestingly people who are long term sick or disabled seem to show improving health, the more hours that they care each week. Overall only 17% of people in this category say that their health is “good” or “very good” but this increases to 20% of people who provide 20-34 hours of care and 19% of people who provide 35 hours of care or more.

**Figure 37: Percentage of people who say their health is very good or good, by employment status, 2011**



Source: Scotland's Census 2011

### 3.5. Carer's allowance

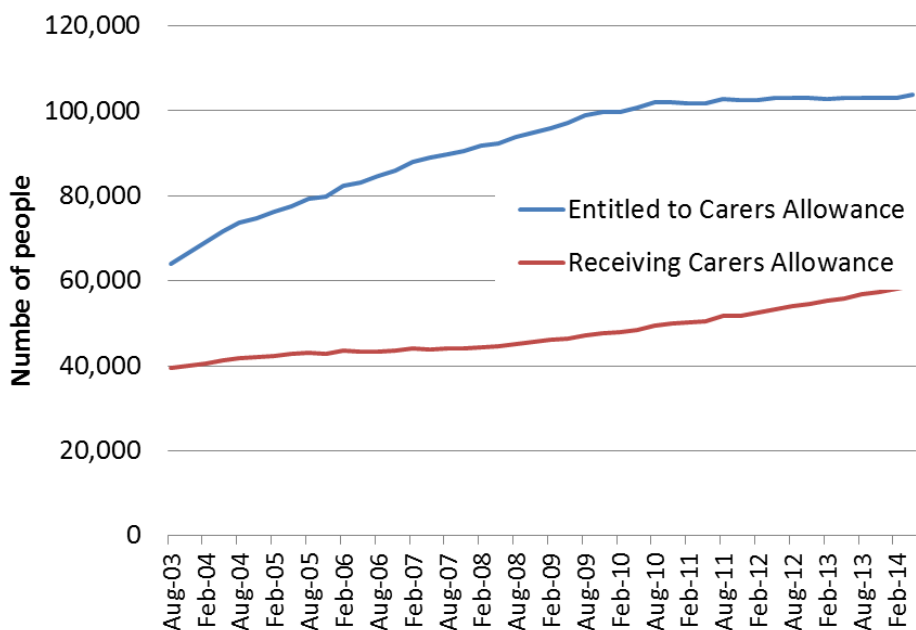


Surveys of carers, which tend to involve those with more intensive caring responsibilities, highlight issues such as debt associated with caring. Carers may face additional financial burdens because of their caring responsibilities through for example higher utility bills, modifications to the home to meet the needs of the cared for person. In a recent UK survey of carers, four in ten carers indicated that they had been in debt as a result of caring and five in ten felt that financial worries were affecting their health (Carers UK, 2013).

Carers who are aged 16 or over and spend at least 35 hours a week caring for someone with substantial caring needs can claim carer's allowance depending on their level of earnings. Carer's allowance is taxable and can also be affected by other benefits such as Universal Credit and Pension Credit.

**Scotland's 2011 Census** shows that nearly 172,600 people provided 35 or more hours of care each week which is the threshold for carer's allowance. **Department for Work and Pensions (DWP)** statistics show that in 2014, around 104,000 of the people who applied for carer's allowance were entitled to it and around 59,000 people actually received carer's allowance.

**Figure 38: People entitled to, and receiving, Carer's Allowance, 2003-2014**



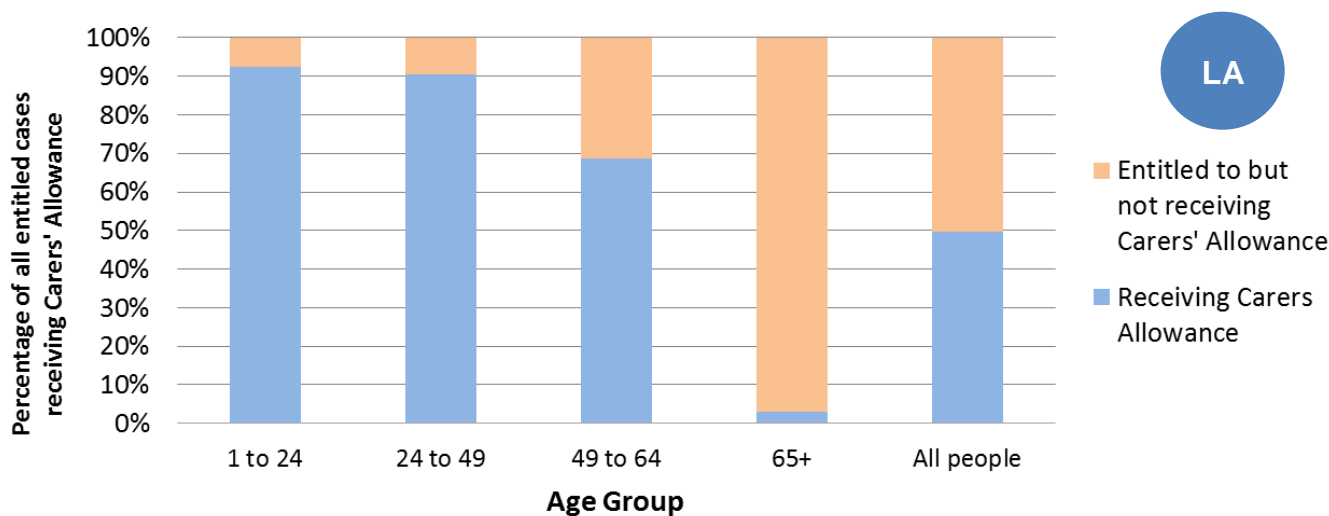
Source: Department for Work and Pensions (2003-2014)

The number of people entitled to carer's allowance in Scotland increased steadily between 2003 and 2010 but has remained fairly level since then at just over 100,000 people.

The number of people receiving carer's allowance has been rising steadily since 2003 to 59,000 people in May 2014.

Currently around 57% of people who are entitled to carer's allowance actually receive it. People may not receive carer's allowance because they are already receiving other benefits such as pension credit. Over 65s are the most likely to not receive carer's allowance when they are entitled to it.

**Figure 39: People in Scotland entitled to, and receiving, Carer's Allowance, by age, 2011**



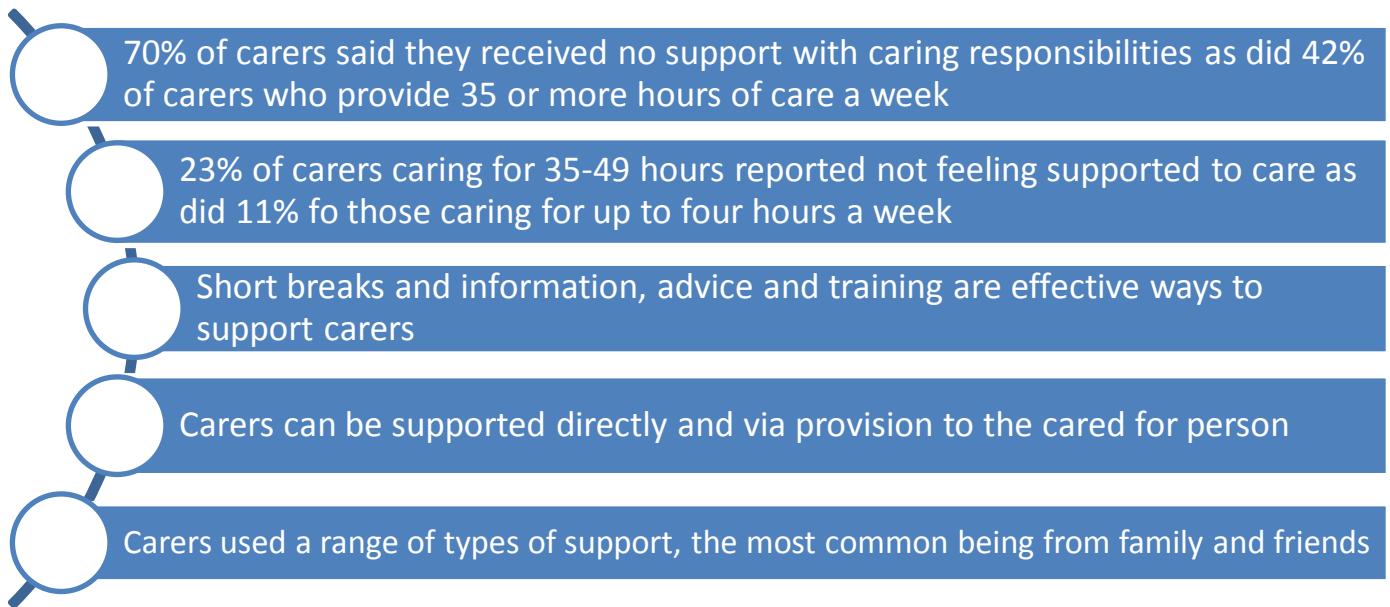
Source: Department for Work and Pensions (2011)



### **3.6. Conclusion**

As with the wider population, more carers of working age are in paid employment. As well as ensuring a break from caring and providing a sense of fulfilment, employment offers a source of income in the short and longer term. However employment alone does not ensure adequate income and financial security. A large minority of fulltime carers are in employment, and many of those caring for over 20 hours are in lower level occupations. Caring can result in carers reducing the hours they work or leaving employment. For some this is the right move. For others timely support would have enabled them to continue in employment.

