

Carers

Joint Strategic Needs Assessment

2017



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Executive Summary

Introduction

A carer is 'anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support'¹.

This JSNA is a needs assessment that:

- Describes the carer population
- Identifies those in priority need
- Highlights where a better service is required

This JSNA will provide insight into the unpaid care provision across Swindon and the extent and nature of local support services. It will inform the targeting of resources and activities in order to drive improvements across carers support infrastructure.

Carers are a socially and demographically diverse group and as the demand for care is projected to grow, people are increasingly likely to become providers of care at some point in their lives. Consideration is given in this report to the personal situations of carers in terms of who they care for, the amount and type of care they provide and the impact that their caring role has on their health, employment situation, finances, quality of life and social relationships. Particular attention is paid to certain groups of carers who face challenging circumstances including young carers, older carers and those caring for people with specific conditions.

National and local policy

The refreshed Carers Strategy of 2010² set out the Government's priorities for carers and identified the actions to be taken to ensure best outcomes for carers. The Care Act 2014 recognised carers in law in the same way as those they care for. Carers who are over 18 are now entitled to an assessment of their support needs.

Local authorities and clinical commissioning groups are required to have local carers' strategies and plans, and budgets for supporting carers. Swindon Borough Council (SBC) and NHS Swindon Clinical Commissioning Group (CCG) are committed to supporting Carers who provide services looking after people in different circumstances. SBC has a statutory duty to offer everyone who defines themselves as being a carer an assessment. The Swindon Carers Centre is commissioned to deliver a range of services to carers in Swindon.

Profile of Carers and the Services they use

No one data source provides a definitive picture of the number of carers locally or their personal circumstances. Self-reported Census data from 2011 provides the most comprehensive picture. At the 2011 Census, 19,140 people in Swindon (9.4%) reported they were providing some level of unpaid care. This is a similar percentage of the population to the national average of 10.4%. An additional 3,724 people

¹ Carers Trust: <http://www.carers.org/role-carer>

² Recognised, Valued and Supported: Next steps for the Carers Strategy. HM Government 2010. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

reported that they provide unpaid care in Swindon in 2011 compared with 2001 (an increase of 23.7%); the increase in numbers of carers is greater than the general population growth (16.4%). The figures and map show that people are providing unpaid care in all parts of Swindon. In general, it appears more people are providing unpaid care in the rural areas but this could be linked to a more elderly population in these areas.

Carers UK has produced a series of research reports, which estimates the latest number of carers in the UK. They estimate there were 21,000 carers in Swindon in 2015. The increase in carers in Swindon of 33.6% since 2001 is the largest percentage increase in the number of carers in the South West, and well above the national average of 17.7%. It is estimated the value of carers in Swindon is just under £400M (up almost £40 million since 2011). Since 2001, the value of care has almost doubled, a 93% increase. 70% of this is attributable to increases in the cost of care and 30% to additional hours of care provided.

Many carers find their role rewarding and want to be there to support their loved ones and often share how valuable they feel their role is. For some carers, calling themselves a 'carer' is vitally important and they feel that it gives value to their role. Many campaigned for this recognition and feel that it more clearly defines what they do to health and care professionals.

Social Care Services

The number of carers assessed has remained stable over the last three years, at around 1,350. 89% of carers known to the Council had their needs assessed in 2015/16. Despite the number of carers assessed each year remaining stable, the number of carer's contacts have fallen year on year in the last three years from 1,349 in 2014/15 to 1,012 in 2016/17. The fall has been across all three broad age groups. Contacts are where a carer has approached Swindon Borough Council through the front door, via adult social care or the duty care team.

Overall, the number of cared for people has increased by 9% between 2014/15 and 2016/17. There have been large increases in the number being given physical support/personal care (90 or 10%) and support with learning disabilities (52 or 29%) but the largest percentage increase has been in those supported with access and mobility issues (57 or 89%).

Swindon carers report a similar quality of life to those in the South West and England overall, although this has deteriorated slightly in all areas between 2012/13 and 2014/15.

Swindon Carers Centre

Swindon Carers Centre (SCC) is a charitable organisation, which is part of the Carers Trust Network, and was established to provide help and support to the 21,000 carers in Swindon. They work in partnership with other organisations, including local NHS services, Swindon Borough Council's Adult Social Care and Children's Services and other local voluntary organisations with the aim of identifying as many carers as possible and to provide the most relevant support for an individuals' caring situation. They also work with the people accessing their services

to raise the profile of carers so carers themselves can have a collective voice in influencing policy makers and service planners.

SCC has 3,863 'active' carers on its database in May 2017 and saw an increase of around 400 (~10%) in 2016/17. The largest increases have been in young adult carers (up ~50%) and in young carers (up ~18%). There are proportionally more carers in the more deprived areas of Swindon. However, this only includes carers registered with the SCC so it may reflect the support and services carers from different deprivation deciles require.

Most carers care for a relation. 28% of dependants are children of carers. 28% are spouses or partners and 29% are parents. The specific health problems of cared for people are not always known but in around 75% of cases their 'service user group' has been recorded. The main service user group is for those with a physical disability (39%) followed by learning disabilities (18%) and neurological conditions (18%).

Swindon Carers Centre (SCC) run an emergency card scheme for carers which enables plans to be put into place quickly to support cared for adults and child should there be an emergency. There are currently 786 carers with 'live' emergency cards.

NHS

It is estimated that 10% of patients on a GP practice list are carers, however, not all are identified by their GP practice and offered the right support. The data on those who are identified is not shared as widely as would be useful, due to there being no current requirement for GP practices to do so.

Carers are an eligible group for receiving an annual influenza vaccination. GP practices are key in identifying those eligible for a vaccination and giving the vaccine. Improving uptake of flu and pneumococcal vaccinations amongst identified population groups is a local priority.

What do people think?

National research has uncovered the hardships of being a carer, for example financial issues and employment issues. A Carers UK survey found that 54% of carers expect their quality of life to get worse in the coming year, while only 6% think it will get better. Carers' priorities included improving financial support, improving carers' health and strengthening rights for carers who want and need to juggle work with care with more statutory rights to time off from work to care.

A Carers survey was distributed by Healthwatch in June 2017 to obtain the views of local service users. There were 171 responses to the survey and these were from a wide range of carers. 69% percent had used the Swindon Carers Centre and 13% did so a lot. 57% of respondents would go there for information and advice, which was higher than any other information source. More than 50% of people thought that each SCC service named in the survey worked well.

The two main factors that carers said helped them in their caring role were personal motivation and respite care. Respondents often mentioned SCC's role as working

well in supporting them but 'soft' factors such as having someone to talk to and meeting other carers were also considered valuable. Carers said they wanted more information, advice and support on a range of topics and for processes such as assessments and medical appointments to happen faster.

Young carers

In Swindon, in 2011, 551 children aged 15 and under and 1,029 aged 16 to 24 reported as providing unpaid care in the Census, representing 1.3% and 4.5% of the age groups.

Young carers want to do the same things that other young people do. They want help at school, with finances, and dealing with family crises. They want to be less isolated and involved in planning for their cared for person. In Swindon, young carers are not identified in routine data on educational performance. This means that the educational performance of young carers cannot be measured.

The Swindon Carers Centre has developed a Young Carer Award for Schools, which currently involves 61 Swindon schools or colleges. Most, if not all, schools in Swindon have a person in school to support young carers and can offer counselling sessions, a quiet place after or during school to complete homework, etc. Swindon Carers Centre offer a support group to young people aged 16 – 25 which addresses the specific needs of young carers as they move to adulthood.

Elderly carers

In Swindon, in 2011, 13.6% of the population aged 65 and over were providing some form of unpaid care, compared to 9.4% in people of all ages. Carers aged 60–69 often juggle caring with the demands of work and financial pressures while those aged over 70 may be more likely to find it difficult to cope with the physical demands of caring. The health and wellbeing of older carers has been highlighted by the Princess Royal Trust for Carers as an area of significant concern.

Carers of people with mental ill-health

Caring for someone with mental health needs presents different challenges for their carer compared with a physical illness or disability. This may be because of the stigma of mental health, it's often hidden and fluctuating nature and legal and ethical issues. There are 358 'active' carers who care for an adult with mental health problems in touch with SCC. Forty four of these carers are aged over 65.

The impact of caring can lead to the loss of contact with friends and family, challenges with partners, and isolation from others they work with due to pressures of the caring responsibilities.

Carers of people with learning disabilities

Based on SBC data, 118 carers aged over 65 known to SBC Adult Social Care were caring for an adult with LD. At least an additional 63 are known to SCC. Of the 118 carers only 36 (31%) have a current record for assessment or review at SBC. Whilst no-one can predict when carers will be unable/unavailable to care the age of 46 has been identified as a time by when adults with a learning disability are more likely to live in residential or nursing care. 58 of the people cared for by the 118 carers are aged 46 or older. Of these 58, 35 are cared for by carers over 75 years.

Carers with multiple caring roles

The term 'sandwich generation' is often used to refer to those looking after young children at the same time as caring for older parents. The pressure of combined caring responsibilities can take a serious toll on families' health, finances, careers and relationships. Eleven percent of carers at SCC care for 2 or more people and 21 carers are providing care for 4 or more people. Only 38 carers providing care to parents and offspring are known to SCC which possibly indicates we are not aware of many of these carers.

The health of carers

Carers UK found that 84% of carers surveyed said that caring has a negative impact on health. Nine in 10 (92%) of carers said that their mental health has been affected by caring. The health of carers deteriorates more quickly than that of non-carers due to the lack of support (often due to a lack of awareness of support available).

In Swindon, a 15 year old female could expect to live a further 68 years (based on 2010-12 data) and spend 8.6 of these providing unpaid care (12.6%). Whereas a 15 year old male could expect to live a further 64.9 years and spend 6.7 of these providing unpaid care (10.3%). Although spending this number of years in a caring role is not ideal the expected number of years of unpaid care from the age of 15 is statistically significantly lower in Swindon than England overall.

Carers for people at the end of life

It is estimated there are around half a million people in the UK at any one time providing care for someone with a life-limiting illness. Inevitably, carers of people who are dying will have to face bereavement and a change in their role. SCC continue to offer support for up to six months after the cared for person has died, and carers can continue to access groups and activities for up to 18 months.

Evidence of effectiveness and cost effectiveness

There is little or no consistent evidence was found that interventions for carers improve carers' wellbeing or quality of life. This is not the same as saying that there is evidence that interventions for carers do not have benefits or are not cost effective. However, many interventions result in increased carer satisfaction. The best evidence is that education, training and information for carers (particularly when targeted at a particular patient group) improve knowledge and caring 'abilities'.

There are gaps in the limited UK-based evidence that supporting carers reduces service use in those they are caring for. This is not the same as saying there is evidence that interventions are not effective. There is some evidence that there are delays in admission to residential care associated with home help care, day care and (for some groups) institutional day care.

There are a number of studies which have quantified the value of the unpaid care provided in England and the UK. Carers are estimated to save the UK economy £119 billion a year in care costs, more than the entire NHS budget and equivalent to £18,473 per year for every carer in the UK. Studies indicate a positive return on investment in supporting carers.

Projections

SBC projections estimate that Swindon's population could increase to 240,000 persons by 2021, and 265,400 by 2031, equivalent to growth of approximately 14% from 2011 to 2021, and a further 10% from 2021 to 2031. The largest increase in persons will be in the 65 to 74 age group, projected to be 12,900 more by 2031. However, the 85+ age group will have the largest growth rate at approximately 136%. By 2031 the population aged over 65 is projected to grow by 25,900 persons to reach a total of 55,000 by 2031, accounting for 46% of total population growth.

The total number of carers is projected to rise to 23,504 in 2021 and to 26,222 by 2031, a 33% rise overall. Because the over 65 population is projected to increase the most, the number of carers in this age group is also projected to increase the most, up from 3,960 in 2011 to 7,500 in 2031 (up 89%).

Recommendations

- Further investment in Young Adult Carers (YAC) Services – the transition from children to adult services is challenging, YAC need recognising in their own right.
- To develop a Swindon Carers Strategy and action plan based on the findings and key messages from this report aligned to the Memorandum of Understanding.
- Sign up by the Carers Leads group to implement and monitor the Swindon Carers Strategy – including key priorities such as: ill health, social isolation and crisis, retirement, bereavement, changes in caring role, coming home from hospital and first access of formal care and support and ensure interventions are targeted towards these.
- It is recommended that the default position should be that every carer over 65 has an Emergency Card.
- That the Pilot employer award standards has a full follow up report on findings and next steps.
- Promotion of the Carers Support Scheme. This is a fund that Carers can access but which is currently not being fully allocated.
- To raise awareness of the specific needs of carers aged 85 and over and ensure services offered are appropriate and targeted.
- Build strong links with the provider of the Reducing Loneliness and Isolation contract in order to support carers who are experiencing this.
- To gain a better understanding of the wider offer for Carers Breaks and how these are accessed, the impact and outcomes.

Introduction

What is a carer?

Although there is no single definition of ‘carer’, a carer is generally described as a person of any age providing unpaid care to an ill, frail or disabled family member, friend or partner. This may include physical care or emotional support, advice and advocacy. It is important to note that a carer is not a volunteer who has been placed in a caring role by a voluntary organisation, nor someone who is paid as a care worker or personal assistant. Clause 10 of the 2014 Care Act defines a carer as: ‘an adult who provides or intends to provide care for another adult (‘adult needing care’)³. The Carers Trust builds on this further and describes the role of a carer as ‘anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support⁴. The Children and Families Act 2014⁵ includes new duties for the assessment of young carers and parent carers of children under 18.

Unpaid carers make an important contribution to the overall supply of care services. As the population grows and ages, an increasing number of people are likely to continue to provide significant levels of care. The value of unpaid care in Swindon is estimated to be £395 million per year⁶. As such, it is important to recognise the potential impact that providing many hours of care each week may have on carers’ own quality of life – their physical and mental health, employment opportunities and social and leisure activities.

Many carers find their role rewarding and want to be there to support their loved ones and often share how valuable they feel their role is. For some carers, calling themselves a ‘carer’ is vitally important and they feel that it gives value to their role. Many campaigned for this recognition and feel that it more clearly defines what they do to health and care professionals.

Swindon’s JSNA process

Understanding Swindon’s changing population, the factors that affect health and wellbeing, the town’s assets and the implications for future services are important in setting priorities and planning future services.

