

SECTION 3: CARERS AND YOUNG CARERS

Introduction

The government's National Carers Strategy defines a carer as follows:

"A carer spends a significant portion of their life providing unpaid support to family and potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health problem or substance misuse problems" (DoH, 2008).

Within this over-arching definition of a carer, there are a number of different carer groups, including:

- Young Carers (children and young people under the age of 18)
- Young Adult Carers (aged between 16 and 25)
- Parent Carers of a disabled child or young person under the age of 18
- Adults Carers of adults over the age of 18

Around 2 million people become carers each year. However Carers UK found that 65% of people with a caring responsibility did not identify themselves as carers in their first year of caring. For just under a third (32%) it took five years before they recognised themselves as a carer. ('In the Know: The Importance of Information for Carers', Carers UK, 2006).

For some people, the level of their caring responsibilities increases gradually over time, whereas others become a carer suddenly. Many of the groups of people identified in other sections of the JSNA rely on support from unpaid carers to enable them to lead their daily lives. However many of the people providing this support do not readily describe themselves as carers because for them the caring relationship is simply part of their everyday life.

Information provided by Carers UK in 2011 indicated that carers save the UK £119 billion per year, an average of £18,473 per carer. This information was updated in 'Valuing Carers 2015: The rising value of carer's support' and indicates that carers now save the UK £132 billion per year, an average of £19,336 per carer. In Darlington, this equates to £224 million, an increase of £12 million since 2011 (see table below):

Fig 44: Carers' Statistics

Number of carers in 2015	Change in number of carers 2011-15	Value in 2011	Value in 2015	Change 2011-15	
Numbers	%	(£millions)	(£millions)	(£millions)	%
11,413	3.3	212	224	12	5.7

What are the levels of need?

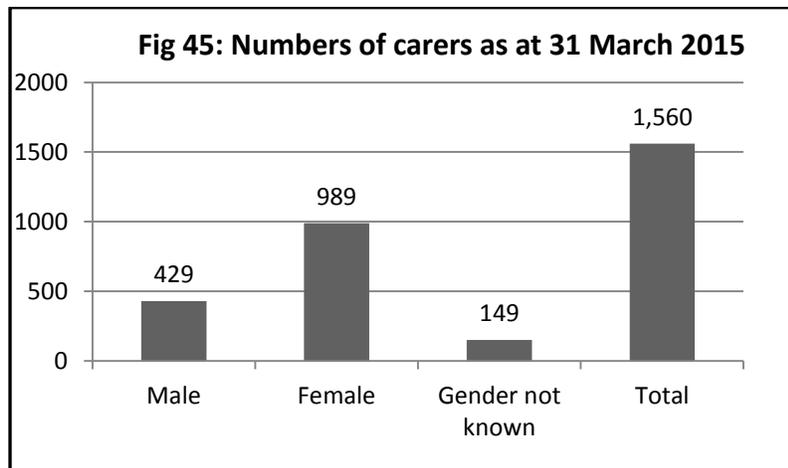
The 2011 census indicated that the number of carers in England and Wales has increased to 5.8 million (10.5% of the population) and that the greatest increase had been in those providing over 20 hours care per week - the point at which caring starts to impact on the health and wellbeing of the carer, and their ability to hold down paid employment alongside their caring responsibilities (Carers UK press release, 11th December 2012). There had also been an increase in the numbers providing over 50 hours care per week.

National census data indicates a 35% increase in the number of carers aged 65+ (the fastest growing age group) and an increase of 24% in the number of carers aged under the age of 24. The gender ratio is 58% women and 42% men.

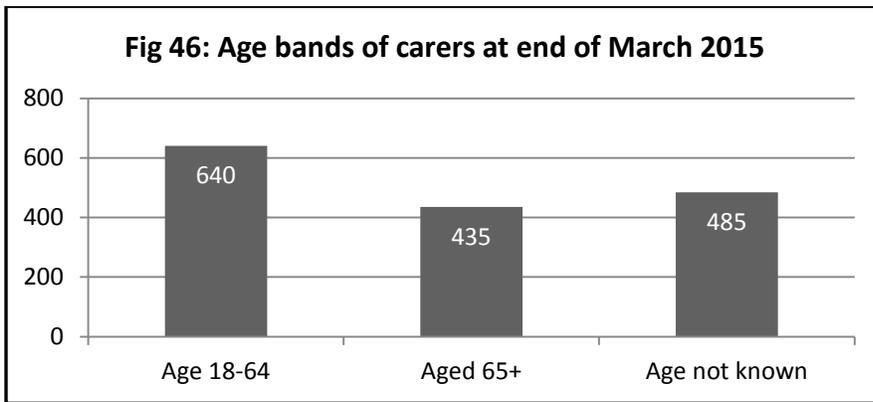
In the North East there has been a 4% increase in carer numbers, but Darlington's numbers have increased by 10% (the highest in the North East region).