## 4. CHAPTER 4: SUPPORT FOR CARERS



### 4.1. Introduction

Generally the purpose of support is to reduce the negative psychological, physical and financial effects that caring can have on a carer. The support is often intended to promote carers' wellbeing which can also permit them to continue to provide care and even prevent older people's admission to institutional care (Yeandle & Wigfield, 2011; Seddon, et al., 2010; Pickard, 2004).

There are many forms of carer support including; information, advice and training; practical support; counselling; short breaks and finance. Carers receive support from numerous sources; family, friends and other carers; paid staff; volunteers and via the state. This chapter presents data from two Scottish Government surveys on the proportion of carers in receipt of, and their needs for, support. This is complimented by findings from a research review on the effectiveness of short breaks and information provision for carers and some of the difficulties for carers in accessing support.

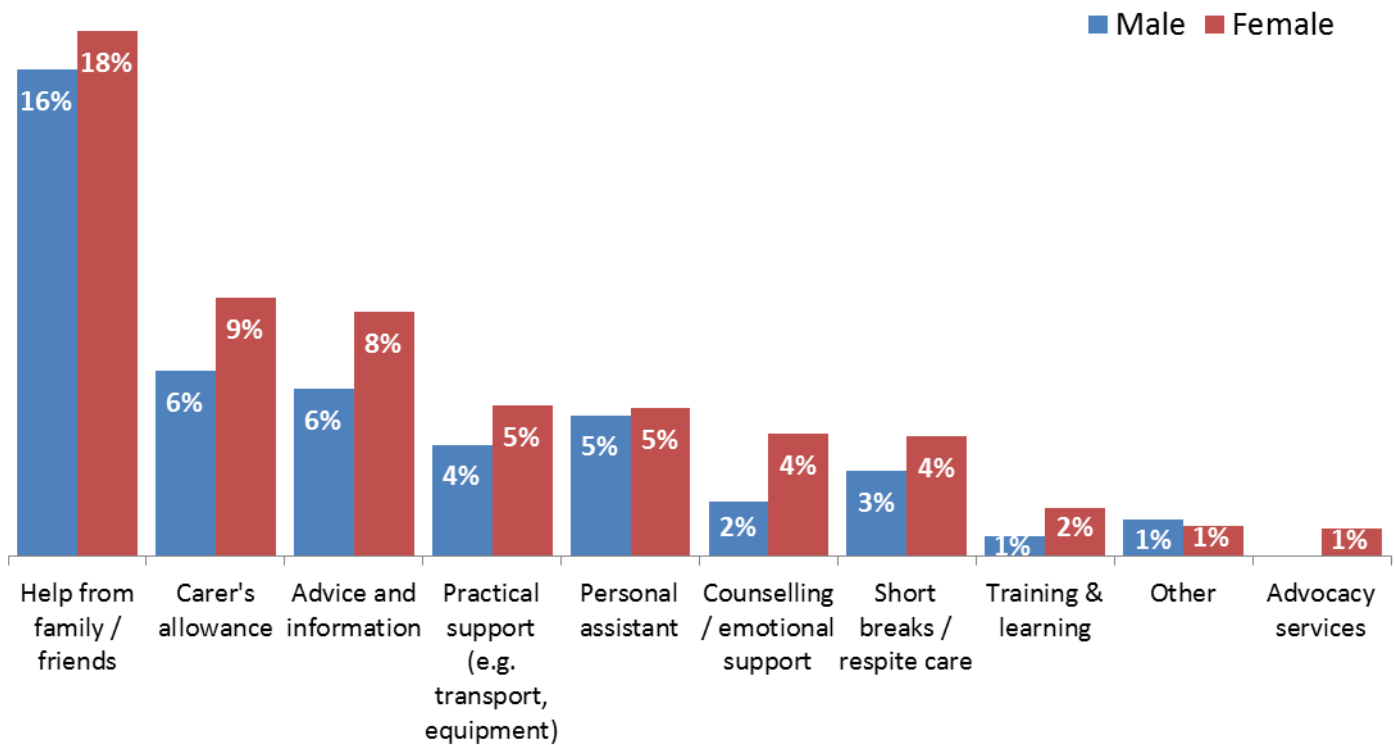
### 4.2. Support received by carers

**SHeS** shows that around 70% of carers said that they received no support with their caring responsibilities. This was slightly higher for men with 72% saying they received no support compared with 68% of women. The likelihood of support did increase with number of hours of care; 42% of carers providing 35 hours or more of care say that they did not receive any support.

The **SHeS** shows the range of support received and the source. The single greatest source was family and friends followed by carer's allowance and then advice and information. In all cases, women were more likely to have support than men:

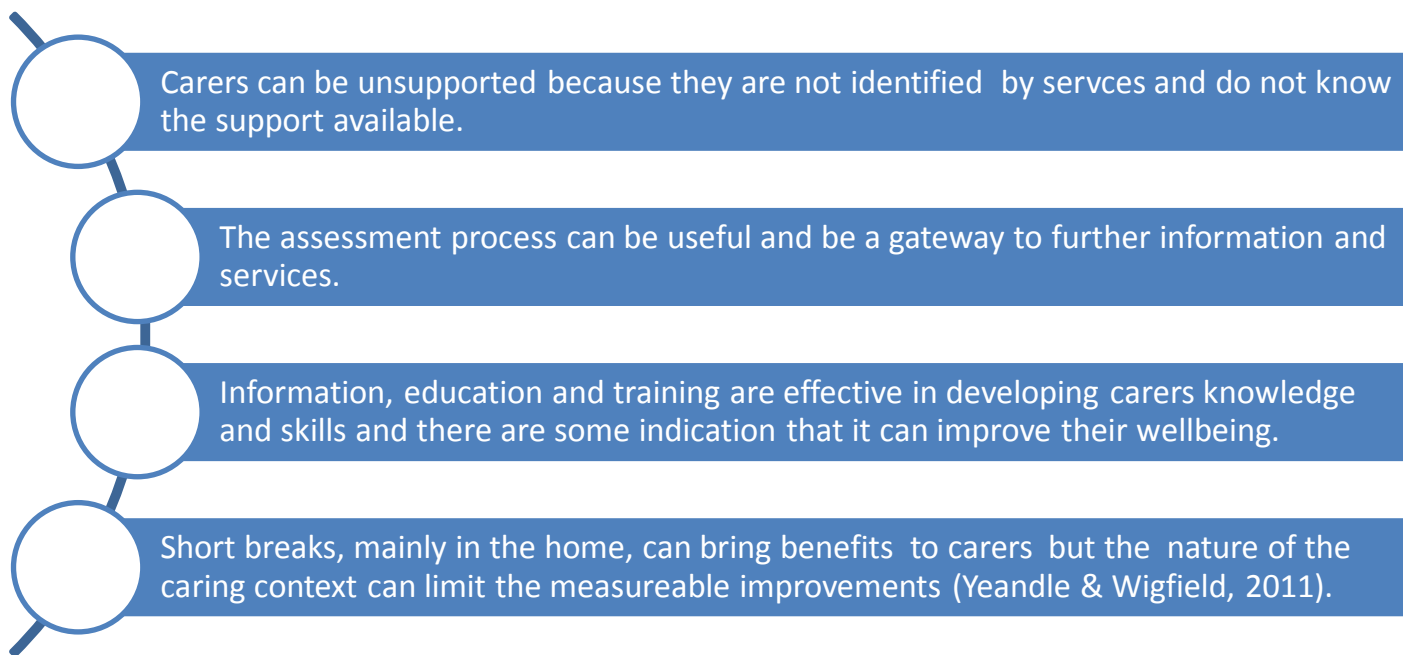
- 18% of women and 16% of men said that they received support from family and friends;
- 9% of women and 6% of men had support in the form of carer's allowance;
- 8% of women and 6% of men received advice and information to help them in their caring role;
- 5% of women and 4% of men had practical support such as help with transport or equipment;
- 5% of women and men had help provided by a personal assistant, community nurse, home help or similar;
- 4% of women and 2% of men had counselling or emotional support;
- 4% of women and 3% of men received help taking a short break or getting respite from caring;
- 2% of women and 1% of men had training and learning to help them in their caring role.