Health Needs Assessments (HNA) are a systematic way of investigating the health and healthcare needs of a population, and the services available to meet those needs. A HNA identifies what works well, as well as scope for improvement, drawing on best practice to provide an evidence base to compare local provision against. HNA also results in action to address gaps and improve service planning, commissioning and policy in the future.

³ Care Act 2014: http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

⁴ Carers Trust: <http://www.carers.org/role-carer>

⁵ Children and Families Act: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

⁶ Valuing Carers 2015, Carers UK, London, 2015: Publication code: UK4073 | ISBN: 978-1-873747-52-0. <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

Joint Strategic Needs Assessment (JSNA) is a process for understanding the current and future health and wellbeing needs of the local population. In particular a JSNA helps us to understand:

- What we know about the current health and wellbeing needs of local people
- How their needs are currently being met
- What we think their future needs are likely to be; and
- How their needs can be best met in the future.

Aims of this JSNA:

- Describe the carer population in Swindon
- Highlight where a better service is required
- Identify those in priority need

This needs assessment will inform the targeting of resources and activities in order to drive improvements across carers support infrastructure, specifically in terms of:

- Early identification of carers – effective signposting to right support
- Increased numbers of carers accessing commissioned support services
- Increased numbers of carers accessing a Carers Assessment
- Carers are able to access services/support they need at the right time in the right place

It is intended to provide insight into the unpaid care provision across Swindon and the extent and nature of local support services.

Carers are a socially and demographically diverse group and as the demand for care is projected to grow, people are increasingly likely to become providers of care at some point in their lives. Consideration is given in this report to the personal situations of carers in terms of who they care for, the amount and type of care they provide and the impact that their caring role has on their health, employment situation, finances, quality of life and social relationships. Particular attention is paid to certain groups of carers who face challenging circumstances including young carers, older carers and those caring for people with specific conditions such as learning disabilities and mental health.

This involves gathering different types of information, interpreting it and pointing to the priorities for improving health and wellbeing in Swindon.

The JSNA process involves many different partners and is overseen by Swindon's Health and Wellbeing Board.

National and local policy

National policy

Carers Strategy

The refreshed Carers Strategy of 2010⁷ set out the Government's priorities for carers and identified the actions to be taken to ensure best outcomes for carers, including:

- 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 outset, both in designing local care provision and in planning individual packages of care.
- 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.

Local authorities and clinical commissioning groups are required to have local carers' strategies and plans, and budgets for supporting carers. The NHS Outcomes Framework places specific emphasis on the provision of carers' breaks and support.

The Care Act

The Care Act 2014 recognises carers in law in the same way as those they care for. Carers who are over 18 are entitled to an assessment of their support needs. This prompted a shift to self-directed support and flexibility in fitting services around the family. The Care Act has a key underpinning principle in the prevention of the escalation of need.

The overarching aims and principles of the Care Act are to modernise social care legislation. It simplifies, consolidates and improves existing legislation; "putting carers on an equal legal footing to those they care for and putting their needs at the centre of the legislation".

Local authorities will be under a duty to provide services through the integration of health services and other care and support providers where it would:

- Improve the wellbeing of the adults or carers needing care and support.
- Contribute towards the prevention or development of needs.
- Improve the quality of care and support provision.

The Care Act places an overarching duty to promote wellbeing. It aims to prevent and reduce needs through early identification, the provision of information and advice, integration, assessments and family based support (including Family assessments and care planning). Local Authorities have a duty of market shaping, to offer more choice; and are expected to adopt an asset based approach of taking

⁷ Recognised, Valued and Supported: Next steps for the Carers Strategy. HM Government 2010. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

into account what individuals, family and community have to help people meet their own needs.

The impact assessment of the Care Act found that the new duties would result in an increase in the numbers of carers being assessed and becoming eligible for support. The Government's analysis shows that, whilst this would lead to an increase in demand for resources, and a need to commission further carer's support, it would be cost effective to meet carers' needs as a preventative measure.

The focus on information and support follows studies and consultation with carers showing that involving carers provides better outcomes for the person with care needs; and provides peace of mind for carers that the person they care for is receiving the best and appropriate treatment; together these result in better health for carers.

The Care Act places a duty on local authorities to provide accessible information and advice that meets the needs of their population. Information and advice must be open to everyone who would benefit from it. People access information and advice from a wide variety of sources:

- Internet
- Friends
- Carers' centres
- Newsletter
- Other carers

Carer's assessments should establish not only the carer's needs for support but the sustainability of the caring role itself, which includes both practical and emotional support the carer provides to the person they are caring for. The assessment should take into consideration the carers activities beyond their caring role and the impact of caring on those activities. It should particularly consider whether the carer works, or wishes to work, and what obstacles their caring responsibilities present to their ability to do so. Carers' assessments should also assess whether the carer wants to or is able to continue in their caring role, this should be without judgement.

NHS England's commitment to carers (2014)⁸

NHS England has carried out engagement with carers to identify what is important for carers. The key themes were:

- Recognise me as a carer (this may not always be as 'carers' but simply as parents, children, partners, friends and members of our local communities).
- Information is shared with me and other professionals.
- Signpost information for me and help link professionals together.
- Care is flexible and is available when it suits me and the person I care for.
- Recognise that I also may need help both in my caring role and in maintaining my own health and wellbeing.
- Respect, involve and treat me as an expert in care.

⁸ <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

- Treat me with dignity and compassion.

Based on these themes, NHS England has developed 37 commitments⁹ around the following priorities:

1. Raising the profile of carers.
2. Education, training and information.
3. Service development.
4. Person-centred, well-coordinated care.
5. Primary care.
6. Commissioning support.

Since the NHS England Commitment to Carers report was produced a further document has been developed called 'An integrated approach to identifying and assessing Carer health and wellbeing'¹⁰ This paper builds on the work started by the NHS England Commitment to Carers that was published in May 2014, and which sought to give the five and a half million Carers in England the recognition and support they need to provide invaluable care for the person they care for.

The paper addresses changes to the way in which Carer health and wellbeing need is identified, assessed, and supported, as a result of changes introduced by the Care Act 2014 and the Children and Families Act 2014. It is, essentially, a resource to help promote working together between Adult social care services, Children's services, NHS commissioners and providers, and third sector organisations that support Carers, of all ages, with a specific focus on developing an integrated approach to the identification, assessment and support of Carers and their families across health and social care. To support this joint working, a template Memorandum of Understanding, to be discussed and agreed locally, is included.

A secondary purpose of this paper is to provide clarity and ensure consistency around the language of care and caring. In some cases, different sectors of care are not clear about their duties under the relevant legislation, that the duties of co-operation between agencies are not clearly understood, and that there are variations in understanding some of the terms used.

An additional purpose of this paper is to identify positive practice in supporting Carers, with a particular focus on Carers from vulnerable communities or at key transition points, in order to reduce health inequalities.

The Better Care Fund (BCF)

This was launched in 2014 and aims to transform local health and social care services so that they work together to provide better joined up care and support, through CCGs and local authorities agreeing joint plans and agreeing to pool elements of their budgets.

⁹ NHS England's commitment to carers (2014). Available at: <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

¹⁰ An integrated approach to identifying and assessing Carer health and wellbeing, NHS England/Patient Experience Team May 2016. <https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/>

Local Health and Wellbeing Boards are responsible for overseeing agreement of the joint plan and for ensuring that funds are used in accordance with the agreed plan. There is a requirement that plans outline the support that would be made available to Carers, reflecting the retention of £130m to fund Carers breaks in 2016/17.

Given the above responsibilities, it is suggested that all partners on the local Health and Wellbeing Board sign the Memorandum of Understanding in order to demonstrate commitment to the duties of co-operation and promotion of wellbeing, as well as the wider commitment to identifying, recognising, assessing and supporting Carers.

Policy relating to Young Carers

The Children and Families Act (2014) states that:

(1) A local authority in England must assess whether a young carer within their area has needs for support and, if so, what those needs are, if:

- (a) It appears to the authority that the young carer may have needs for support, or.
- (b) The authority receive a request from the young carer or a parent of the young carer to assess the young carer's needs for support.

The refreshed Carers Strategy of 2010¹¹ states that: 'Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.'

The United Nations Convention on the Rights of a Child (UNCRC) (1989) identifies that 'Every child has the right to participate fully in family, cultural and social life. It is an integral part of the role of all health and social care services to uphold this convention.'

General Medical Council Guidance for Doctors (2007)¹² requires that 'Doctors should be aware of the needs and welfare of children and young people when they see patients who are parents or carers, or who are cared for by children or young people.'

Local policy

Swindon Borough Council (SBC) is committed to supporting Carers who provide services looking after people in different circumstances. Carers are a vital resource for society; they support their loved ones to stay in their homes and improve the lives of adults. Under the Care Act 2014, SBC has a statutory duty to offer everyone who defines themselves as being a carer an assessment. SBC have a pledge to increase the percentage of carer's assessments/reviews that are completed.

¹¹ Recognised, Valued and Supported: Next steps for the Carers Strategy. HM Government 2010. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf

¹² General Medical Council (2007) 0-18 years guidance for all doctors. Available at: http://www.gmc-uk.org/static/documents/content/0-18_years_-_English_0414.pdf

Swindon Carers Centre (SCC)

As part of the SBC offer to carers the Swindon Carers Centre is commissioned to deliver the following support to carers in Swindon:

- Information
- Carers Assessments
- Signpost to other relevant organisations
- Give one-to-one support, including assistance in accessing services
- Access to breaks and complementary therapies
- Training sessions and self-help groups
- Emergency card scheme¹³

Carers Leads Group Swindon

The Carers Leads Group Swindon is a newly formed (2017) multi agency group where partners agree to co-operate with each other to promote the wellbeing of individual Carers, and to adopt a whole family approach in their work to support local Carers of all ages, in order to:

- maintain the independence and physical and mental health of Carers and their families
- empower and support Carers to manage their caring roles and have a life outside of caring
- ensure that Carers receive the right support, at the right time, in the right place
- respect Carers' decisions about how much care they will provide and respect Carers' decisions about not providing care at all

The group will have a focus on the Memorandum of Understanding (MOU) that is described in the previous section: an integrated approach to identifying and assessing carer health and wellbeing.

Employment

Swindon Carers Centre have launched a Pilot employer award standards scheme in partnership with SCC and SBC. This award will help employers to support Carers in the workplace.

¹³ <http://www.swindoncarers.org.uk/for-carers/emergency-card-scheme/>

Profile of Carers and the Services they use

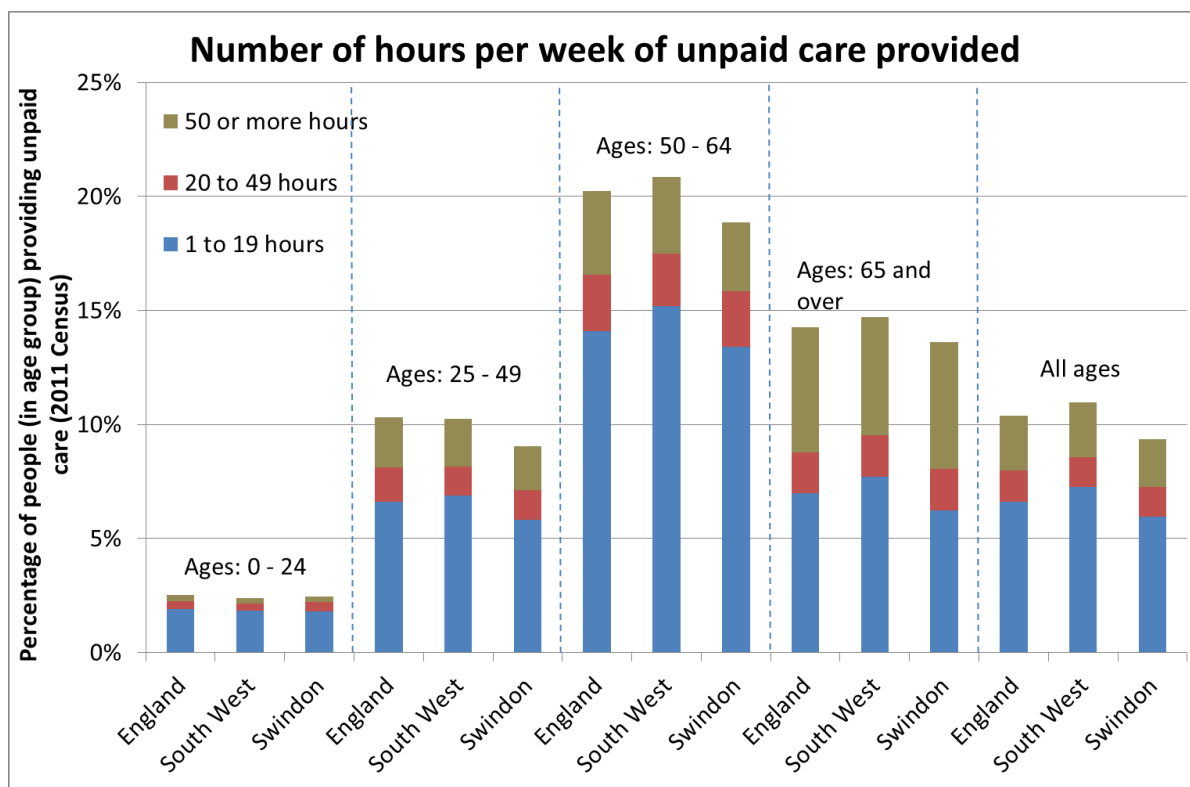
No one data source provides a definitive picture of the number of carers locally or their personal circumstances. Self-reported Census data from 2011 provides the most comprehensive picture.

2011 Census

At the 2011 Census, 19,140 people in Swindon (9.4%) reported they were providing some level of unpaid care. This is a similar percentage of the population to the national average of 10.4%

Figure 1 and table 1 shows the number of hours of care provided by age group. Overall, 4,355 (22%) carers provide 50 hours or more of care. However, in the 65 and over age group the percentage rises to 41% (1,567). These percentages are similar to the national averages.

Figure 1: Provision of unpaid care in Swindon in 2011



Source: ONS, 2001 & 2011 Census

In Swindon, in 2011, 43% of carers were male and 57% female, which is similar to the gender difference nationally. The gender split was fairly consistent over the age groups with the highest percentage of male carers in the 65 plus age bracket (47%). The percentages of carers providing 50 hours or more care were also very similar between the genders with the biggest difference seen in the 25 to 49 age group where 23% of women provided 50 hours care compared to 18% of men.