In 2001, there were 10,064 carers in Darlington, 2,330 of who were providing care for 50 or more hours per week. By 2011, this number had increased to 11,033 of whom 2,758 were providing care for 50 or more hours per week.

As at 31st March 2015, there were a total of 1,560 carers on the register held by DAD Carers Support Service. Of these 429 (27.5%) were male, 989 (63.5%) female and 142 (9%) unknown.

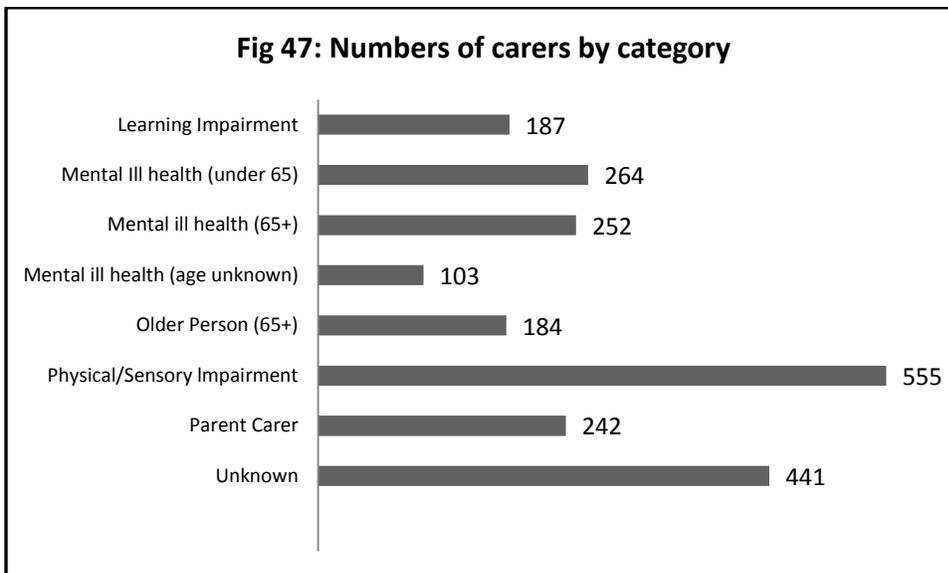


The ages of carers is only known in 69% of cases where 640 (41%) of these were aged 18 – 64, 435 (28%) aged 65+ and a large number 485 (31%) their age is unknown.