**Figure 40: Support received by carers, 2012/2013**



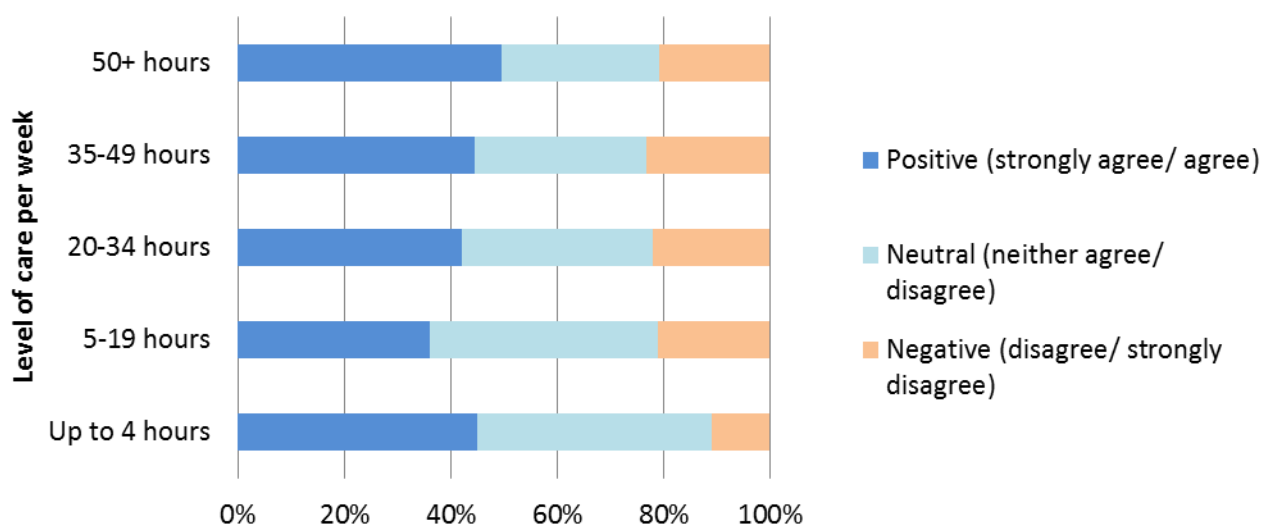
**Source:** Scottish Health Survey 2012/2013

### 4.3. Carers' experience of support



The **Scottish Health and Care Experience Survey (HACE)** (Scottish Government, 2014a) shows that many carers are not seeking support. Overall 44% of respondents reported feeling supported to continue caring, whilst 18% did not. Whether respondents feel supported to continue care was related to the number of hours caring. Whereas one in ten respondents caring for up to 4 hours per week reported not feeling supported to continue caring, this rose to over one in five respondents caring for five hours or more and to almost one quarter (23%) of those caring for 35-49 hours (Scottish Government, 2014a).

**Figure 41: Proportion of carers who feel supported, 2013/14**



Percentage responses to statement – “I feel supported to continue caring”

Source: 2013/14 Health and Care Experience Survey

#### 4.4. Ways to support carers

Carers can be supported directly and via provision to the cared for person, as illustrated by the SHeS support received categories. Direct support is provision to the carer, e.g. support groups, training and information. Support via the cared for person is, firstly, provision where the express purpose is to support the carer, e.g. respite care. Secondly it is core services for the cared for person where (incidental) benefits are accrued by the carer (Rand & Malley, 2014; Yeandle & Wigfield, 2011; Parker, et al., 2010; Pickard, 2004). These core services include “personal care services, domestic services...and so on” and there is evidence that these can be the most effective support to carers (Pickard et al., 2004: 9). Indeed a well-established stream of social policy advocates, in line with the independent living agenda, that policy, practice and resources should be directed to support all individuals to live independently (Pickard, 2004). The aspiration is that this will eliminate reliance on family and friends for care (Scourfield, 2005; Pickard, 2004). Scotland’s carers policy recognises that provision for the cared for person is integral to carer’s outcomes, but is in line with the “dual focus” perspective. This views caring as happening and taking place in a relationship (Scottish Government, 2010a). Consequently the interests of the carer and cared for person can be shared and coincide; or they can differ and even be in conflict (Rand & Malley, 2014; Pickard, 2004). Provision to each party should recognise these permutations and so each should be assessed independently and together and their separate and shared needs addressed (Pickard, 2004). This also means that the effectiveness of support should take into consideration the impact on the carer and cared for person. In this report the focus is on support from public services, aimed at and effective for carers (Pickard, 2004).

#### 4.5. Access to support

The **HACE survey** findings indicate that at least one in five carers are not sufficiently supported to continue caring (Scottish Government 2014a). The low visibility of carers is one of the numerous reasons that this is the case. Only when professionals and services recognise that individuals are providing care were they likely to signpost them to support (IRISS, Shared Care & Coalition of Carers in Scotland, 2012; Jarvis & Worth, 2004;). However even carers known to local authorities were often unaware of available support (Seddon, et al., 2010). Once they and their needs were identified, carers reported delays in receiving support and practical assistance (such as equipment) (Rand & Malley, 2014). For others the information and support was too late and key decisions taken or a crisis had already occurred (Yeandle & Wigfield, 2011).

Carers themselves can have reasons for being reluctant to involve external services. They may resist external provision due to a strong personal commitment, or obligation, to provide the care; or they can be wary about the upheaval services might bring (Yeandle, et al., 2007a). Young carers reported that they are anxious about being known to public services and the risk of separation from their family (Smyth, et al., 2011). Young and adult carers were found to keep their role hidden to avoid stigma, particularly if they were caring for someone with a drug or mental health problems (Smyth, et al., 2011). Understanding why carers can be reluctant to seek support can inform strategies for improving personal contacts with carers en route to providing them with support. What research identified about what constitutes effective, timely support is the subject of the next section.

## **4.6. Types of support**

### **4.6.1. Support that benefits carers**

This section considers assessment, short breaks and information as three main methods to support carers. The evidence on their impact is not entirely consistent or conclusive but findings point towards positive benefits (Parker, et al., 2010). There are also a range of interventions to support carers and include, inter alia, therapy, counselling, stress management, relaxation and behavioural management skills and specialist support (Parker, et al., 2010). However inadequate evaluations mean it is not possible to draw firm conclusion about the effectiveness of these interventions and so these are not included in this brief review (Parker, et al., 2010).

### **4.6.2. Carers' assessment**

The purpose of a carer's assessment is to identify needs in, and alongside, the caring role. This is the basis for deciding support needs, how these may be addressed and if a service will be provided. The actual assessment process can be beneficial to carers and provide them with emotional support by recognising the contribution they are making and giving them the opportunity to talk through their role (Gray & Birrell, 2013). But research has found that carers are not always aware they have had an assessment nor given an opportunity for an assessment separate, or of equal weight, to that of the cared for person (Newbronner, et al., 2013; Gamiz & Tsegai, 2013). In some instances carers perceived an assessment as a judgement of their ability to provide care (Gamiz & Tsegai, 2013). Staff training and knowledge; time, resources and eligibility criteria can affect whether an assessment takes place (Scourfield, 2005). Whilst an assessment can be a gateway to further information and advice often there is no further support, or it is delayed or it does not meet carer expectations (Victor, 2009). The process for the assessment seems to affect its utility and contribution to an individual's outcomes. A small research project in Scotland found that even with outcomes and carer focused assessments, the method used for assessment was important (Gamiz & Tsegai, 2013). Assessment that involved a conversation with practitioners contributed to more effective outcomes (Gamiz & Tsegai, 2013). Voluntary sector carers' organisations were found to be able to focus more clearly on the carer than statutory organisations where there were different roles and approaches (Gamiz & Tsegai, 2013).