Table 1: Number and percentage of carers providing 50 hours or more care, Swindon, 2011

Swindon	Number	% of age group
0 to 24	161	10%
25 to 49	1521	21%
50 to 64	1106	16%
65 and over	1567	41%
All ages	4355	22%

Source: ONS, 2001 & 2011 Census

An additional 3,724 people reported that they provide unpaid care in Swindon in 2011 compared with 2001 (an increase of 23.7%); the increase in numbers of carers is greater than the general population growth (16.4%). The percentage providing unpaid care was also slightly higher in Swindon in 2011 compared to 2001 (9.7% v 8.8%), in line with the national trend.

Table 2 shows the increase in the number of people reporting that they provide unpaid care at Census 2001 and at Census 2011 by age group. The largest percentage increase has been in young people, aged under 25 with an additional 610 young carers in 2011 compared to 2001. This compares to a rise of 24% nationally in this age group. In Swindon, the number of male carers rose by 23% and females carers by 24%.

Table 2: Number of people that provide unpaid care, by age group, Swindon 2001 and 2011

	2001	2011	Change	% Change
0 to 24	965	1,575	610	63%
25 to 49	6,613	7,194	581	9%
50 to 64	5,319	6,862	1,543	29%
65 and over	2,829	3,819	990	35%
All ages	15,726	19,450	3,724	24%

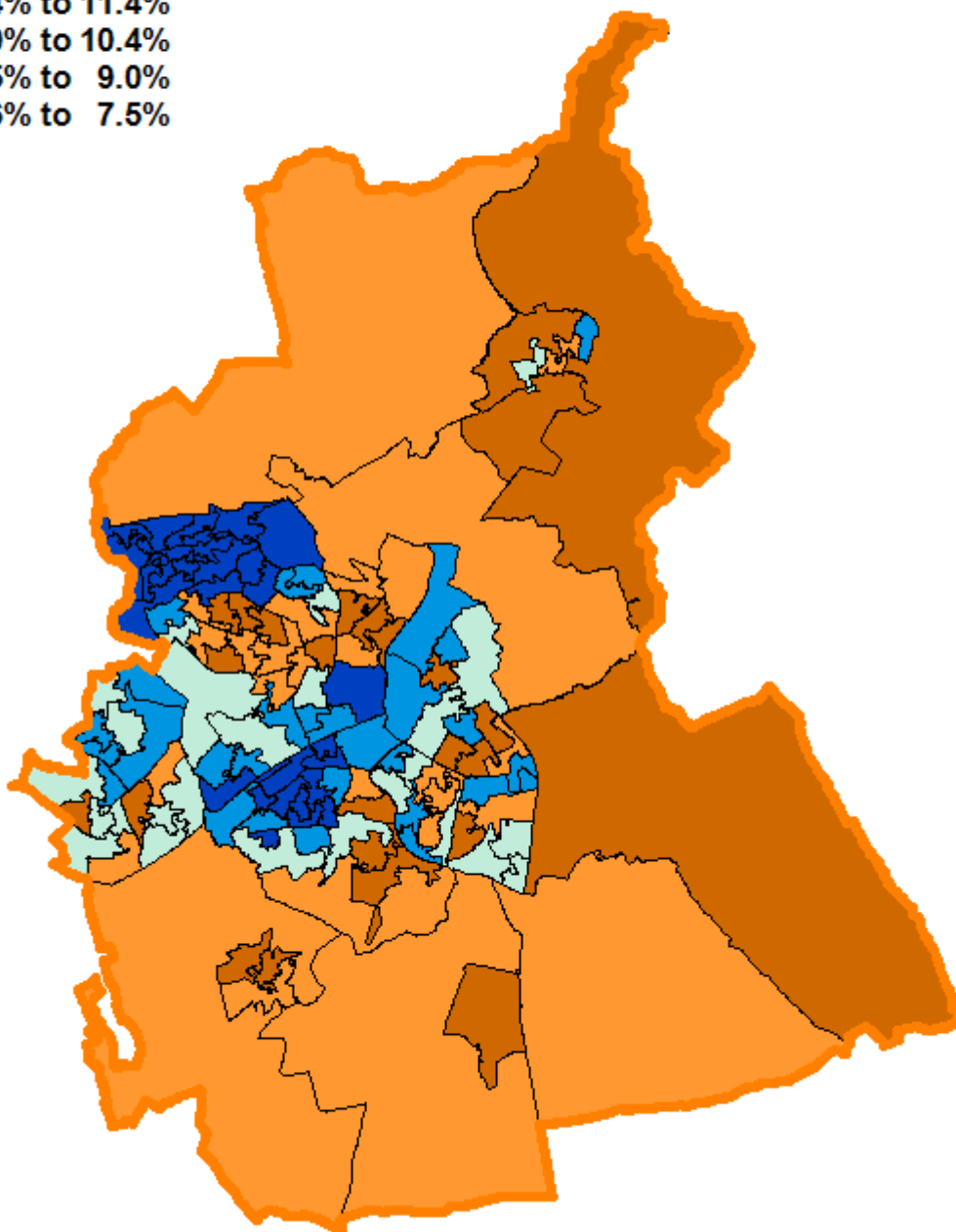
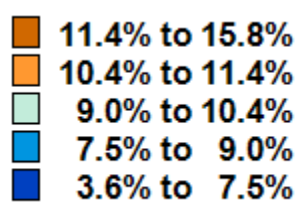
Source: ONS, 2001 & 2011 Census

Small area analysis and deprivation

Analysis of 2011 Census was carried out using Lower Super Output Areas (LSOAs) which are small area geographies used by the Office for National Statistics to analyse and release data at local level. There are 132 LSOAs in Swindon.

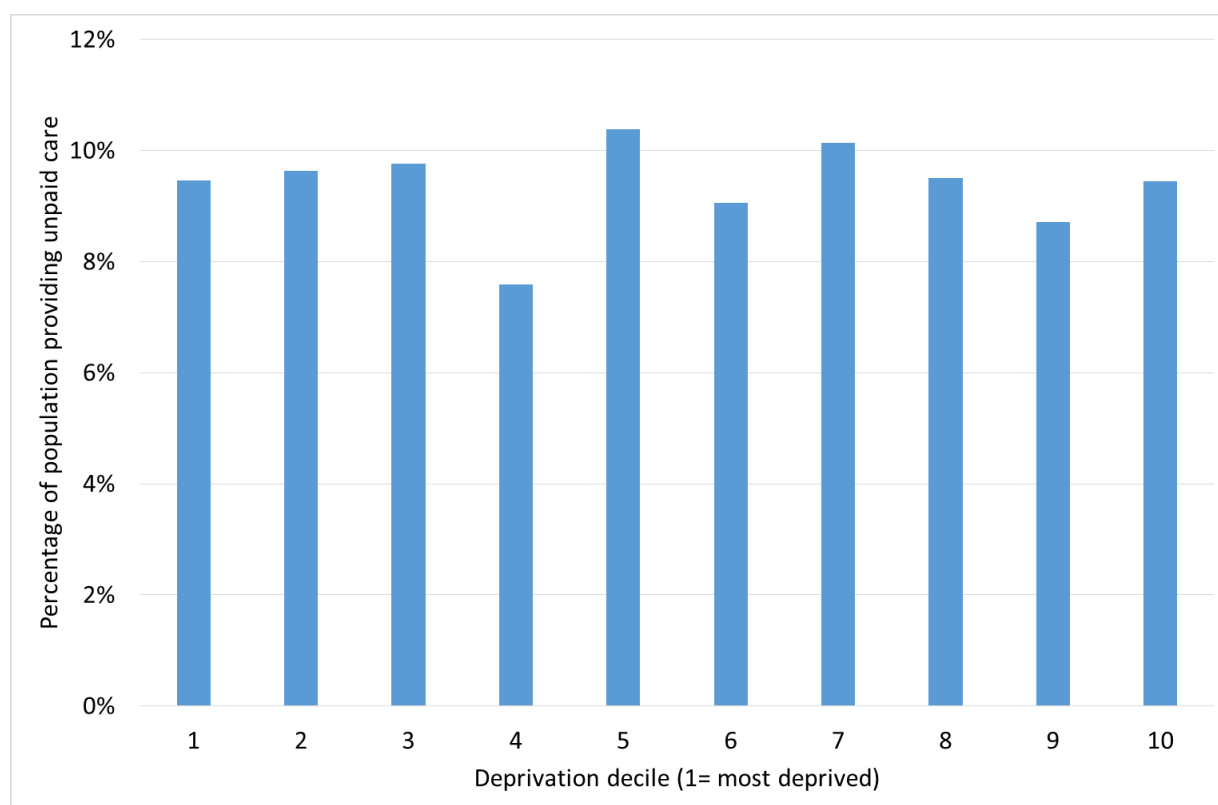
The map in figure 2 below shows that people are providing unpaid care in all parts of Swindon. In general, it appears more people are providing unpaid care in the rural areas but this could be linked to a more elderly population in these areas.

The percentage of people providing unpaid care varies from 15.8% in Lawn north west LSOA to 3.6% in Okus west. Similarly the percentage of people providing 50 or more hours of unpaid care varies across LSOAs from 4.5% in Park South central to 0.5% in Okus west and St Andrew west.

Figure 2: percentage of people providing unpaid care by LSOA, Swindon, 2011

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Map created by Tom Frost, Senior Public Health Intelligence Analyst
Swindon Borough Council, 2017

In Swindon, (as shown by figure 3) there is little difference in the percentage of unpaid care between the most and least deprived areas.

Figure 3: Distribution of carers in Swindon by deprivation decile

Source: ONS, Census 2011, IMD 2015

Two influences on the amount and distribution of unpaid care across deprivation deciles are, firstly, that people in less deprived areas live longer, and therefore their populations are somewhat older and more at risk of surviving into states of dependency, whereas in the most deprived areas the mortality rate is higher.

A second potential influence is where care is being provided. There may be carers living in less deprived areas who could be providing care for people in more deprived areas, where need is likely to be greater, which would counter any relationship with deprivation.

Carers UK 2015 estimates

Carers UK have produced a series of research report which estimates the latest number of carers in the UK and the value to the UK economy of the support they provide. The latest report is for 2015¹⁴.

The report estimates the number of carers in 2015 by applying the 2011 Census local carer prevalence rates by age, sex and amount of care to the official 2015 population projections.

¹⁴ Valuing Carers 2015, Carers UK, London, 2015: Publication code: UK4073 | ISBN: 978-1-873747-52-0. <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

Table 3: Estimate of carers in 2015 and their value to the economy

Area	Carers 2015	Change (01-15)	Change (11-15)	Value in 2001 (£m)	Value in 2011 (£m)	Value in 2015 (£m)
Swindon	21,006	33.6%	7.8%	176	359	395
South West	600,612	22.0%	5.3%	5,450	10,170	10,947
England	5,712,398	17.7%	5.2%	55,443	100,973	108,418

Source: Carers UK

The increase in carers in Swindon of 33.6% since 2001 is the largest percentage increase in the number of carers in the South West, and well above the national average of 17.7%.

The estimated value of carers in Swindon is £395 million per year (up £36 million since 2011).

A rise in the cost of providing care, and a dramatic increase in the amount of unpaid care being provided by family and friends, have both contributed to the rise in the value of unpaid care. The 7% national increase attributable to increased hours of unpaid care since 2011 is particularly remarkable. It results mainly (82%) from the increased hours of care carers are providing, and partly (18%) from the increased hourly cost of paid home care. Since 2001, the value of care has almost doubled – a 93% increase. 70% of this is attributable to increases in the cost of care and 30% to additional hours of care provided.

Carer's Allowance

This is an allowance that can be claimed by Carers who are looking after someone for 35 hours a week or more. It is not a means tested benefit, however, there is a cap on how much a carers can earn and be entitled to.

Carer's allowance eligibility

You might be able to get Carer's Allowance if all of the following apply:

- you're 16 or over
- you spend at least 35 hours a week caring for someone
- you've been in England, Scotland or Wales for at least 2 of the last 3 years (this doesn't apply if you're a refugee or have humanitarian protection status)
- you normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces
- you're not in full-time education
- you're not studying for 21 hours a week or more
- you earn no more than £116 a week after tax and some expenses - these will be assessed when you apply
- you're not subject to immigration control

The number of people in receipt of CA in Swindon has over doubled between 2006 and 2016. There are now a total of 2,260 people receiving CA. 24% of recipients are male and 76% female. This is a much more pronounced gender difference than in the 2011 Census figures on those providing unpaid care. The majority of those receiving CA are of working age.

Table 4: Claimants of Carers Allowance, Swindon, 2006 and 2016

Age	Males		Females	
	2006	2016	2006	2016
aged under 18	~	~	~	10
aged 18-24	10	30	30	60
aged 25-29	10	20	60	160
aged 30-34	10	50	100	240
aged 35-39	20	40	150	230
aged 40-44	30	50	140	230
aged 45-49	30	70	120	250
aged 50-54	20	100	70	220
aged 55-59	40	70	140	170
aged 60-64	50	90	30	110
aged 65 and over	10	10	30	30
Total	220	540	870	1,720

Source: Nomis.

Note: column totals may not equal the sum of the constituent rows because of rounding.

The increase in people claiming CA has been larger in Swindon than in the South West or England overall as shown in Table 5.