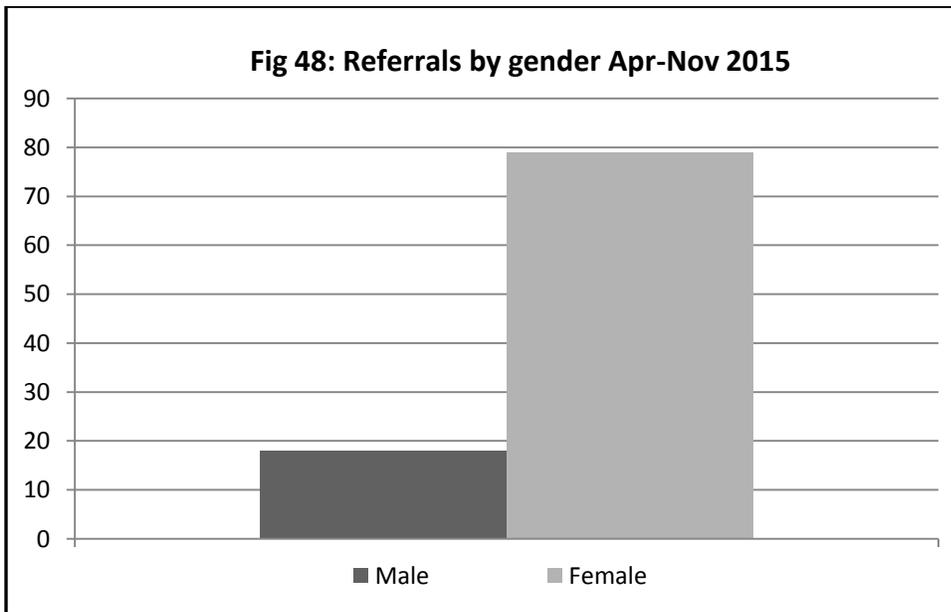


At the end of November 2015 there were 1,657 carers on the register held by DAD Carers Support Service. Of these 447 (27%) were male, 1,068 (64%) female and 142 (9%) unknown. 703 (42%) of these were aged 18 – 64, 462 (28%) aged 65+ and 492 (30%) age unknown.

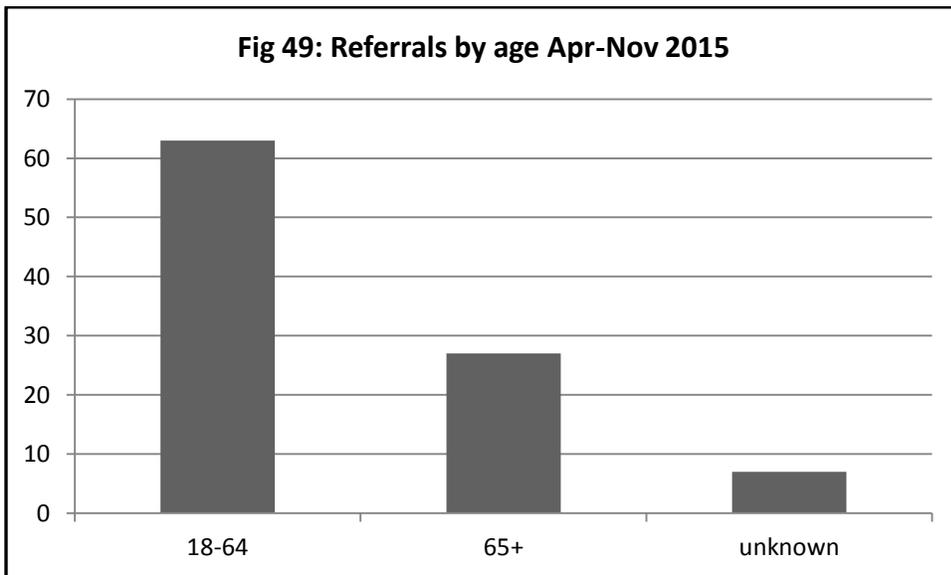
Details of the people cared for the period ended 30 November 2015 are shown in the chart below. The total is higher than the number of individual carers registered due to the multiple categories of person cared for in some cases.



For the period from 1st April – 30th November 2015, the service received 97 new referrals, of which 18 (18.5%) were male, 79 (81.5%) female. Where ages are known, 63 (65%) are aged 18 – 64, 27 (28%) aged 65+ and seven (7%) where age is unknown.