### **4.6.3. Information and training for carers**

Information, education and training have a positive impact on carers' knowledge, skills, mental health and ability to cope (Parker, et al., 2010). These types of support, accompanied by a social component i.e. carers meet with each other, were found to impact positively on psychological well-being (Parker, et al., 2010). Studies found educational interventions reduced depression, certainly in the first few months of caring (Parker, et al., 2010). Studies on carers' of stroke patients found weak evidence but positive impact of education and training on the carers' mental health (Parker, et al., 2010). Information at an early stage was found to improve carers' knowledge. Information reduced depression for those caring for people with dementia but simultaneously increased anxiety for this group and offered no improvement in psychological well-being, carers' burden or quality of life for carers (Parker, et al., 2010). For carers, primarily of older people, information improved their confidence in caring (Yeandle & Wigfield, 2011) and alleviated concerns their actions were inadequate or even harmful (Yeandle, et al., 2007a).

#### 4.6.4. Carers' identified needs and sources of information

Information and advice is sought by carers, particularly at the outset of caring, since many are new to the role and when there are changes in the caring situation. Research with carers found information should be timely, specific and provided by organisations with specialist knowledge on caring (Newbronner, et al., 2013; Yeandle & Wigfield, 2011; Yeandle, et al., 2007a). Carers identified a wide range of beneficial information-based input including:

- Being told about the caring implications and implications for their role when an individual is diagnosed with dementia (Newbronner, et al., 2013).
- Assistance and advocacy to navigate the complexity of the health and social care systems (McPherson, et al., 2014).
- Financial advice such as on eligibility for benefits.
- Legal advice on employment rights or obtaining "Power of Attorney".
- Information on support groups, short breaks and training on coping skills and managing difficult behaviour.
- Help on dealing with the difficult aspects conditions i.e. challenging behaviour by dementia sufferers (McPherson, et al., 2014; Newbronner, et al., 2013; Parker, et al., 2010; Seddon, et al., 2010; Yeandle, et al., 2007a).

Carers entering into a care giving role feel unprepared for the role and their new tasks. Some feel that their role is imposed on them and that little information is provided about how to care for the person. In an Australian qualitative study (Grimmer et al., 2004) new carers for an elderly person after discharge from acute hospital, reported that they wanted to care but felt their inexperience made day-to-day life more difficult as they adjusted to their role. Carers worried about some of the small practical things and felt that their anxieties were compounded by a lack of information provided to them:

*They must think that by some chance or miracle that you can lift the person, and bathe and dress that person. I mean, you've got to work it out for yourself (Wife of person with physical disability.)* (Grimmer 2004).

Carers of those with dementia, and couples in same sex relationships, reported information and advice from informal support networks was useful as these also offered mutual support and reduced isolation (Newbronner, et al., 2013). In a similar vein informal networks could be the most effective way to communicate with carers, although it may take a professional to direct a carer to these. Carers did proactively seek information but wanted recommended websites to be confident that the content is accurate and current (Newbronner, et al., 2013).

#### 4.6.5. Short breaks and respite care

Short breaks for carers encompasses diverse provision that can be utilised for a range of purposes. The Scottish Government Carers' Strategy (2010a) statement on short breaks illustrates the range in nature and scope;

"The break might be during the daytime or overnight. The break might be for a couple of hours or for much longer. It might involve the cared-for person having a break away from home, thus benefitting the carer in that they have time for themselves. Or the carer might have a break away, with services being put in place to support the cared-for person. Some people want to have a break together, with additional support to make this happen. Sometimes the service is provided in the home for the cared-for person, with the carer having time to do something themselves for a couple of hours during the day" (Scottish Government 2010a:78).

The Scottish Government publishes annual information on Respite Care Services (Scottish Government 2014b). This shows that:

- There were 203,090 overnight and daytime respite weeks\* provided in Scotland in 2013/14. At least a further 12,590 weeks were provided through Direct Payments\*\*.
- The carers of older people (aged 65+) benefitted from 53% of the respite care provided in 2013/14, those of adults aged 18-64 from 36% and those of young people (aged 0-17) from 11%.

\* Seven respite nights equal one respite week and 52.5 hours equal one respite week.

\*\* Only 18 out of 32 Local Authorities were able to submit Direct Payment information

#### **4.6.6. Nature of short breaks**

Short breaks are for carers “to have a break from their normal routine and the demands in the caring situation” (IRISS, Shared Care & Coalition of Carers in Scotland, 2012). They can reduce the number of hours provided by the carer or provide a brief rest from caring (Phillipson, et al., 2014). The provision can be in the cared for persons home or an external venue. The break can be; for hours or days; frequent or infrequent; on an ongoing, intermittent or one off basis. The carer is the intended beneficiary, although the cared for person is often the recipient of the short break and they may or may not benefit from the break. Short breaks can be taken by the carer and cared for person together to benefit both.

#### **4.6.7. Impact of short breaks**

Most research on the effect of short breaks for carers considers the impact on the psychological health of carers (carer burden); the physical health (including reducing mortality); general wellbeing; and ability to continue in employment (Pickard, 2004). Studies have produced differing and even contradictory conclusions on the impact for carers and this is often due to the nature and quality of the evaluation rather than the actual short break (Parker, et al., 2010; Mason, et al., 2007; Pickard, 2004). The demands of caring and the deteriorating condition of the cared for person can be such that community support is inevitably a small influence and measurable positive change for carers difficult to detect (Yeandle & Wigfield, 2011; Pickard, 2004). Short breaks can be disruptive for the cared for person and increased post-break stress and guilt in carers has been identified alongside benefits from the break (Balducci, et al., 2014; Parker, et al., 2010). These bi-directional effects bring added complexity to establishing the effectiveness of short breaks.

These complexities notwithstanding, evidence has indicated that short breaks are beneficial. Carers reported that short breaks provided a rest from caring and the opportunity to maintain a life outside caring (IRISS, Shared Care & Coalition of Carers in Scotland, 2012; Mason, et al., 2007). A major research review concluded that short break provision in the form of institutional respite care and day-care services were beneficial and cost effective for carers of older people (Pickard, 2004).

Institutional respite care and day-care services were found to delay admission to residential care for higher care needs older people but not in situations of “bad user-caregiver relationships” and “more reliant care users” (Pickard, 2004). Single studies have found an improvement in a minority of carers over a range of measures including:

- Self-care.
- Coping with stress.
- Quality of caring given.
- Improved social life or taking up a hobby.



- Moving nearer the labour market (e.g. training, considering or contacting an employer).
- Involvement in community and leisure activities (Rand & Malley, 2014; Yeandle & Wigfield, 2011).

Carers in employment benefited from respite care which in turn had a positive effect on them and their ability to continue caring (Yeandle & Wigfield, 2011; Pickard, 2004). In the Yeandle (2011) study half of the respondents experienced no change in wellbeing measures and for one in ten the situation worsened (Yeandle & Wigfield, 2011). Other research concluded that short breaks were neither beneficial nor detrimental to frail older people (Mason, et al., 2007) and negatively impacted on carers' wellbeing and quality of life (Parker, et al., 2010). These differing findings may reflect the complexity of the situation and process and actual provision.