Table 5: Change in number of claimants of Carers Allowance between 2006 and 2016

		2006	2016	Change
Males	Swindon	220	540	145%
	South West	8150	14,820	82%
	England	96,220	186,350	94%
Females	Swindon	870	1,720	98%
	South West	25,380	41,100	62%
	England	288,060	496,320	72%
Persons	Swindon	1,090	2,260	107%
	South West	33,530	55,920	67%
	England	384,280	682,670	78%

Source: Nomis

Social Care Services

Carer’s Assessments

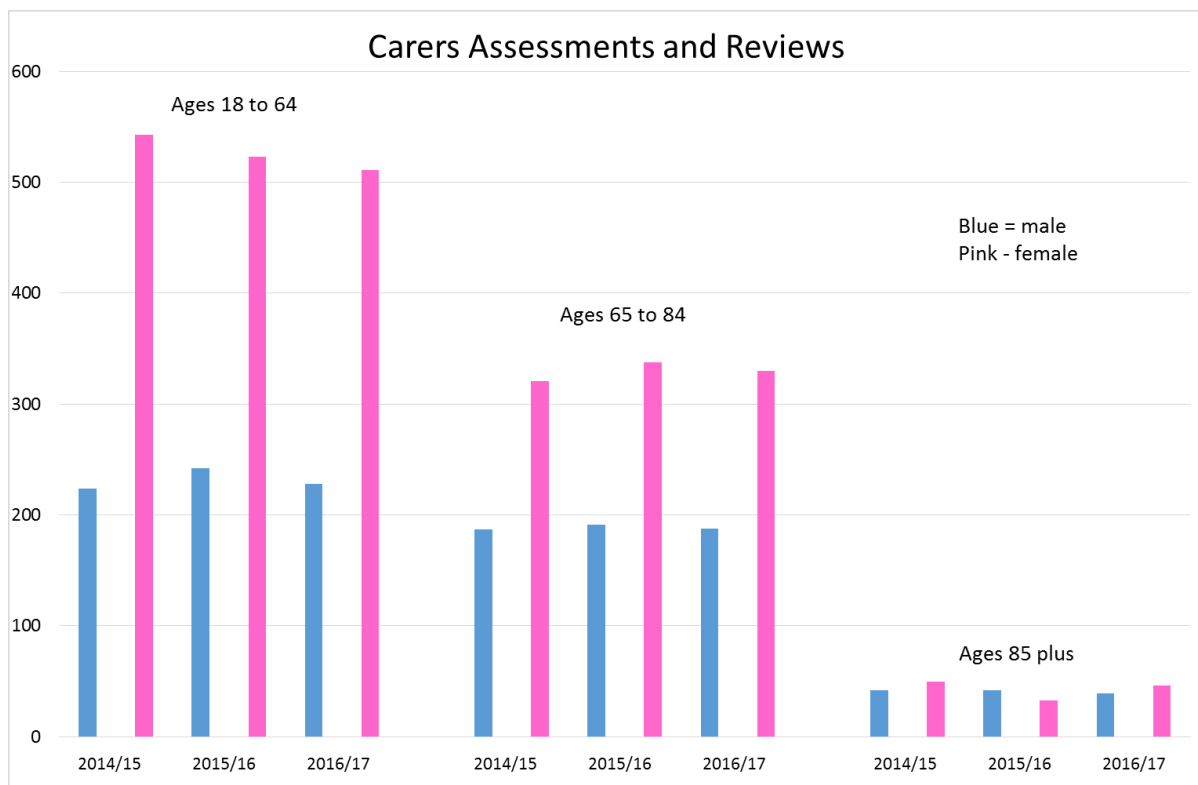
Under The Care Act 2014 and the Children and Families Act 2014 carers are entitled to request an assessment of need regardless of their income and finances or their level of need. Young carers and the parents of disabled children are also included in within this.

The benefit of having an assessment is that it gives carers the opportunity to express their feelings and needs as a carer. The Assessment will identify any care and support needs and provide information and advice about services aimed at meeting those needs.

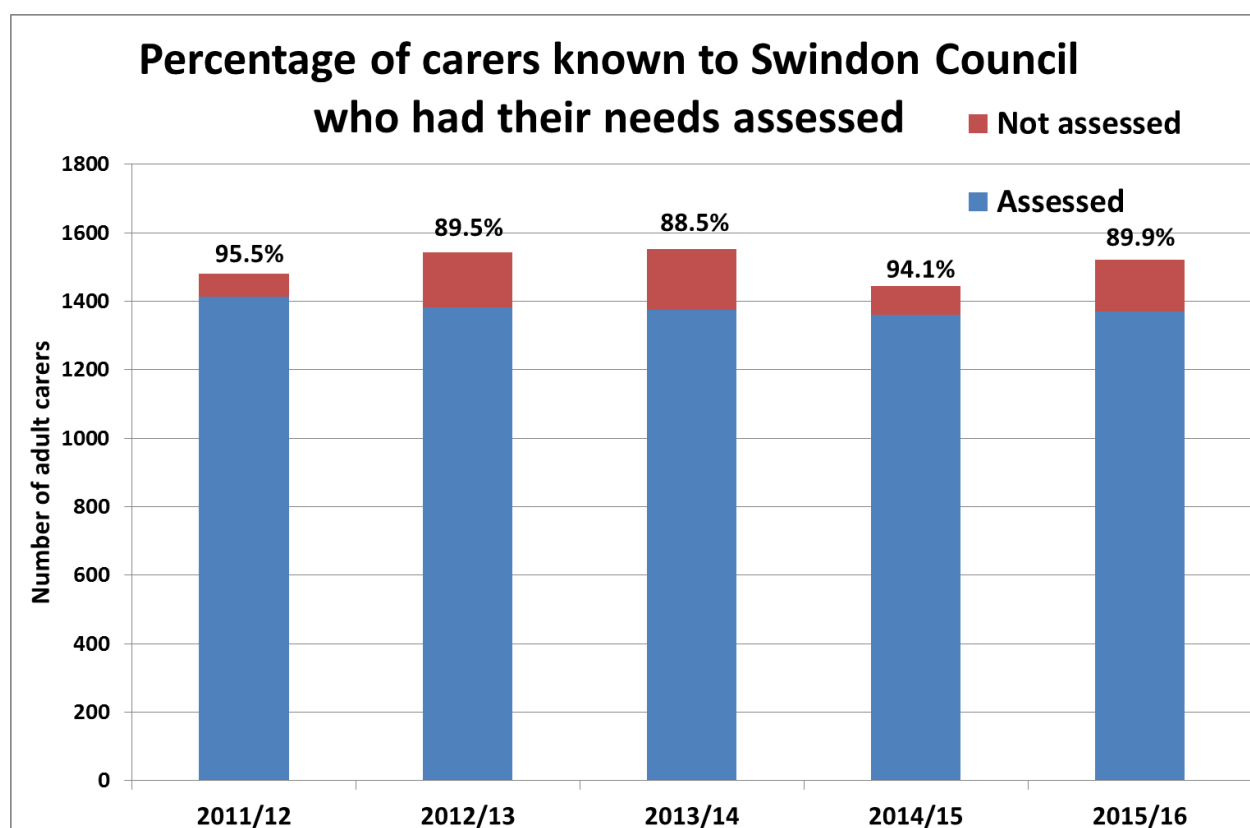
Swindon Borough Council has four priorities, one of which is ‘to help people to help themselves while always protecting our most vulnerable’, under this priority sits pledge 26 which aims “to ensure that more people and their carers are supported to live as independently as possible”. The Council is working with Swindon Carers Centre, Avon and Wiltshire Mental Health Partnership (AWP) and the Community Navigators (Community Navigators support adults with long-term health conditions who are at high-risk of hospital admission to care for themselves better and are based in GP practices) to ensure more carer’s assessments are in place and reviewed appropriately.

The number of carers assessed has remained stable over the last three years, at around 1,350.

Figure 4: Carer’s Assessments and Reviews, 2014/15 – 2016/17



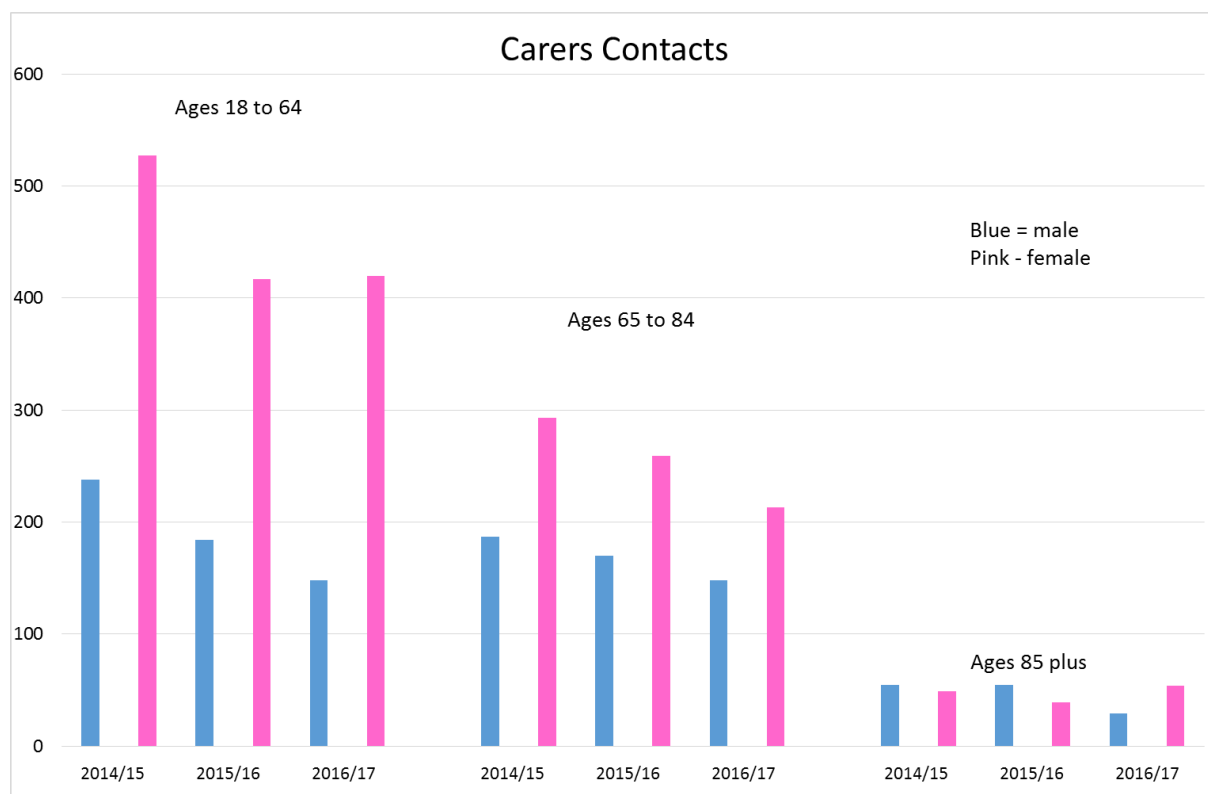
Source: SBC, Adult Social Care

Figure 5: Carers who had their needs assessed, 2011-12 - 2015/16

Source: SBC, Adult Social Care

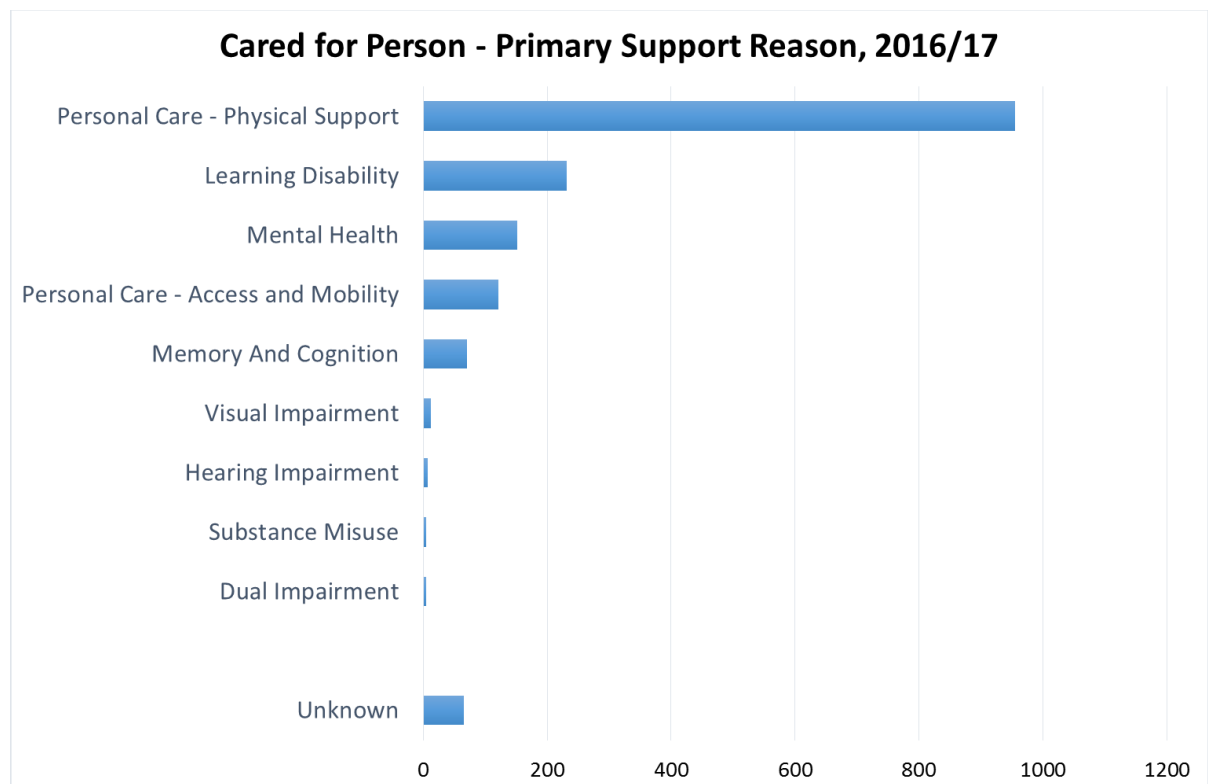
Despite the number of carers assessed each year remaining stable, the number of carer's contacts have fallen year on year in the last three years from 1,349 in 2014/15 to 1,012 in 2016/17. The fall has been across all three broad age groups. Contacts are where a carer has approached Swindon Borough Council through the front door, via adult social care or the duty care team. However, there has been an increase of 12% of carers registering with Swindon Carers Centre since 2015/16, and a 52% increase in Carers assessments carried out by SCC since 2015/16. A further 195% increase has been reported of carers using the SCC Carer Support Line since 2015/16. This demonstrates improved awareness of the Swindon Carers Centre and the impact the service has had on demand on Adult Social Care services.

Figure 6: Carers Contacts, 2014/15 – 2016/17



Source: SBC, Adult Social Care

Figure 7: Primary Support Reason of cared for person, 2016/17



Source: SBC, Adult Social Care

In 2016/17, 73% of people who were being cared for because of a learning disability were aged between 18 and 64 as were 60% of those with a mental health problem. This compares to 54% of cared for people overall. In contrast, only 34% of those being cared for because of memory or cognition problems were aged between 18 and 64 as were 47% of those being given personal care because of access or mobility issues.

Table 6: Primary Support Reason of cared for person, 2016/17, by broad age range

Primary Support Reason	% aged 18 to 64	% aged 65 or older
Personal Care - Physical Support	50%	50%
Learning Disability	73%	27%
Mental Health	66%	34%
Personal Care - Access and Mobility	47%	53%
Memory And Cognition	34%	66%
Other	55%	45%
Unknown	59%	41%
Total	54%	46%

Source: SBC, Adult Social Care

Overall, the number of cared for people has increased by 9% between 2014/15 and 2016/17. There have been large increases in the number being given physical support/personal care (90 or 10%) and support with learning disabilities (52 or 29%) but the largest percentage increase has been in those supported with access and mobility issues (57 or 89%). The increases in LD and access and mobility come from across the age groups but the increase in physical support/personal care is entirely driven by the increase in the 65 to 84 age group (73 or 22%).