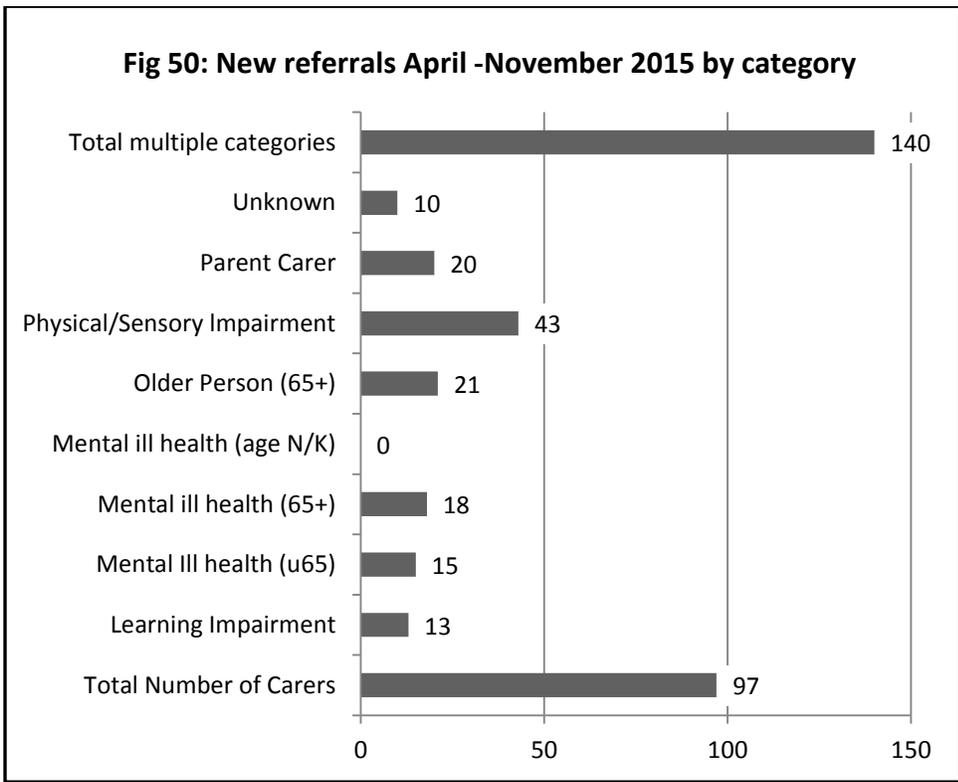


Source: Darlington Association on Disability 2015



Source: Darlington Association on Disability 2015

Details of the people cared for by the carers referred from 1st April – 30th November 2015 are shown in the chart on page 5. The total (140) is higher than the number of individual carers (97) registered due to the multiple categories of person cared for in some cases.



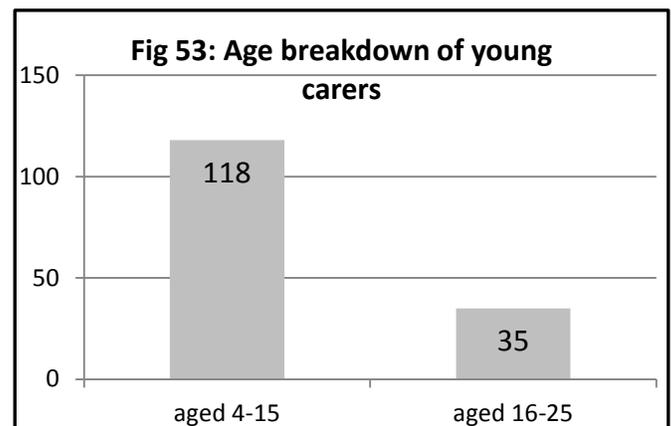
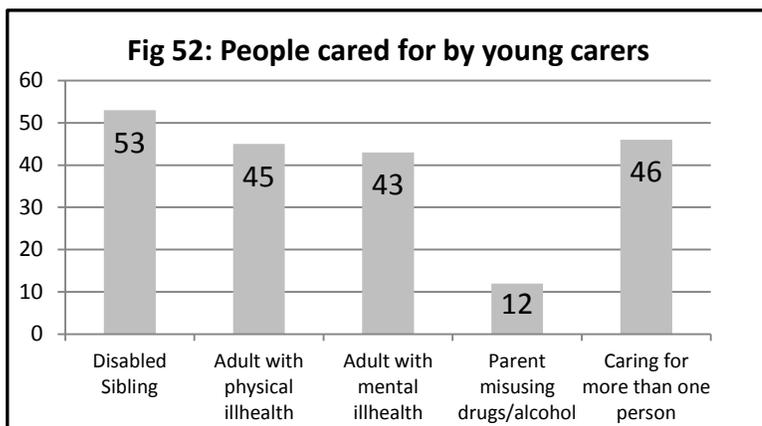
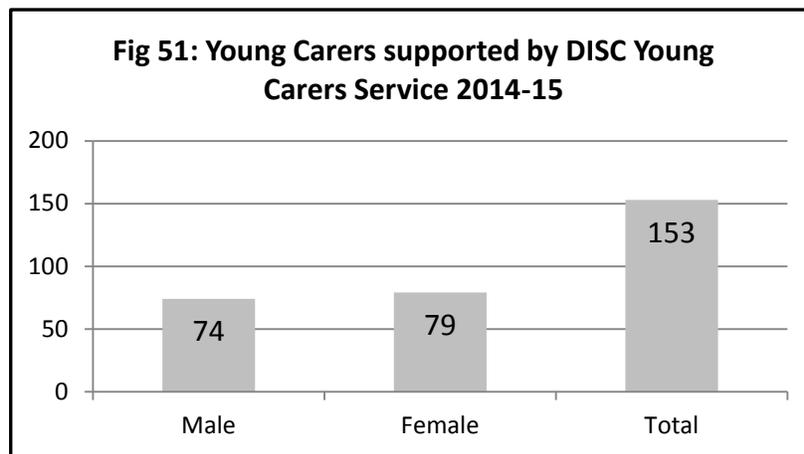
Source: Darlington Association on Disability 2015