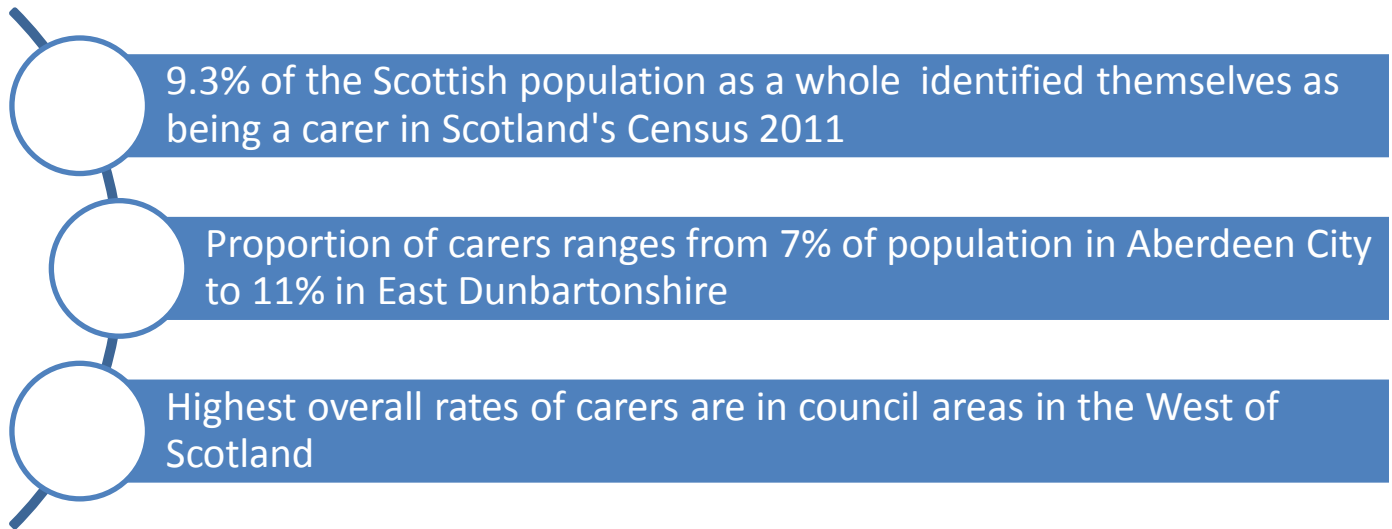
#### **4.6.8. Issues in take up of short breaks**

Research found that there are structural and individual issues involved in carers' access to short break. Obtaining provision is one aspect and studies found there to be shortages in rural and urban areas, long waiting times and ineligibility for statutory services (IRISS, Shared Care & Coalition of Carers in Scotland, 2012; Yeandle & Wigfield, 2011; Mason, et al., 2007). Many carers did not know how to obtain a short break and navigating the systems to access these could be difficult (IRISS, Shared Care & Coalition of Carers in Scotland, 2012). Socio-economic factors have an impact and older people and carers on lower incomes were less likely to have had a break (Phillipson, et al., 2014). Some carers expressed concerns around the quality of provision, including lack of trained staff, although there were examples of good, personalised service (Carers UK, 2014; Mason, et al., 2007). Short breaks could be less likely where the cared for person was reluctant to go to residential care even for a short period or eschewed public services generally (Carers UK, 2014; Mason, et al., 2007). Feedback from carers in Scotland indicated satisfaction with the options for, and the support received to organise short breaks. There was less satisfaction with the number and types of services to meet cultural, clinical and practical needs e.g. night services (IRISS, Shared Care & Coalition of Carers in Scotland, 2012). So short breaks are important for carers and can be of benefit but to achieve this can require squaring a number of elements.

#### **4.7. Conclusion**

Whilst the majority of carers do not have support, those providing greater numbers of hours care seem more likely to receive support. However at least one in five carers caring for five hours or more did not feel supported to continue caring, although some of these may be receiving an element of support. Carers value and can benefit mentally and physically from tailored, timely information, advice and training. Findings on the impact of short breaks are mixed, although they have been found to be beneficial to the carer. Day care and other provision during the day seem to be effective and more likely to be accepted by the carer and cared for person than residential care. However in many cases caring is demanding and becomes more so with the deterioration of the cared for person. This can limit the wellbeing of carers, even when they are effectively supported.

## 5. CHAPTER 5: WHERE DO CARERS LIVE?

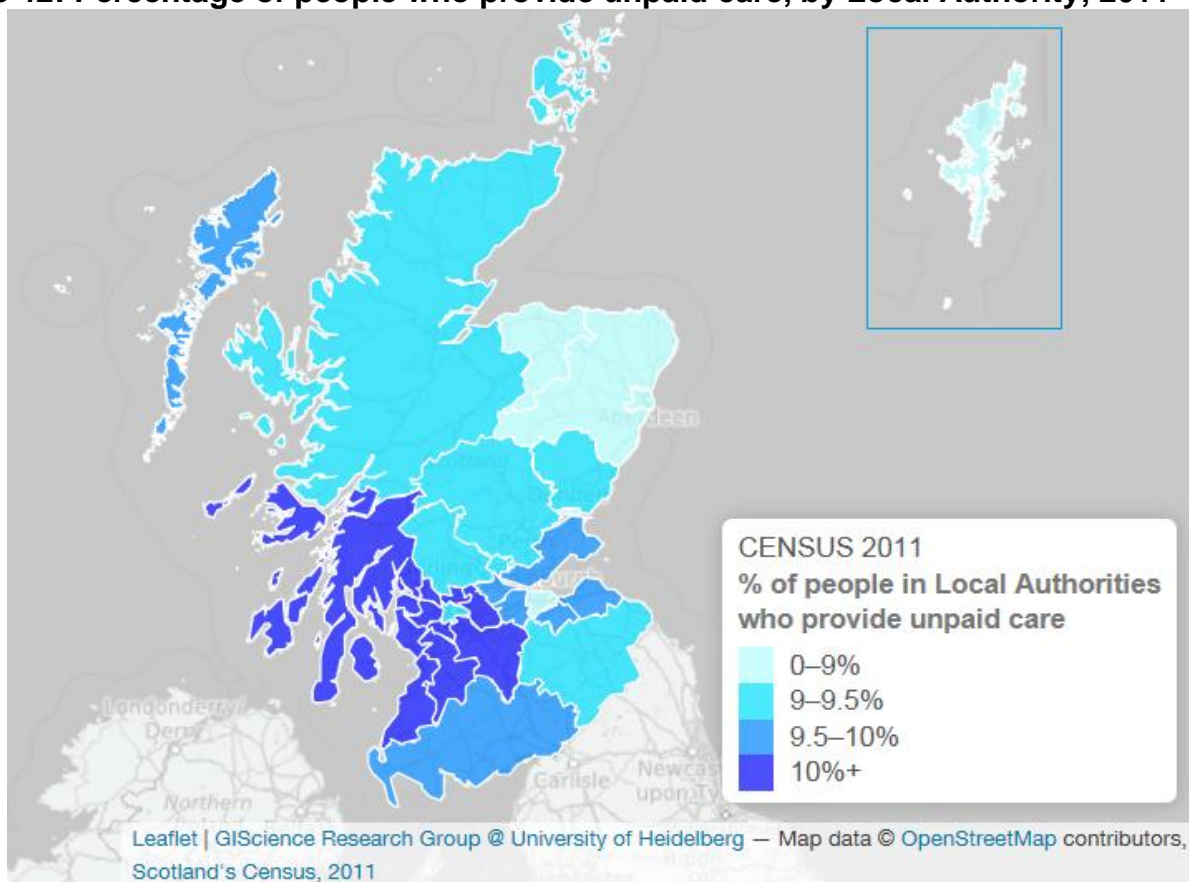


### 5.1. Introduction

Carers are found across Scotland, and in this section we give a picture of the proportion in each Local Authority area.

### 5.2. Carers by local authority area

Figure 42: Percentage of people who provide unpaid care, by Local Authority, 2011



Interactive map available at:

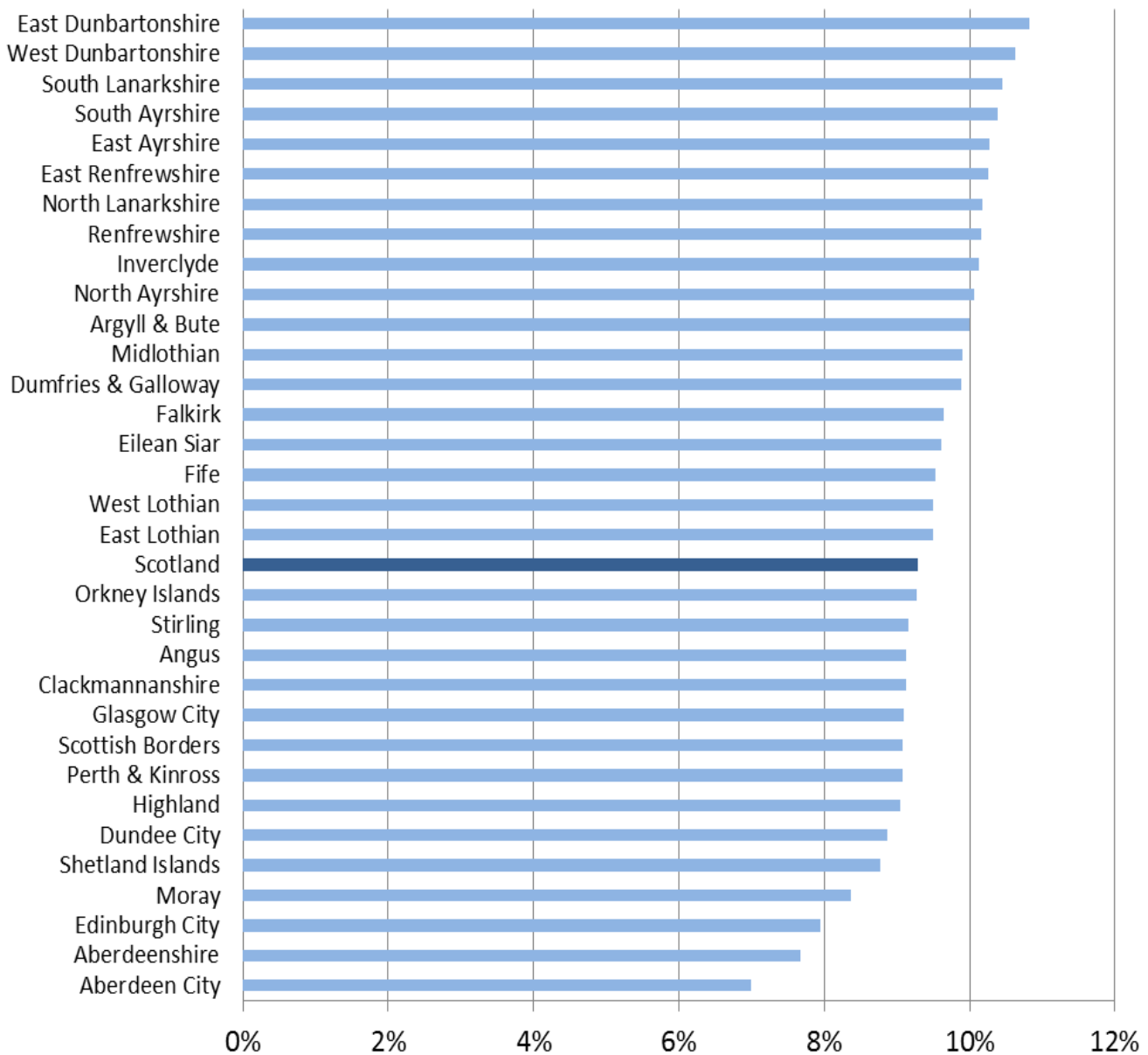
[https://c5aa50a6216d1f7da7c1ec1cec7d1391cee7df41.googleusercontent.com/host/0B\\_cx2PbyKhK6clJMKlzbmVITjQ/LACMap\\_2011carers.html](https://c5aa50a6216d1f7da7c1ec1cec7d1391cee7df41.googleusercontent.com/host/0B_cx2PbyKhK6clJMKlzbmVITjQ/LACMap_2011carers.html)

Source: Scotland's 2011 Census

**Scotland's 2011 Census** shows that 9.3% of the Scottish population as a whole identified themselves as being a carer but this varies quite considerably across Scotland.

The highest rates of caring tend to be in council areas towards the west coast of Scotland. East and West Dunbartonshire show the highest rates at nearly 11% of the population. Aberdeen City has the lowest rate at 7%.

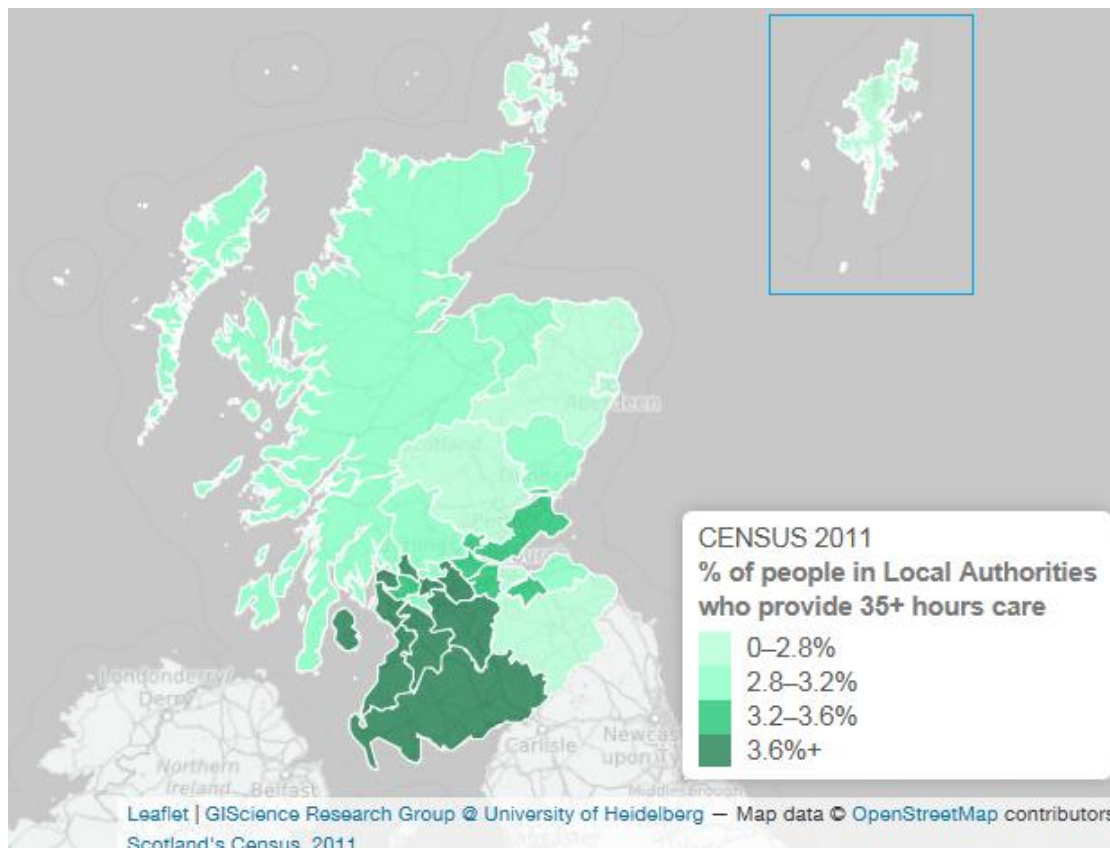
**Figure 43: Percentage of population providing care , Scotland 2011**



**Source:** Scotland's 2011 Census

However looking at the hours of care provided in different local authorities in Scotland tells a different story. Looking at councils according to the proportion of carers who say that they care for 35 hours a week or more (the rate at which Carer's allowance can be claimed) and representing a significant amount of caring over the course of a week (equivalent to carrying out a full-time job):

**Figure 44: % of people who provide 35 or more hours of care per week, by Local Authority, 2011**



Interactive map available at: [https://c5aa50a6216d1f7da7c1ec1cec7d1391cee7df41.googledrive.com/host/0B\\_cx2PbyKhK6cllJMklzbnVITiQ/LACMap\\_2011carers\\_35+.html](https://c5aa50a6216d1f7da7c1ec1cec7d1391cee7df41.googledrive.com/host/0B_cx2PbyKhK6cllJMklzbnVITiQ/LACMap_2011carers_35+.html)