The numbers supported with mental health issues or memory and cognition needs has fallen by 20% and 41% respectively in the 3-year period. The fall in mental health has been concentrated in the 65 plus age groups whereas for memory and cognition it has been mainly in the 18 to 64 age range.

Table 7: Primary Support Reason of cared for person, change between 2014/15 and 2016/17

Primary Support reason	2014/15	2016/17	Change	% change
Learning Disability	180	232	52	29%
Mental Health	189	151	-38	-20%
Personal Care - Access and Mobility	64	121	57	89%
Personal Care – Physical Support	865	955	90	10%
Dual Impairment	6	5	-1	-17%
Hearing Impairment	11	7	-4	-36%
Visual Impairment	19	12	-7	-37%
Substance Misuse	0	5	5	N/A
Memory and Cognition	118	70	-48	-41%
Unknown	43	66	23	53%
Total	1495	1624	129	9%

Source: SBC, Adult Social Care

Carers Support Scheme

Swindon Borough Council Carers Support Scheme offers a one-off payment of up to £500 to carers within the Swindon Borough Council / NHS Swindon area. The Carer Support Scheme aims to give carers choice and control over the support they receive. Often, this might be some time away from their caring role. This can include, Gym Membership, Complementary therapies, a holiday/short break, or it can be used for driving lessons, garden maintenance, or a new washing machine. The support scheme application should enable the carer to identify the type of support that would benefit them in their caring role and in turn, help maintain their health and well-being. In 2016/17, 78 applications were agreed, with a total of £33,000 being awarded.

Respite care

Respite care is the term used for replacement services which enable carers to take a break from caring. This can include a range of things, such as employing someone to sit with the person you care for, cook for them, take them to a day centre, or arranging temporary residential care.

A carer's assessment or the assessment for the person cared will inform whether this is a service a carer can claim, respite services are means-tested and administered by Adult Social Care services.

Carers Personal Budgets

Personal Budget refers to the amount it would cost to meet a carers agreed support needs and gives the carer the independence and control to choose the best support for their needs. Carers will be eligible for a personal budget if they have been assessed as needing support to help them to live independently.

Swindon Borough Council use the carer's assessment and care planning processes to determine the carers' personal budget. It will be set at an amount that enables the carer to meet their needs so that they can continue to fulfil their caring role and takes

into account the outcomes that the carer wishes to achieve in their day to day life. This includes their own wellbeing wishes and /or aspirations concerning paid employment, education, training or recreation if the provision of support can contribute to these outcomes.

The manner in which the personal budget will be used to meet the carers' needs will be agreed as part of the planning process.

Carers' will not be charged for any aspect of the support provided by the Council. This includes any provision of a 'sitting service' for the adult who is being cared for. However, if the carers' needs for support are being met through the provision of extra care for the adult being cared for, these services may be chargeable to the adult being cared for in accordance with the Council's Fairer Charging Policy. The carer will not be charged. This does not impact on the ability of a carer to use a direct payment to pay for extra care or direct care from their direct payment.

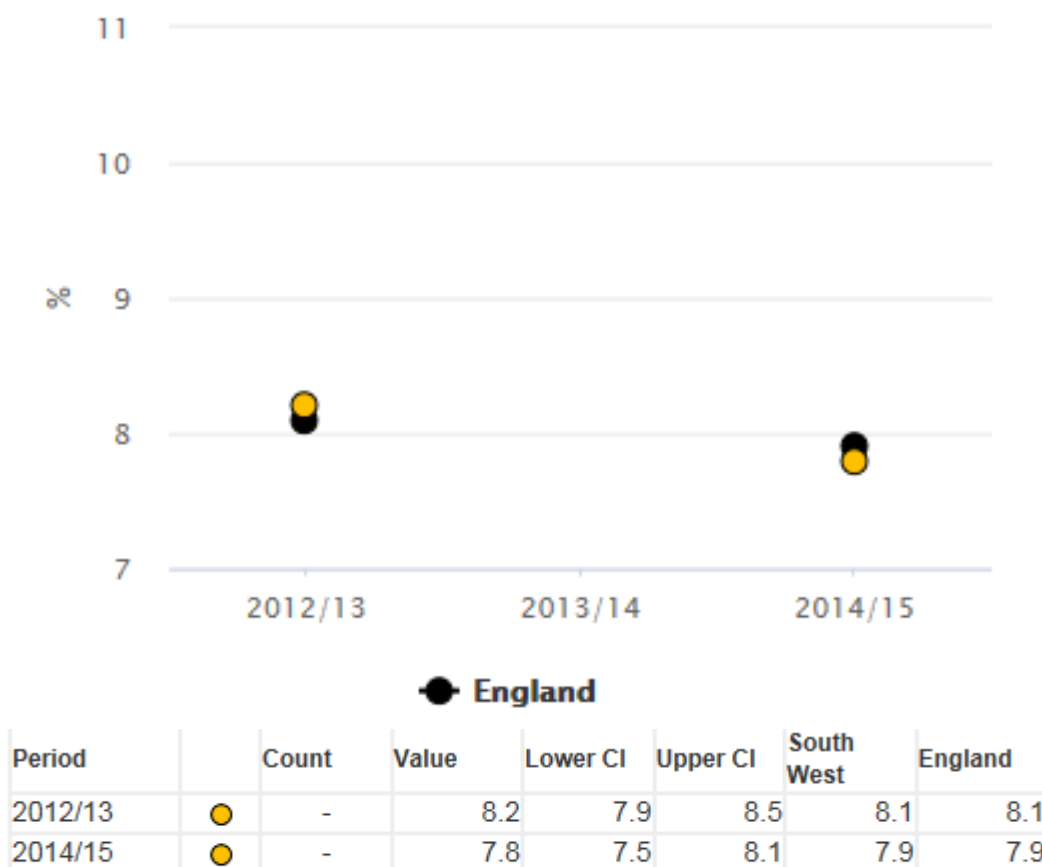
Adult Social Care Survey – Carers results

User experience information is critical for understanding the impact of services, for enabling choice and for informing service development. Therefore, an adult social care survey is carried out every two years which asks users of adult social care services about the care and support services they receive and their quality of life. The results are used in the Adult Social Care Outcomes Framework (ASCOF).

85% of carers who responded to the 2016/17 Swindon Adult Social Care survey said they had informed their GP that they were a carer. All carers aged 85 or over had informed their GP and there was little difference other than that between the age groups. 10% of carers in the survey were dissatisfied with the support they received through their GP practice, again this varied little by age other than no carers aged 85 or older being dissatisfied.

Swindon carers report a similar quality of life to those in the South West and England overall, although this has deteriorated slightly in all areas in the two years between surveys.

Figure 8: Carer-reported quality of life (ASCOF 1D)

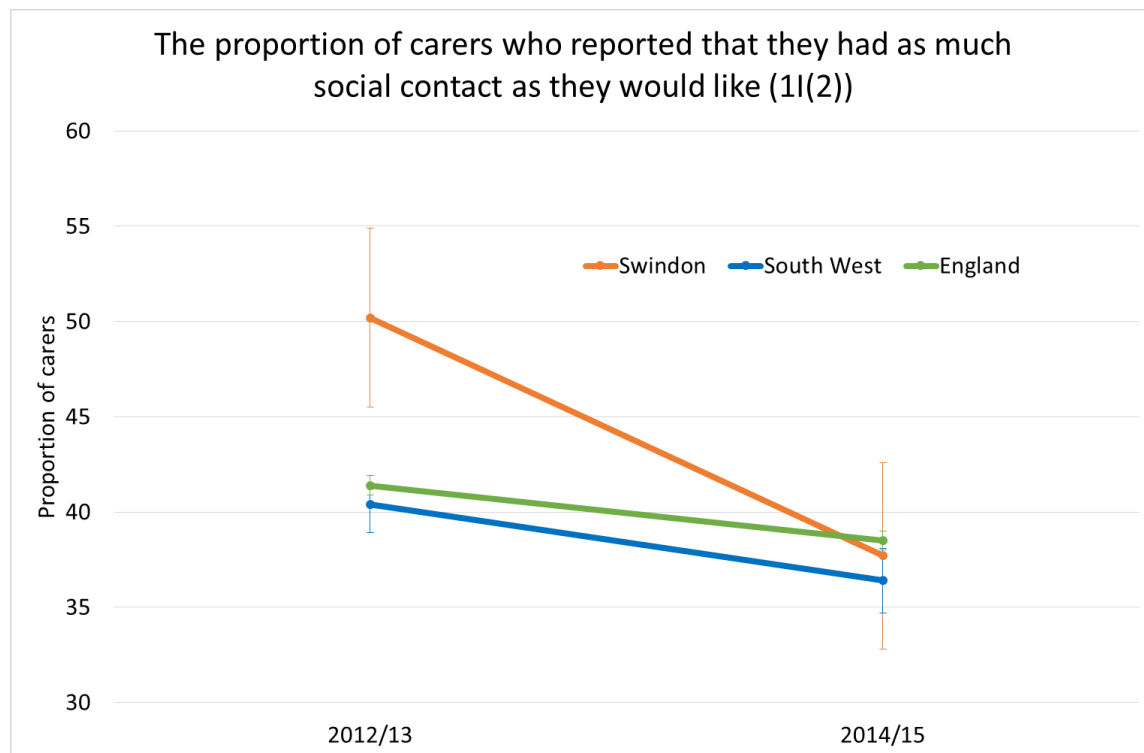


Source: NHS digital, ASCOF

Source: PHE fingertips, Adult Social Care: <https://fingertips.phe.org.uk/profile/adultsocialcare>

The proportion of Swindon carers who report that they have as much social contact as they would like was much higher than for the South West or England in 2012/13. However, the proportion has fallen between 2012/13 and 2014/15 and Swindon is now similar to other areas.

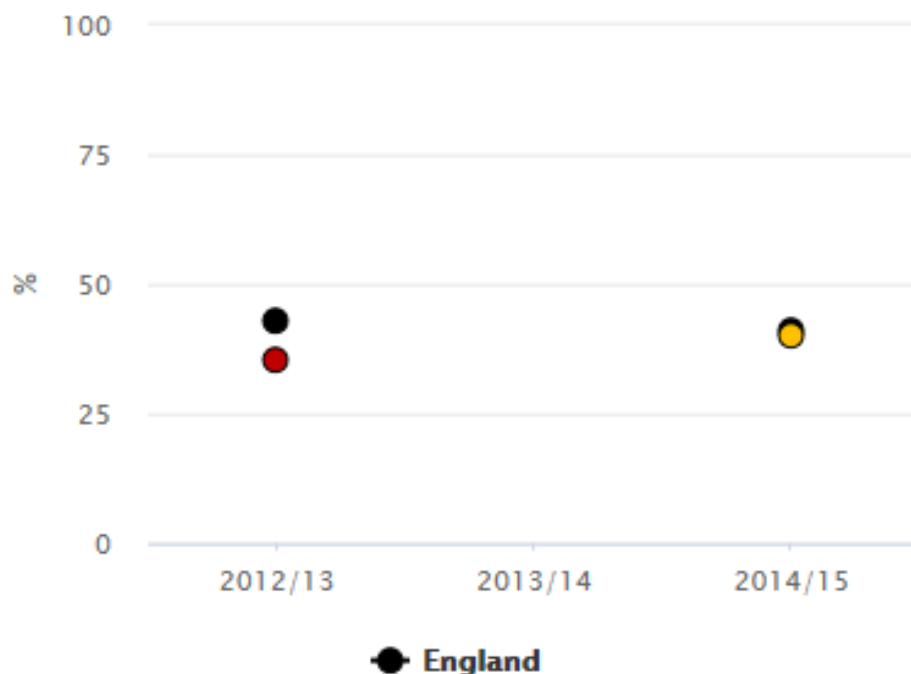
Figure 9: The proportion of carers who reported that they had as much social contact as they would like (11(2))



Source: NHS Digital (ASCOF)

Satisfaction with social services has risen amongst Swindon carers between 2012/13 and 2014/15 and is now only slightly lower than satisfaction levels in the South West and England.

Figure 10: Overall satisfaction of carers with social services (3B)



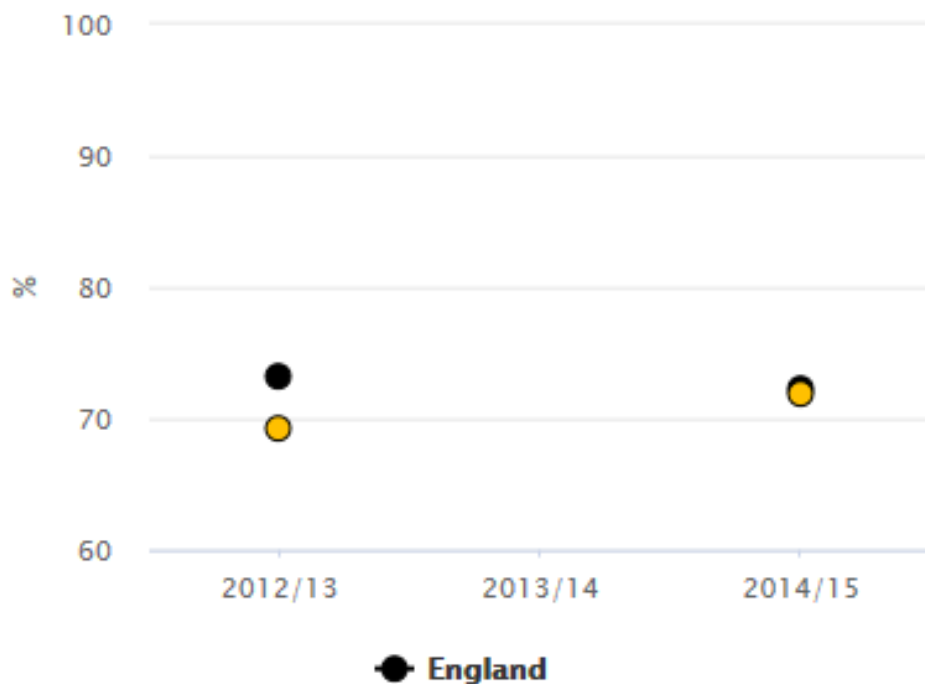
Period	Count	Value	Lower CI	Upper CI	South West	England
2012/13	-	35.5	29.4	41.6	46.4	43.1
2014/15	-	40.0	34.3	45.7	41.9	41.2

Source: NHS digital, ASCOF

Source: PHE fingertips, Adult Social Care: <https://fingertips.phe.org.uk/profile/adultsocialcare>

The proportion of carers who report that they have been included or consulted in discussions about the persons they care for has risen amongst Swindon carers between 2012/13 and 2014/15 and is now only slightly lower than for carers in the South West and England.