Young Carers

In 2001, there were 190 young carers aged 15 and under, 87 aged 16-17, 94 aged 18-19 and 232 aged 20-24 (603 in total). However, research published by the BBC in November 2010 estimates more than four times as many young people act as carers compared with the previous official estimate in the 2001 census. If applied to the 2001 Darlington census figures, this would suggest that there are likely to be at least 760 young carers aged 15 and under, 348 aged 16-17, 376 aged 18-19 and 928 aged 20-24 (2,412 in total).

2011 census information shows 738 young carers aged 0-24.

In Darlington, young carers are supported by DISC Young Carers Service. In the period April 2014 to March 2015, 153 young people were supported. The following graphs show the breakdown between male and female young carers, age breakdown of young carers and the needs of people looked after by young carers.



Which groups are most vulnerable?

All carers face similar issues in relation to trying to balance the impact of taking on a caring role with their lives and responsibilities before this took place. However, some groups of carers experience specific issues.

Older Carers

More than 1 in 8 people over the age of 60 is a carer. This includes people caring for adult sons/daughters with impairments or caring for spouses or parents. A survey carried out with 639 older carers aged 60 –94 by the Princess Royal Trust for Carers 'Always on Call, Always Concerned - A Survey of the Experiences of Older Carers' (Princess Royal Trust for Carers, 2011) identifies a number of issues that they face:

- 68% reported a negative impact on their physical health
- 68.8% identified a detrimental effect on their mental health
- 65% have a long term health problem or disability themselves
- 38.5% reported that they were not able to have a break from their caring role

Carers of people with dementia

- Unpaid carers provide a major part of the support to people with dementia. This includes carers both under and over retirement age.
- Dementia is becoming an increasingly significant issue in the workplace as more and more people are combining work with caring for someone with dementia.
- The Carers UK 'State of Caring Survey' 2013 found that nearly one in five carers were looking after a family member with dementia and that these carers were more likely than other carers to be combining work with caring.
- Information published by Age Concern in 2007 shows that a third of people who provide unpaid care to an older person with dementia have depression.

Carers of people with palliative illness

These carers face similar issues to others carers, however, they are also likely to face some specific difficulties:

- The nature of palliative illness means that carers often adopt this role with little notice and deal with rapid and unpredictable changes
- These carers face the emotional strain of anticipating the death of the person they care for.
- As many people do not identify themselves as carers within the first year of this role, many palliative care carers miss out on support.
- Many children and young people are affected when an adult close to them has a life-limiting illness, but their needs are not always recognised

Carers of people with mental ill health

Research indicates that supporting people with severe mental illness is demanding and impacts on the carer's own health and wellbeing. Among all mental health carers depression, worry and sleeplessness are reported as commonplace. Where problems are most severe for the service user, the impact on the carer is the greatest. ('Under Pressure', Rethink, November 2003).

This report also shows that carers who receive timely information; are in contact with professionals; feel involved, valued and respected and have their own needs assessed and met experience fewer and less severe adverse effects to their own mental and physical health, family relationships, finances and careers and have more time for their own leisure pursuits.