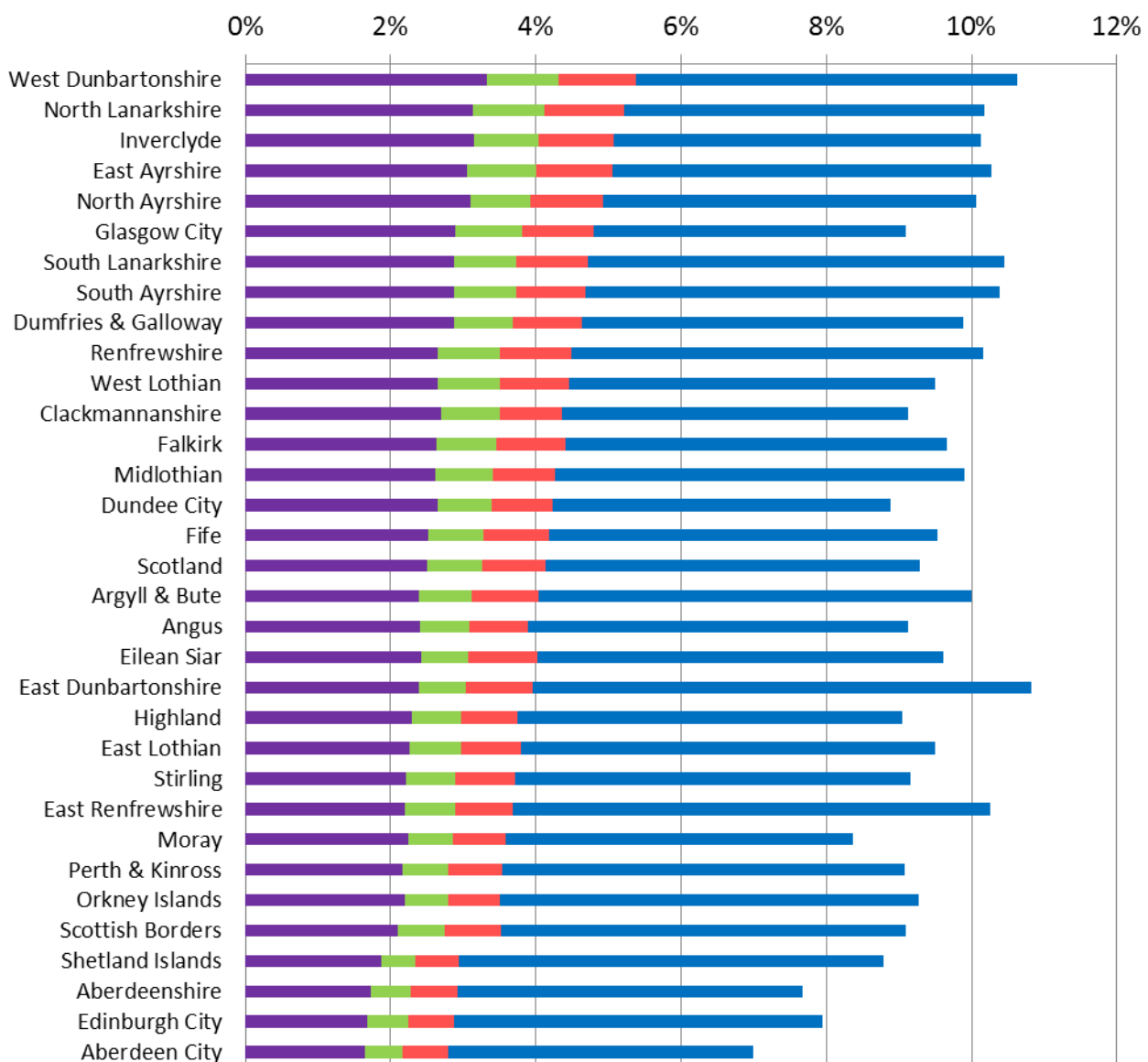
**Source:** Scotland's 2011 Census

Again the highest rates appear to be in the west of Scotland but East Dunbartonshire which has the highest rate overall of carers is now in the second half of the table so has a below average rate of carers who care for 35 hours a week or more. East Renfrewshire is similar; both these areas have high levels of caring but not high levels of intensive caring.

Conversely, Glasgow and Dundee are both in the bottom half of the table showing the overall rate of caring but have moved to the top half of the table for carers who care for 35 hours a week or more so while these two areas don't have high levels of overall caring they do have a higher proportion of carers caring for 35 hours a week or more. This could be linked to the deprivation analysis looked at in Chapter 1.

**Figure 45: Percentage of population providing care, by intensity of caring, Scotland 2011**  
 (Ranked according to percentage of population providing 35 hours of care each week)

■ 50+ hours per week ■ 35-49 hours per week ■ 20-34 hours per week ■ 1-19 hours per week



**Source:** Scotland's 2011 Census

This analysis shows that the prevalence of caring varies widely from one local authority to another, both in terms of overall numbers of carers and those where high levels of caring are involved. The reasons for this are likely to be complex and will be heavily influenced by the socio-demographic compositions of the populations.

### 5.3. Carers in urban and rural areas

Scotland's 2011 Census allows us to look at carers and where they live in Scotland categorised according to the urban / rural classification.

<http://www.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification>

UR1 - Large Urban Areas -Settlements of 125,000 or more people.

UR2 - Other Urban Areas

UR3 - Accessible small Towns

UR4 - Remote Small Towns

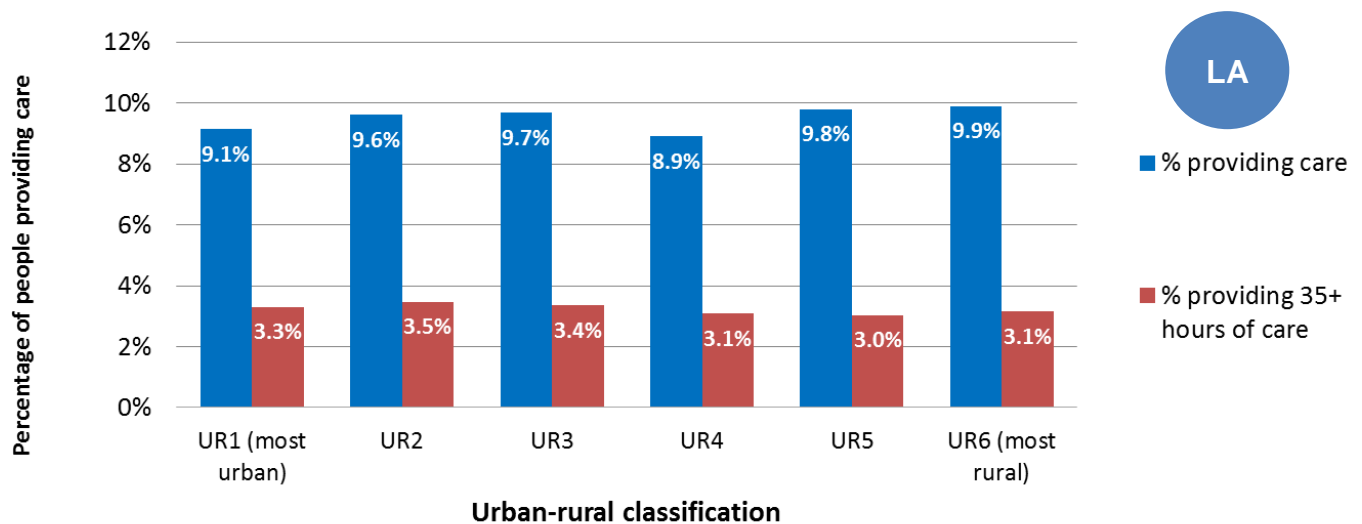
UR5 - Very Remote Small Towns

UR6 - Accessible Rural

UR7 - Remote Rural

UR8 - Very Remote Rural

Figure 46: Proportion of people providing care in each urban / rural area, 2011



Source: Scotland's 2011 Census

Overall the proportion of people providing care in each urban / rural classification varies from 8.9% in accessible small towns to 9.9% in the very remote rural areas. The proportion of people providing 35 hours of care a week or more varies from 3.0% in very remote small towns to 3.5% in other urban areas. Again the reasons for this are likely to be complex and will be influenced by the socio-demographic composition of the populations as well as the availability of local services.

## 6. CHAPTER 6: CONCLUSIONS

The contribution made by unpaid carers is well established, as is the recognition that people providing care can need and should have support. In this report we show carers in Scotland today. We have analysed large population datasets and set out who and where carers are. We've highlighted the health and wellbeing challenges that carers may experience particularly for those for whom the caring load is considerably higher. We've also examined international research on effective support for carers to promote carers' health and prevent ill-health.

### 6.1. Profile of carers

Carers are a diverse group, comprising both men and women, from all ethnicities and age groups from the very young to those in their later years. They are part of all Scotland's communities; urban and rural, deprived through to wealthy. They are in full-time education, paid employment, caring full time, unemployed and retired. Their caring can be for a few hours to full time.

However this analysis has shown that the number of carers and intensity of caring is more common in some groups than others:

- Women comprise the majority of carers, although men comprise 40% and genders are in equal proportions in the oldest age group.
- High intensity carers (over 35 hours) are drawn disproportionately from the most deprived areas.
- Similarly carers are most commonly aged 55-64 and many of them provide over 20 hours care, but it is carers aged 65 and over that are the highest providers of this level of care.
- A higher proportion of young carers are in lone parent families and they have more intense caring responsibilities.
- More young people in the most deprived areas are carers.