Figure 11: The proportion of carers who report that they have been included or consulted in discussion about the person they care for (3C)



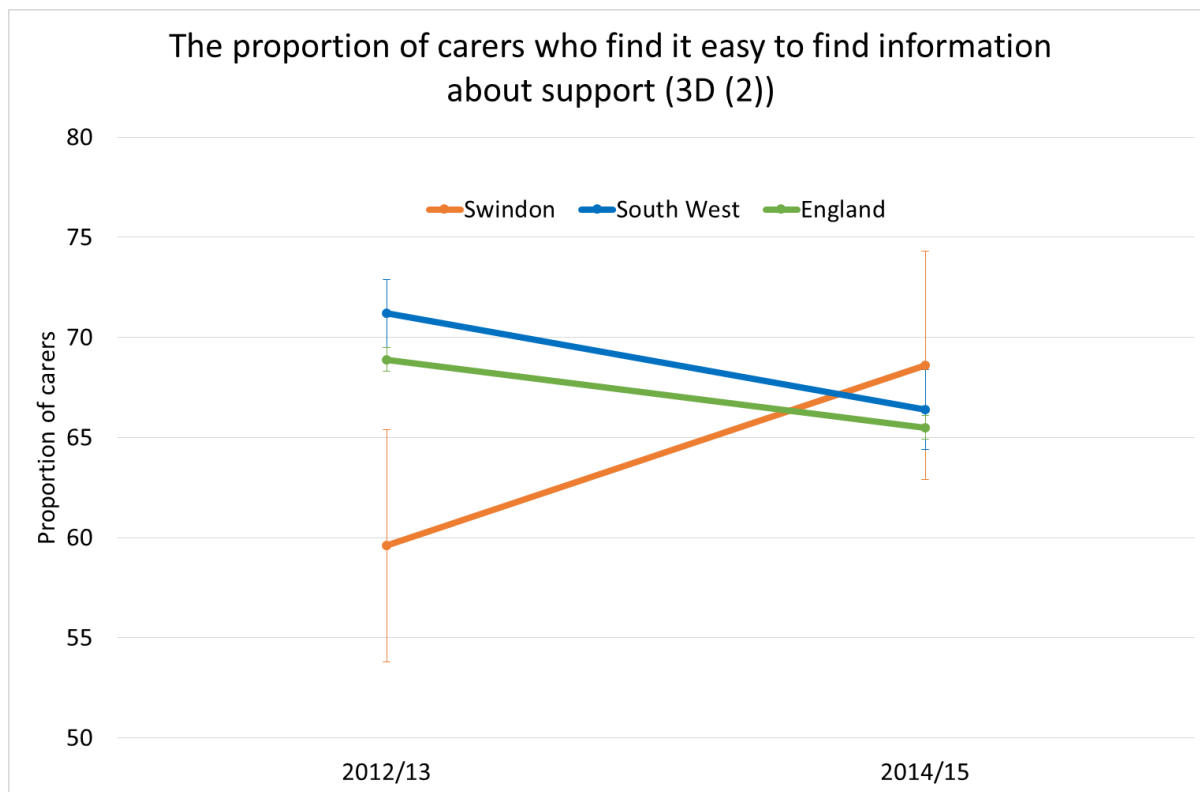
Period	Count	Value	Lower CI	Upper CI	South West	England
2012/13	-	69.3	63.5	75.1	73.3	73.3
2014/15	-	71.8	66.1	77.5	72.1	72.3

Source: NHS digital, ASCOF

Source: PHE fingertips, Adult Social Care: <https://fingertips.phe.org.uk/profile/adultsocialcare>

The proportion of Swindon carers who report that they find it easy to find information about support was much lower than for the South West or England in 2012/13. However, the proportion has risen between 2012/13 and 2014/15 and Swindon is now similar to other areas.

Figure 12: The proportion of carers who find it easy to find information about support (3D (2))



Source: NHS Digital (ASCOF)

Swindon Carers Centre

Swindon Carers Centre (SCC) is a charitable organisation, which is part of the Carers Trust Network, and was established to provide help and support to the 21,000 carers in Swindon. They work in partnership with other organisations, including local NHS services, Swindon Borough Council's Adult Social Care and Children's Services and other local voluntary organisations with the aim of identifying as many carers as possible and to provide the most relevant support for their caring situation. They also work with them to raise the profile of carers so carers themselves can have a collective voice in influencing policy makers and service planners.

SCC provides:

- Assessment, advice and support for adult, parent, young adult carers and young carers, including a carers' Emergency Card scheme.
- Information to carers about benefits.
- Opportunities for carers to have a break from caring, including specific activities for older carers.
- Young Adult Carer activity group.
- Outreach activities to raise awareness of carers' and their needs and help carers to self-identify.
- Regular group sessions for young carers assessed as in most need.
- Holiday activities accessible to all registered young carers.
- Information, Advice, Guidance and Signposting: SCC run various information, advice and guidance sessions. Carers can also book an appointment to complete a Carers assessment with a Carer Support Practitioner.
- Specific Sessions and Training: SCC also organises and delivers various specific sessions on pertinent topics such as Manual Handling, Wellbeing courses- that include CALM, (Mindfulness and relaxation), Stress and Mood management, Overcoming Panic, Anxiety and Worry. Workshops in CV writing and back to work. Condition specific sessions for young carers.

The Carers centre also offer the following services:

- Carers Newsletter and E-Bulletin: The Newsletter is produced quarterly and E-Bulletin is produced monthly and in addition to listing important contact details they give details of various events and sessions for Carers provided by both professional and community organisations. The magazine features articles on topical issues such as welfare reform and changes to the benefit system and articles about local sources of support within the community.
- SCC organise and run the Carers Rights Day: In 2016 the theme was 'Missing out? Know your rights'. There were talks and workshops around carers' rights and local support available delivered by Swindon Carers Centre, Swindon Borough Council, NHS England, Avon and Wiltshire Mental Health Partnership and Swindon Citizen and Advice and Robert Buckland MP. Speakers were also available for a question and answer session.

- Awareness Raising Sessions: SCC organise various sessions during the year either separately or with partner organisations to try to identify 'hidden carers' and to raise awareness of the potential support available. For example last year sessions were put on during Carers Week to raise awareness plus on Carers Rights Day around Carers and employment.
- Information, Advice, Guidance and Signposting: SCC run various information, advice and guidance sessions. Carers can also book an appointment to complete a Carers' assessment with one of the staff.
- Specific Sessions and Training: SCC also organises and delivers various specific sessions on pertinent topics such as Manual Handling, Wellbeing courses- that include CALM, (Mindfulness and relaxation), Stress and Mood management, Overcoming Panic, Anxiety and Worry. Workshops in CV writing and back to work.

Additionally, SCC:

- Works with GPs and other health/social care services to improve recognition and good practice regarding carers.
- Works with Great Western Hospital (GWH) to help recognise and support carers using GWH.
- Works with schools and colleges to develop good practice in relation to young carers and continues to deliver the Young Carer Award.

Swindon Carers Centre Annual Report for 2016/17 reported:

- 100% of carers reported that their carer's assessment met their needs.
- 100% carers reported they feel able to make informed decisions about their caring role following their carers assessment
- 1,967 attendances at adult and parent carer groups, activities and events
- 100% adult carers who attended specific information events/training reported better understanding of a diagnosis and condition management
- A 12% increase in the number of adult carer registrations with SCC
- 1,345 attendances at young carer groups and holiday activities.
- 100% young carers reported that attending groups provided a break
- 98% young carers made new friends at groups and activities provided by SCC

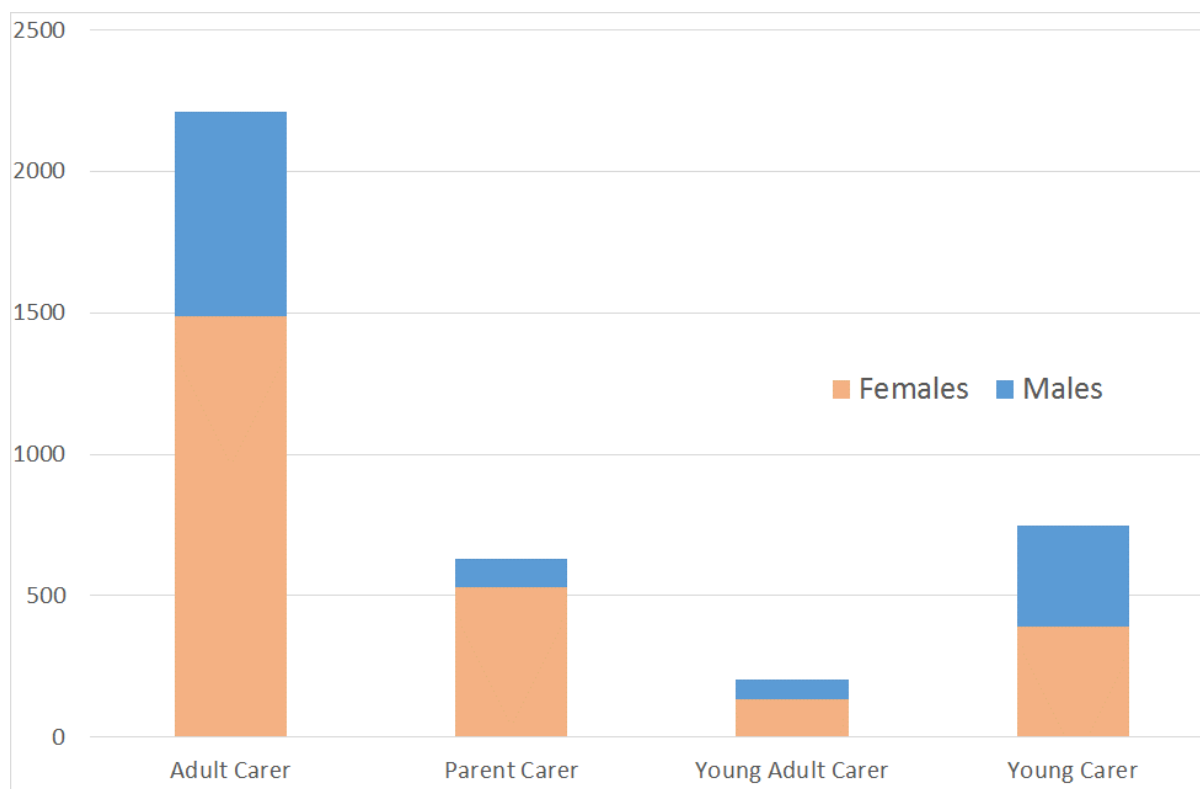
Known Carers engaged and receiving services from SCC

Only a fraction of the carers in Swindon will be known to SCC. Many will either not seek services or will approach the Council directly. Referrals to SCC come from a very wide variety of sources and around half of clients are self-referred. SCC has 3,863 carers engaged and receiving services on its database in May 2017¹⁵ and this increased by around 400 (~10%) since the previous year. The largest increases have been in young adult carers (up ~50%) and in young carers (up ~18%). There was only a 5% rise in parent carers. The majority (84%) of parent carers are female

¹⁵ Only includes carers who consented for their data to be shared.

but young carers are split almost equally between the genders (52% female and 48% male).

Figure 13: Number of Carers by Carer category, May 2017



Source: SCC (53 carers excluded due to incomplete information)

Carers known to SCC come from every age range from 0-9 to 90 plus.

Table 8: Carers known to SCC by age and gender, May 2017

	Female	Male	Total
0-9	100	106	206
10-14	211	187	398
15-17	116	93	209
18-19	50	20	70
20-29	110	38	148
30-39	239	65	304
40-49	390	115	505
50-59	435	169	604
60-69	343	149	492
70-79	243	142	385
80-89	143	120	263
90 plus	13	15	28
Total	2,393	1,219	3,612

Source: SCC (251 carers excluded due to incomplete information)

66% of carers are female and 34% male. The gender difference is most pronounced in the working age groups.

23% of carers are under 18, 43% between the ages of 20 and 59 and 32% are aged 60 or older of whom 291 are 80 or older (8%).

89% of carers about whom ethnicity is recorded are White British.

Table 9: Number of hours unpaid care provided by age group

Age\Hours	1 to 10	11 to 30	31 to 49	50+	Total
Under 18	302	273	37	2	614
18-39	17	57	56	173	303
40-59	31	136	121	329	617
60-79	20	86	116	338	560
80 plus		14	37	137	188
Total	370	566	367	979	2282

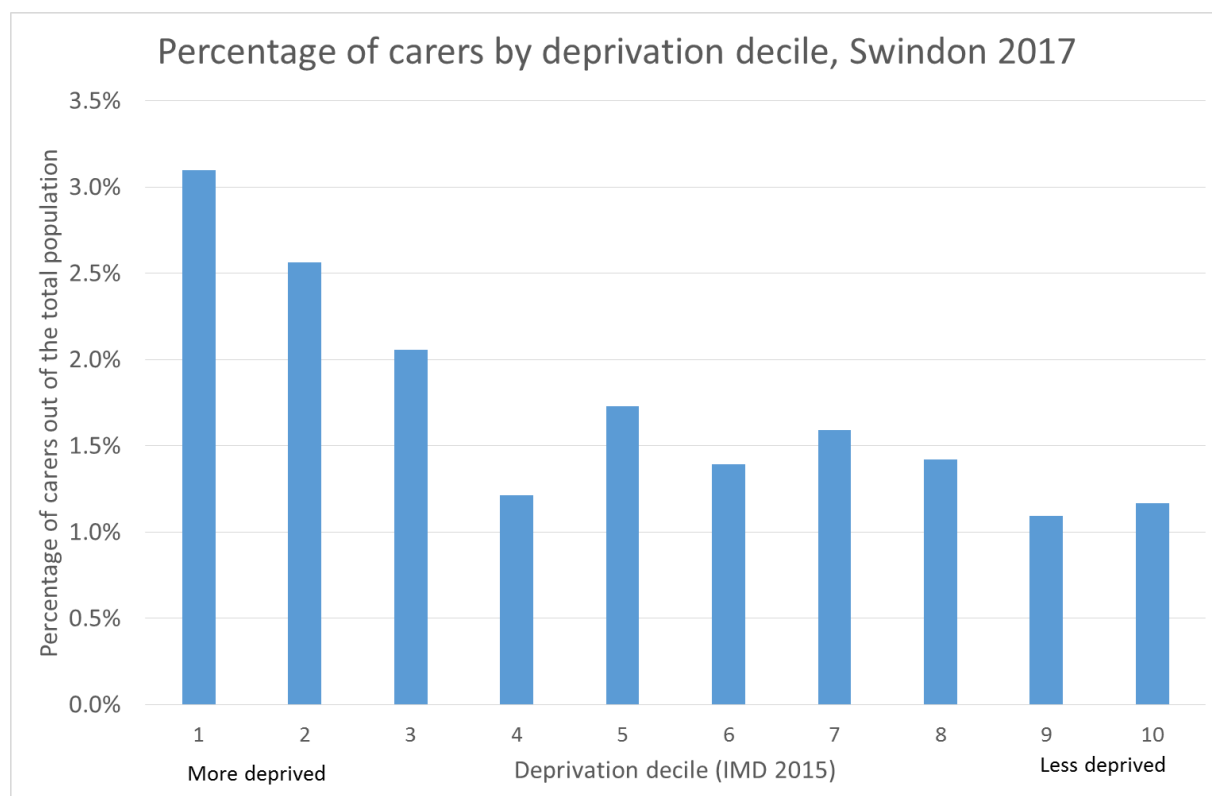
Source: SCC (1,581 carers excluded due to incomplete information)

Young carers are more likely to provide less hours of care. 49% provide 1 to 10 hours and 44% 11 to 30 hours but 6% are providing over 30 hours care per week. In contrast, 73% of carers aged 80 plus provide over 50 hours of care per week.