Young carers and young adult carers

National research indicates that caring can have detrimental effects on children both during their childhood and in later life. ('Young Carers: Something to think about', 1997). This includes:

- problems at school, completing homework and getting qualifications
- isolation from other children and other family members
- lack of time for play, sport or leisure activities
- conflict between the needs of the person they are looking after and their own needs
- feeling that there is no one there for them and that professionals do not listen to them
- lack of recognition for their contribution
- feeling that they are different from other children
- feeling that no one understands their experience
- problems moving into adulthood

'Young carers transitions into adulthood' (June 2000) highlights a variety of longer-term consequences including decreased educational, social and employment opportunities. More recent research undertaken by the Princess Royal Trust ('Young Adult Carers in the UK', Princess Royal Trust, 2009) indicates a lack of support for young carers moving into adulthood. This research found strong evidence of financial hardship, little time for relaxation and an impact on access to further education, training or employment.

In order to reduce the possible effects of caring and to maximise their life chances, young carers need:

- recognition of their role
- support with caring tasks
- information about support available to them
- emotional support, and especially someone they can talk to about their feelings

Specific issues arising from parental mental ill health and/or substance misuse

There has been a growing awareness that young carers tend to be particularly hidden in families where there is parental mental health and/ or substance misuse issues (alcohol and drug misuse).

Children in these families may be caring for one or both parents and/or their siblings, but there are wider concerns about their emotional and physical welfare and safety and the impact that their family life may have on their long-term outcomes.

The Hidden Harm report from the Advisory Council on the Misuse of Drugs (2003) estimated that there were between 250,000 and 350,000 children of problem drug users in the UK. The Government and the National Treatment Agency working together believe that where a household with a substance - misusing parent has a child of 12 years or over, that child is highly likely to be a young carer. Similarly it is estimated that between 780,000 and 1.3 million children are living with adults with an alcohol problem (Alcohol Harm Reduction Strategy for England, 2004)

However a research paper from BioMed Public Health published in October 2009 uses analysis of five UK national household surveys. They found evidence from the surveys to show that current Government estimates of the number of children living with substance misusing parents (alcohol and drugs) are significantly underestimating the problem. They do note:

‘Whilst harm from parental substance use is not inevitable, the number of children living with substance misusing parents exceeds earlier estimates. Widespread patterns of binge drinking and recreational drug use may expose children to sub-optimal care and substance-using role models.’

This research means that, although not all of these children will be young carers, a number of them are likely to be. Therefore the estimates of young carers in the UK are certain to be higher than previously thought. Agencies already struggle to clearly identify young carers in their local area, and numbers of young carers with substance misusing parents are even more difficult to identify because of the hidden nature of this particular group of children and young people.

Working carers (‘The business case for supporting working carers’, Employers for Carers and Carers UK, 2013)

One in nine people in any workforce juggle work and caring responsibilities. 90% of working carers are aged 30+ and the peak age for caring is 45-64. Many carers (one in six) give up or cut back on work to care which is a loss for both themselves and their employers, who lose valued employees with skills and experience and also incur costs in recruiting new workers.

It has been shown that flexible working benefits both employers and employees by:

- attracting and retaining staff,
- reducing stress, sick leave and absenteeism,
- reducing recruitment and training costs,
- increasing resilience and productivity
- improving service delivery
- producing cost savings
- improving people management
- increasing staff morale

What are people telling us?

The vision of the 2008 National Carers Strategy is that ‘by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.’

By 2018:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role
- Carers will be able to have a life of their own alongside their caring role
- Carers will be supported so that they are not forced into financial hardship by their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the ‘Every Child Matters’ outcomes

The National Carers Strategy was refreshed in 2010 with advice from the Standing Commission on Carers and responses received to the consultation. Four priority areas were identified:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the onset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfil their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well

These priorities are reflected in [Darlington’s Carers’ Strategy and Implementation Plan](#) and [Young Carers’ Action Plan 2013-16](#).

What are the issues?

Caring can have an impact on a number of areas of carers’ lives:

- Financially, as carers often face a lower income due to having to give up employment or to reduce working hours in order to care, or are unable to take opportunities for promotion. Carers also face higher costs due to increased living expenses associated with ill health and impairment.
- Health – both mental and physical.
- Personal relationships and inclusion in society – many carers become isolated due to no longer having time to maintain their own personal relationships or employment status.

These impacts can be compounded by a lack of understanding and responsiveness from statutory and other services about carers' needs and the effect that inflexible service provision can have on them.

Another key challenge is to ensure that carers are enabled to recognise their caring role and to access the information they need to support them in it.