### 6.2. Carers' health and wellbeing

While caring can be an extremely rewarding experience, this review has pointed to considerable evidence which suggests that carers often experience poor mental and physical health arising from their caring giving role. For some this may be compounded by existing inequalities. Those most at risk are carers in more complex and demanding caring situations. Although these carers may represent a minority of the carer population, they nonetheless provide the bulk of unpaid care.

Our analysis has shown that the pattern of caring has changed. While there has been a very small increase in the number of carers, there are more carers providing more intensive care. This has important policy and practice implications, since carers with heavier care burdens are often drawn disproportionately from the caring groups identified above.

For those providing more intensive care, there can be financial and social challenges. While employment may sustain carers in their role, some carers struggle with combining a job and caring and either have to adjust working pattern or stop work altogether. Furthermore carers may face additional financial burdens associated with their caring responsibilities. As care load increases,

carers can be at risk of social isolation as it can be difficult to maintain or foster social networks or pursue hobbies.

### **6.3. Support for carers**

The review has highlighted the need to support carers in demanding care situations, particularly those providing higher levels of caring over an extended period since it is they that are most likely to experience psychological distress. Many of these carers do not have support, although those providing greater numbers of hours care seem more likely to receive it. More carers caring for five hours or more reported not feeling supported to continue caring than those caring for fewer hours. Indeed not all carers receive support and not all reported they needed or wanted it.

It is also important also to take a preventative approach which involves support for carers at early stages and when caring is less intensive. Identification of these carers and providing information and advice can be effective in supporting them in their caring role. Information and training is also beneficial throughout the caring period and at key times of change in the cared for person's condition. Carers value short breaks and although ensuring these have positive impact is complex, they have been found to be beneficial. Day care and other support during the day seem to be effective and more likely to be accepted by the carers and cared for person than residential care.

The review also showed that caring can be associated with poor physical health, albeit to a lesser degree than psychological distress, therefore interventions to support carers should also focus on physical health promotion such as providing opportunities for exercise, health eating, and preventative care visits.

While we have focused this review on direct support for carers, it is important to consider this in context of the cared for person. Carers and their relationship with the cared for person (s) are so closely intertwined. What impacts on the cared for person will have a bearing on carers and vice versa. Accordingly high quality care for the cared for person can provide the most effective support to carers.

Above all, any form of support should be timely, person-centred and based around the needs of the carer and their caring situation. This should be informed by carers' socio-economic situation and issues particularly relevant to them as carers.



## 7. CHAPTER 7: BACKGROUND INFORMATION

### 7.1. Rationale for publication

The main carers' strategies in Scotland are: **Caring Together: The Carers' Strategy for Scotland 2010 – 2015** and **Getting it Right for Young Carers 2010 – 2015**:

<http://www.gov.scot/Publications/2010/07/23153304/2> Developed jointly by the Scottish Government and the Convention of Local Authorities in Scotland, in partnership with carer, third and statutory sector organisations, they set out a range of actions to improve support to carers and young carers through better identification, assessment, information and advice, carer support, participation and partnership working.

### 7.2. Scottish Carers' Policy

This publication aims to bring together some of the key statistics on carers and caring alongside references to relevant pieces of research. Much of the data is sourced from Scotland's 2011 Census and there is potential to carry out further analysis of this data source. It has not yet been decided whether this should be a regular publication. We would be interested to hear your views and ideas for any future publications or analysis. You can do this by emailing us at

[SWStat@Scotland.gsi.gov.uk](mailto:SWStat@Scotland.gsi.gov.uk)

The **Carers (Scotland) Bill**: <http://bit.ly/1GmvTpC> was introduced into the Scottish Parliament on 9 March 2015. The legislation aims to ensure that carers are better supported to enable them to continue to care, if they so wish, in good health and to have a life alongside caring. In relation to young carers, the intention is that they should have a childhood similar to their non-carer peers.

### 7.3. Sources of data

#### Scotland's Census 2001 and 2011

<http://www.scotlandscensus.gov.uk/>

Both the 2001 census and the 2011 Census in Scotland asked a question about unpaid caring. The same question was asked in both years but in 2011 an additional category was asked to allow for analysis of carers who are caring for 35 or more hours per week. This is the level at which carers can become eligible for Carer's allowance.

#### The 2011 Census asked:

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- Long-term physical / mental ill-health / disability; or
- Problems related to old age?
- ◆ Do not count anything you do as part of your paid employment
  - No
  - Yes, 1-19 hours a week
  - Yes, 20-34 hours a week
  - Yes, 35-49 hours a week
  - Yes, 50 or more hours a week

[Scotland's Census 2011 website](#) provides access to a variety of different tools for accessing and analysing census data.

#### The 2001 Census asked:

Do you look after, or give any help or support to family members, friends, neighbours or others because of either:

- Long-term physical or mental ill-health or disability; or
- Problems related to old age?
- ◆ Do not count anything you do as part of your paid employment
- ◆ ✓ time spent in a typical week
  - No
  - Yes, 1-19 hours a week
  - Yes, 20-49 hours a week
  - Yes, 50+ hours a week

For more information from the 2001 census, see the SCROL website at [www.scrol.gov.uk](http://www.scrol.gov.uk)

#### Scottish Health Survey

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/scottish-health-survey>

SHeS provides a detailed picture of the health of the Scottish population in private households and is designed to make a major contribution to the monitoring of health in Scotland.

The Scottish Health Survey (SHeS) has been carried out annually since 2008 and prior to this was carried out in 1995, 1998 and 2003. An annual report is published for each year of the survey (the latest published being 2013). The SHeS includes a number of questions on caring including whether or not the respondent provides care, the number of hours each week providing care, length of time providing care, whether employment has been affected and support received by the carer.

Survey weights are applied to adjust for non-response and to ensure SHeS results reflect the age distribution of the population of Scotland and Scottish areas. Taking into account the complex stratified and clustered survey design, confidence limits around SHeS estimates are provided to indicate the degree of precision.

#### Scottish Health and Care Experience Survey (HACE)

<http://www.gov.scot/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey>

HACE is a biennial care experience postal survey of people registered with a GP practice. The survey is part of the Care Experience Survey Programme and asks people about their experiences of their GP practice, out-of-hours primary care and social care services. A series of questions aimed specifically at carers was introduced in 2013/14. Carers were asked how much they agreed or disagreed with the following statements:

- I have a good balance between caring and other things in my life
- I am still able to spend enough time with people I want to spend time with
- Caring has had a negative impact on my health and wellbeing
- I have a say in services provided for the person I look after
- Services are well coordinated for the person(s) I look after
- I feel supported to continue caring

## **Department of Work and Pensions**

<http://tabulation-tool.dwp.gov.uk/100pc/tabtool.html>

DWP publish statistics on Carer's Allowance.

Analysis of both:

- Carer's Allowance – cases in payment; and
- Carer's Allowance – all entitled cases

has been carried out using the [DWP tabulation tool](#) for inclusion in this publication.

Carer's allowance is available to people who are aged 16 and over and spend at least 35 hours a week caring for someone. They don't have to be related to or live with the person they care for. Carer's allowance is taxable and can also be affected by other benefits. For more information on carer's allowance see <https://www.gov.uk/carers-allowance>

## **Pupil Census.**

The annual pupil census collects information from all publicly funded schools in Scotland. The pupil census captures the educational needs of all students and this category allows schools to identify young carers with additional support needs. <http://www.gov.scot/Topics/Statistics/Browse/School-Education/Summarystatsforschools>

## **National Records of Scotland (NRS)**

For figures that have been expressed as a rate per population, the National Records of Scotland mid-year population estimates for 2013 have been used (the latest available).

<http://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates>

## **7.4. Other Scottish Government publications on Carers**

### **Carers data including Respite Care publications**

<http://www.gov.scot/Topics/Statistics/Browse/Health/Data/Carers>

### **Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland**

<http://www.gov.scot/Resource/Doc/319575/0102110.pdf>

### **Scottish Health Survey Topic Report: Mental Health and Wellbeing**

Section 4.1.11 Unpaid Care - pages 43-45 [www.gov.scot/Publications/2015/01/4163](http://www.gov.scot/Publications/2015/01/4163)

## **7.5. Respondent Burden**

This Release has involved no additional respondent burden as it uses already published sources of data.

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