Parent carers are most likely to provide 50+ hours of care with 76% doing so and a further 18% providing 31 to 49 hours. No parent carers provided less than 11 hours care a week.

Overall, 16% of people provide 1 to 10 hours, 25% provide 11 to 30 hours, 16% 31 to 49 hours and 43% provide 50 or more hours.

There are proportionally more carers in the more deprived areas of Swindon. In the most deprived decile 3.1% of the population are carers and there is a clear gradient through the deciles down to the most affluent decile where only 1.2% of the population are carers. However, this only includes carers registered with the SCC so it may reflect the support and services carers from different deprivation deciles require. For example carers from affluent deciles may use private services. This deprivation gradient is apparent in every age group apart from the 80 plus age group where the percentage of this age group providing unpaid care is fairly similar in each deprivation group.

Figure 14: Distribution of carers by deprivation category

Source: SCC (249 carers excluded to due incomplete information)

SCC have information on the health of 69% of carers. Of these, 43% said they had a disability or health issue. The reasons for ill health or disability have been recorded. The most common conditions were:

- Physical disability (23%)
- Depression (9%)
- Arthritis (8%)
- Poor mental health (5%).

Not surprisingly poor health is more common amongst older carers with 73% of carers aged 80 plus having a disability or health issue compared to 48% of those aged 40 to 59 and only 13% of those aged under 18. Because information isn't available for around one third of carers these figures aren't comparable with the health of the general population in Swindon.

Cared for people

Most carers care for a relation. 28% of dependants are children of carers. 28% are spouses or partners and 29% are parents. Friends and neighbours only make up 2% of those cared for by people providing unpaid care.

Table 10: Dependants relationship to carer

Dependants relationship to carer	
Grandparents	47
Mother	771
Father	279
Husband	530
Wife	373
Other partners	112
Siblings	390
Children	1,008
Grandchildren	18
Other relation	63
Friend or neighbour	62

Source: SCC (269 excluded due to lack of information)

Health of cared for people

The specific health problems of cared for people are not always known but in around 75% of cases their 'service user group' has been recorded. The main service user group is for those with a physical disability (39%) followed by learning disabilities (18%) and neurological conditions (18%).

Table 11: Service User Group of Cared for Person

Service User group	Number	%
Physical Disability / Illness	1,095	39%
Mental Health Issues	369	13%
Dementia/Alzheimer's	81	3%
Learning Difficulties / Disability	514	18%
Sensory Impairment	48	2%
Neurological Conditions	512	18%
Stroke	67	2%
Addiction Issues	27	1%
Other Health Condition	85	3%
TOTAL	2,798	100%
Unknown	1,124	
Grand Total	3,922	

Source: SCC

Data collection processes have changed over the years and may explain why there are a large number of people with an unknown service user group in the table above. Reporting has improved and information collected is more thorough giving more satisfactory data.

Carers have a range of roles regarding safeguarding – they can be the person who raises the concern, themselves be vulnerable to harm and abuse, or can be abusers themselves.

There were six safeguarding alerts for vulnerable adults and five for child protection issues in 2016/17, a small rise from 2015/16.

Emergency Card Scheme

Swindon Carers Centre (SCC) run an emergency card scheme for carers which enables plans to be put into place quickly to support cared for adults and children should there be an emergency. The individualised emergency plans are developed by the carer with help from staff at Swindon Carers Centre if required. The plan has information about the carer and cared for person and what the carer wants to happen if an emergency prevents them from carrying on with their caring responsibilities. For young carers under the age of 16, the plan will say who will look after them in an emergency situation, often families have their own contingency plans in place. The emergency plan is registered with the Urgent Care Centre at Great Western Hospital, Swindon. Carers are issued with a card similar to a credit card with a unique number linking to their emergency plan and a 24-hour telephone number. In an emergency, anyone finding the card can call the number on the card and quote the unique number. Staff at the Urgent Care Centre will then ensure the emergency plan is put in place.

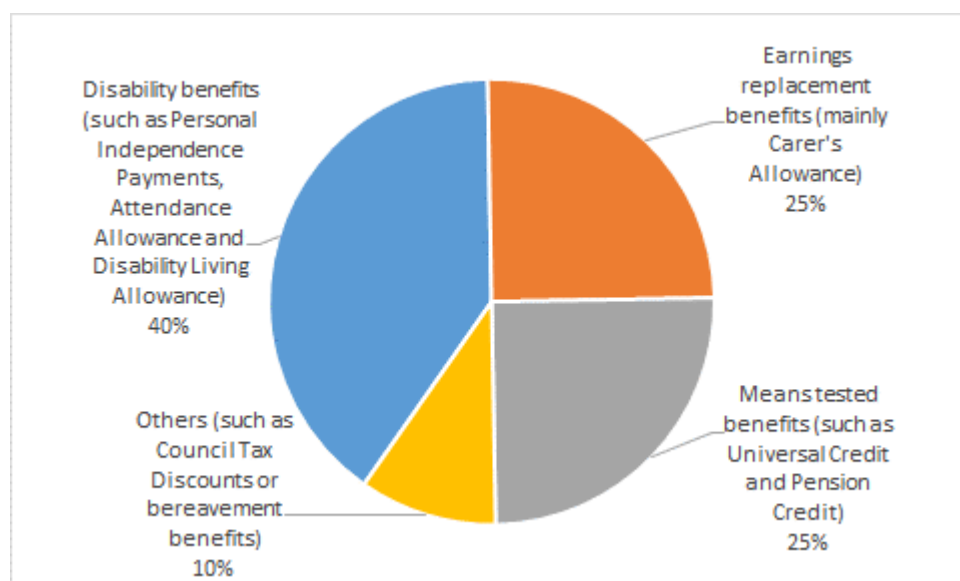
There are currently 786 carers with emergency cards. In 2016/17, 219 adult carers joined the scheme and completed an initial plan, and 363 carers reviewed their plan. Emergency cards are designed to be used rarely. In 2015/16, SCC is aware of three being used and two in 2016/17. However, SCC is only informed if someone phones the Urgent Care Centre to trigger the plan. A carer may use the information contained in the plan themselves to put support in place but SCC wouldn't necessarily be informed of this.

Benefits Service

SCC has a Benefits Service which offers benefits and welfare advice for carers. The main aim of the service is to ensure that carers understand what they may be entitled to and ensures they are assisted in making the claim. The benefits are often interlinked between carer and cared for person and the Benefit Service helps to provide a complete service. The service also helps to reduce the stress and anxiety that carers have by providing information and guidance on changes to benefits in the future.

The total amount of benefits successfully claimed and obtained by SCC carers who used the service in the first 9 months of 2016 was around £200,000. This benefit total is the amount obtained by carers who have gone through the claim process directly with and through the SCC service. This does not include further benefits which would have been obtained by carers who used the SCC service for advice and then went through the claim process themselves.

Figure 15: Benefits obtained by SCC carers through SCC Benefits Service by benefit type



Source: SCC (estimated by Benefits Coordinator, May 2017)

The majority (55%) of benefits were obtained by adult carers. A further 30% by parent carers and 10% by young adult carers with the remaining 5% obtained by young carers.

Other services from SCC

SCC offer a range of training and activities for carers. Some of these are directly in relation to caring duties e.g. a coping with caring courses; dementia and Alzheimer's courses and first aid training. Others are more social in nature such as knitting groups, Carers' Cuppas and family days. There are also groups for those with specialist needs e.g. learning disability and mental health groups and some aimed at specific groups of carers such as men or women or parent carers. In 2016/17, 1,163 carers took part in these activities although many carers will have been to more than one activity.

Signposting

There are numerous other organisations in Swindon who provide support to Carers, most of which are linked to the cared for and are therefore condition specific, such as Prospect, Alzheimer's Society and Stroke. These organisations provide a range of activities varying from carer's cafes, courses and training specific to the cared for illness.

SCC signpost carers to other organisations for help, support and advice. In 2016/17 SCC signposted carers a total of 2,369 times. The main organisations signposted to are in the table below.

Table 12: SCC signposting of carers, 2016/17

Signposted on to	Number Signposted	% of all signposted
SCC Emergency Card Scheme	318	13%
SCC Benefits Advice Internal	258	11%
GP Practice	230	10%
Careline	224	9%
Homeline	105	4%
Swindon Borough Council DISA Website*	94	4%
Adult Community Team	66	3%
Dementia UK	63	3%
Willows Counselling Service	61	3%
Alzheimers Society	60	3%
Other	890	38%
Total	2,369	100%

Source: SCC

Note: * now superseded by the MyCareMySupport website; <http://www.mycaremysupport.co.uk/>

Because many organisations offer support and advice on a wide range of issues and to people with a variety of conditions, issues and questions it has not been possible in the main to provide analysis on the reasons for signposting people on. There are some exceptions where it can be assumed the reasons are closely connected to an organisations core purpose, e.g.

Table 13: SCC referrals to other organisations, 2016/17

Organisation	Signposts
Dementia and Alzheimer's (Dementia UK, Alzheimer's Society, Homecare Choices Dementia Café, Forget-Me-Not Club)	148
Mental Health (Avon and Wiltshire Mental Health Partnership NHS Trust (AWP), LIFT Psychology In Swindon & Wiltshire, Rethink, Swindon Mind)	77
Autism (Autism Alert Card, Discovering Autistic Spectrum Happiness (DASH), National Autistic Society – NAS)	52
Multiple Sclerosis (MS) (MS Society, MS Therapy Centre)	32
Fibromyalgia (Swindon Foggy's)	18
Affected by Cancer (ABC)	16
Stroke (Community Stroke Team, Stroke Association)	17
Sight or hearing loss (Royal National Institute of Blind People, Action On Hearing Loss, Action For the Blind)	13
Bereavement (Cruse Bereavement Care)	8

SCC may signpost a carer to an organisation for information and support for the carer or for the person they care for.

NHS

Carers registered with GPs

Each GP Practice in Swindon holds a register of carers within their practice, however, this data is not shared widely. Swindon Carers Centre encourage Carers to tell their GP they are a carer. SCC also works with GP Practice Carer Leads within each surgery to help highlight and support carers needs.

According to the Care Quality Commission (CQC)¹⁶ it is estimated that 10% of patients on a GP practice list are carers, however, not all are identified by their GP practice and offered the right support. The data on those who are identified is not shared as widely as would be useful, due to there being no current requirement for GP practices to do so.

GP Patient Survey

The General Practice Patient Survey (GPPS)¹⁷ is a national survey conducted by Ipsos MORI. Questionnaires are sent out twice a year to a randomly selected group of patients aged 18 or over who have been continuously registered with a general practice in England for at least six months.

The GP Patient Survey asks respondents whether they provide any unpaid care. However, the survey is not completed by all patients and also excludes patients not in contact with their GP in the survey period. This means the figures do not give a true picture of the number or percentage of carers. In Swindon, 17% of respondents indicated they provided unpaid care. This is similar to England overall, 18%. 3% of respondents in Swindon and England overall indicated they provided 50 hours or more care.

Table 14: Respondents to the GP survey providing unpaid care, Swindon, Jan-Mar, 2017

Q60. Look after/provide support to family etc. for physical or mental ill health/problems in old age		
Base: All		
	%	N
No	83	2493
Yes, 1-9 hours a week	10	314
Yes, 10-19 hours a week	2	57
Yes, 20-34 hours a week	1	42
Yes, 35-49 hours a week	1	16
Yes, 50+ hours a week	3	89
Total		3012

Source: GP Survey Question 60, NHS England: <http://results.gp-patient.co.uk/report/13/Topline.aspx>

Carers and non-carers report a similarly positive overall experience of their GP surgery, with 85% of both groups saying that they have a good (very or fairly good) overall experience of their surgery. However, carers are more likely to have visited their surgery in the past 12 months than non-carers; 86% having seen a GP compared with 83% of non-carers.

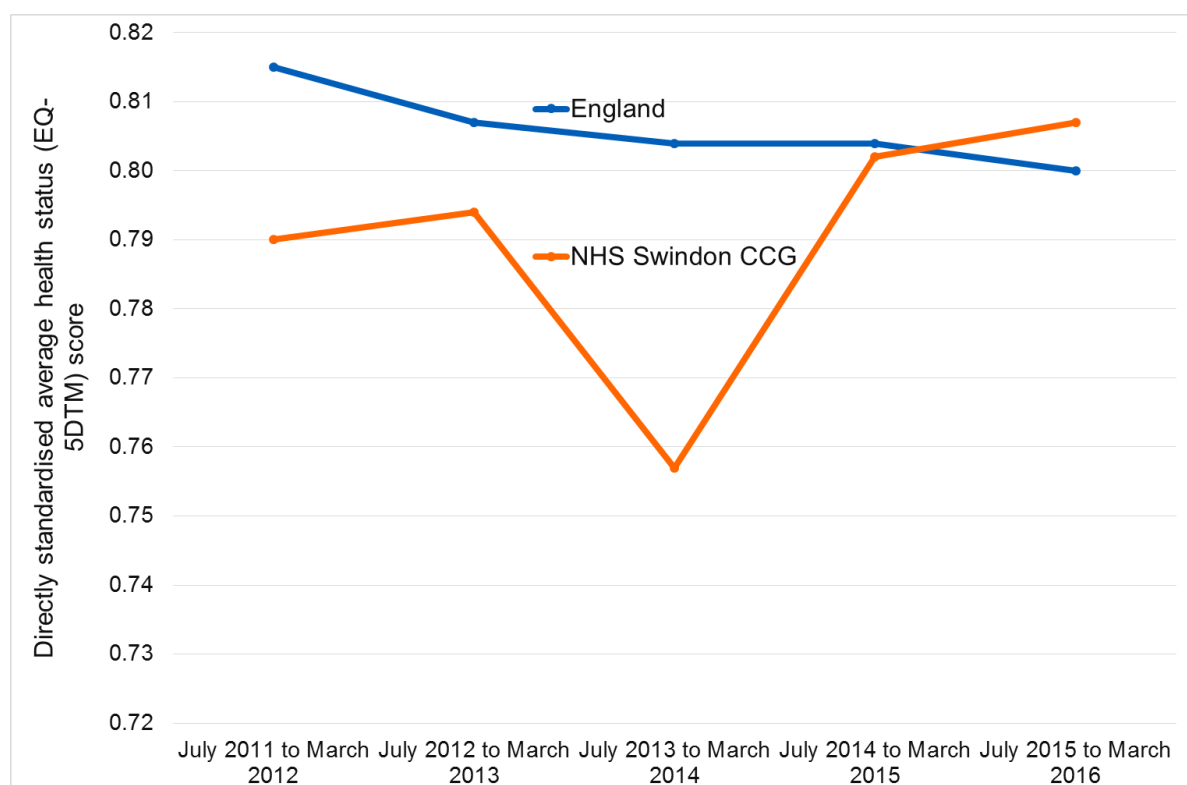
¹⁶ <http://www.cqc.org.uk/guidance-providers/gp-services/nigels-surgery-44-caring-carers-what-does-outstanding-care-look>

¹⁷ <https://www.ipsos.com/ipsos-mori/en-uk/carers-and-gp-services-what-does-gp-patient-survey-say>

Health Related Quality of Life for Carers

The GP patient survey collects data on the health related quality of life for carers in two survey waves each year (July to July) and this is reported in the CCG Outcome Indicator dataset. It measures quality of life using the EuroQol five dimensions questionnaire (EQ-5D) which is a standardized instrument for measuring generic health status. The EQ-5D score is a self-assessment on a scale of 0 to 1 where 0 is death and 1 is best possible health.

Figure 16: Health-related quality of life for carers, age 18 and above.



Source: NHS Digital (GP Patient Survey (<https://gp-patient.co.uk/>))

Between 2011-2012 and 2014-2015 health related quality of life for Swindon carers was lower than for carers in England overall. However, in 2015-2016 health related quality of life for Swindon carers rose to its highest ever level and was above the England value for the first time.

Nationally, the health related quality of life scores from the GP survey are around 2% lower for carers than the general population. However, for Swindon the percentage difference has varied from 3% (2015/16) to 9% (2013/14).

Flu vaccinations

The 2014/15 national flu immunisation programme identifies carers as an eligible group for receiving annual influenza vaccination. More specifically the following group is identified as being eligible: 'Those who are in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill.' GP practices are key in identifying those eligible for a vaccination and giving the vaccine. It is also important that those in contact with carers who may be eligible encourage carers to seek vaccination from their GP.

Improving uptake of flu and pneumococcal vaccinations amongst identified population groups is a project within the Prevention and Proactive Care work stream for Bath and Northeast Somerset (BaNES), Swindon and Wiltshire Sustainability and Transformation Plan (BSW STP).

Swindon are part of a Steering Group looking at how to develop and deliver an implementation project plan aimed at increasing seasonal flu and pneumococcal vaccination rates amongst identified populations, including carers, across the three areas of BaNES, Swindon and Wiltshire.

Great Western Hospital Foundation Trust (GWHFT)

GWHFT recognises that carers of all ages play a very valuable role in supporting and meeting the care needs of those they care for when using the hospital services.

To help support Carers at what can be a stressful time the GWHFT has developed a Carer's Passport. This is available from nursing staff and enables carers to access a range of benefits, including free drinks and parking and discounted food.

If a Carer is admitted to hospital they are encouraged to make staff aware of their caring responsibilities so that extra support can be put in place once they are discharged to help support recovery.

Key issues

The sharing of GP data on carers registered could help support the national flu immunisation programme. It would also be useful in ensuring those carers had information on other services they could access.

What do people think?

Carers UK's State of Caring Survey 2017¹⁸

Carers UK carries out an annual survey of carers to build a picture of the state of caring in the UK.

8 out of 10 (77%) carers buy or receive some form of practical support with their caring role, be that equipment, technology, a break from caring or help from family and friends. However, 1 in 4 carers (23%) who are providing 50 hours or more of care each week are receiving no practical support with their caring role.

Almost half of carers (48%) have practical support in the form of equipment in the home of the person they care for, such as hoists, grab rails or easy grip handles. Nearly a quarter (25%) use technology to help their caring role and 28% have practical support from care workers. Nearly a third (31%) of carers surveyed have help from family or friends, showing the importance of a support network. Almost 1 in 5 carers (18%) have practical support in the form of a break from caring for themselves.

Financial hardship

The survey reported that carers can face higher utility bills, higher transport costs, higher shopping bills, spending on care services and even the cost of home adaptations. Changes to reduce Employment Support Allowance for the work capability group and a further four year freeze of working age benefits mean many carers will again be hit hard. Those responding to the survey are managing on low incomes with over half (48%) of them managing on a gross household monthly income of less than £1,500. 39% are struggling to make ends meet rising to nearly half (52%) of those caring for 35 hours or more per week. A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role.

As a result of financial strain many carers are being forced to make impossible decisions about spending to get by. Of those struggling to make ends meet, nearly half (48%) are cutting back on essentials like food and heating and 1 in 6 (16%) are falling into arrears with housing and utility bills. Others are borrowing money on credit cards (35%), taking out loans (13%) or borrowing from friends or family (30%). Over a third (37%) of carers struggling to make ends meet are using up savings to get by suggesting that their ability to manage is unlikely to be sustainable in the longer term.

Financial hardship is putting further pressure on carers' ability to get practical and emotional support with their caring role as 13% of those struggling financially are cutting back on practical support with caring and 53% are cutting back on seeing friends and families, increasing the isolation that many carers experience.

A large number of carers reported being forced to use their savings (30%), credit cards (26%) or bank account overdrafts (23%) to help them make ends meet. Others

¹⁸ State of Caring 2017 <http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-report-2017>

reported borrowing from family or friends (17%). Altogether, over 1 in 5 (22%) carers struggling to make ends meet said they are in or have been in debt as a result of caring

Paid employment

Three million people, 1 in 9 of the workforce, combine caring for a loved one with paid work. However, combining work and caring can be too much without the support of an understanding, flexible employer and the right health and care services in place that can respond to the care and support needs of the family.

The responses from carers illustrate how caring takes a toll on carers employment opportunities, including career development, promotions and pay rises, as well as impacting upon carers' ability to work at all. And as many as 4 out of 10 carers (43%) said they had given up work completely to care, with 13% reporting that they had retired early to care.

1 in 5 of all carers (21%) said they had reduced their working hours to care. Nearly half of working carers (46%) said that they work the same hours but that their job is negatively affected by caring through tiredness, lateness and stress. 14% of all carers reported having had to take a less qualified job or have turned down promotion to fit around their caring responsibilities.

Carers were asked what would make the most difference in improving their health and wellbeing.

Regular breaks from caring was the most popular choice, with 2 in 5 (42%) placing access to breaks in their top three things. This was followed by good quality care services for the person they care for (35%) and a better income (32%).

Swindon Healthwatch Carers Survey

A Carers survey was distributed by Healthwatch in June 2017 to obtain the views of local service users. This was distributed to known carers via the on line tool Survey Monkey, and paper questionnaires distributed via several organisations who come into contact with Carers, including Swindon Carers Centre. The survey was not random and therefore is not statistically representative of all carers in Swindon but provides insight into their views about local services and support.

There were 171 responses to the survey and these were from a wide range of carers. Carers of partners, parents, children, siblings, other relatives and friends and neighbours were all represented and the cared for people were from every age group from under 18 to 85 and over. The reasons for caring were also varied: the most common reason was physical disability or illness (54%), followed by mental health conditions (31%); neurological conditions (29%) and learning disabilities (28%).

The carers themselves were more likely to be in the 30-74 bracket but there were some respondents from every age group. 73% of responses were from women and 25% were from people with disabilities.

69% had used the Swindon Carers Centre and 13% did so 'a lot'. 57% of respondents would go there for information and advice, which was higher than any other option given to respondents. After friends and family (42%) the next most

likely service contact points for people to try were Sanford House and SBC/social worker (18% each). If respondents wanted support in a non-medical emergency they were most likely to turn to friends or family (33%) and then the Carers Centre (19%). 12% would use their GP, 8% careline/homeline but a small proportion would use NHS 111 (5%) or an out of hours service (3%).

Carers were then asked which services they knew about, which ones they used and how well they thought the services worked – see tables 15 and 16 below. The emergency card services was the most used with 59% of respondents using it. The least used service was support in hospital or primary care (23%) but a large percentage (46%) didn't know about this service. The best known services were the emergency card scheme (82%) and support as a young carer (81%).

Table 15: SCC Services that carers knew about and used

	I used this service	I didn't know about this service	I didn't use this service	I didn't know about this but I will use it now
Emergency Card scheme	59%	18%	18%	4%
Carers Assessment	54%	24%	19%	3%
Welfare and Benefits advice	52%	28%	16%	4%
Provide advice and signposting	52%	24%	21%	4%
Be on the end of a phone for you to talk things through	48%	22%	23%	7%
Support as an Adult Carer	48%	25%	25%	3%
Advise you of your rights as a carer	46%	32%	14%	8%
Support as Young Carer	42%	19%	40%	0%
Link you to our own Carer groups	42%	30%	25%	4%
Support as a Parent Carer	40%	28%	25%	7%
Training sessions and self-help groups	40%	29%	27%	4%
Access to breaks and complementary therapies	37%	26%	28%	9%
Offer Home Visits	34%	37%	22%	7%
Review of caring role	33%	29%	28%	10%
Support as a Young Adult Carer	27%	20%	51%	2%
Support in hospital/GP's	23%	46%	23%	9%

Source: Healthwatch Carers Survey

More than 50% of people thought that each SCC service worked well. The services the highest percentages of people said worked well were the emergency card scheme (93%), advice on rights as a carer (87%) and general support via phone (85%). The services the lowest percentages of people said worked well were support in hospital or primary care (52%), support as a young carer (65%) and access to breaks and complementary therapy (69%).

Table 16: Satisfaction with SCC Services

	This works well	This works well but could be improved	This didn't work well for me
Emergency Card scheme	93%	3%	3%
Advise you of your rights as a carer	87%	6%	7%
Be on the end of a phone for you to talk things through	85%	9%	6%
Support as an Adult Carer	83%	9%	9%
Training sessions and self-help groups	83%	7%	11%
Carers Assessment	82%	10%	8%
Offer Home Visits	81%	14%	5%
Welfare and Benefits advice	81%	10%	9%
Link you to our own Carer groups	81%	8%	12%
Provide advice and signposting	80%	16%	4%
Review of caring role	77%	15%	8%
Support as a Parent Carer	77%	17%	7%
Support as a Young Adult Carer	75%	8%	17%
Access to breaks and complementary therapies	69%	19%	12%
Support as Young Carer	65%	25%	10%
Support in hospital/GP's	52%	17%	30%

Source: Healthwatch Carers Survey

The survey also asked about what helps carers continue in their role and what support works well and what could be improved. These questions were open ended and carers could write whatever they felt.

Respondents gave a very wide range of factors that helped them in their caring role. Some people interpreted this in terms of services and others in terms of more personal factors. The responses were categorised and two main factors that were mentioned were personal motivation (e.g. love, duty, faith, family) which seemed to be about why they cared and how they kept going and respite care where the carer had a break from caring and time for their interests. Support from many sources was also commonly mentioned, especially family and friends and Swindon Carers Centre. Other factors mentioned included housing adaptation, aids and equipment in the home, carers allowance, direct payments, emergency card, emotional/mental health support, their employer, exercise, financial support, medical support, online support, Swindon Borough Council, school and someone to talk to.

Table 17: What are the key things that help you to continue in your caring role? Top seven answers

Factor	Mentions
Personal motivation	25
Respite	25
Support from family and friends	19
Swindon Carers Centre	18
Meeting other carers	10
Home visits	8
GP	6
I don't get help	11

Source: Healthwatch Carers Survey

Respondents were asked to think about the carers service, care assessor roles, carers groups and other locality based services when considering what support works well for them as a carer. Again, a very wide range of answers was supplied. SCC was mentioned explicitly 21 times although many other responses implied that SCC were involved in their support. Meeting other carers, having someone to talk to and knowing help is available were all considered to be support aspects that worked well, as were the plethora of groups, courses and activities. Again, respite and time out were mentioned by many respondents as something that worked well. Four respondents mentioned the Parkinsons nurse/support group/exercise class. Other support mentioned included Aiming High, benefits advice, coffee mornings, counselling, crafts, aids and equipment in the home, emergency card, first aid training, GP, home visits/sitting service, occupational therapy, pamper days/vouchers, signposting information, social worker and working.

Table 18: What support works well for you as a carer? Top nine answers

Factor	Mentions
Swindon Carers Centre	21
Meeting other carers	19
Groups	11
Time out	10
Respite	9
Courses	7
Activities	7
Someone to talk to	6
Knowing help is available	6
Don't use any support	32

Source: Healthwatch Carers Survey

Respondents were asked to think about any gaps in services or services that didn't meet their needs as a carer when considering what areas could work better for them as a carer. The views of the respondents varied massively with some being very happy with the current support they received, e.g. "None, it is brilliant" but others being very unhappy with every aspect, e.g. "Where to start????!!!".

Some carers mentioned wanting services that actually exist, e.g. counselling which highlights that there could be issues with making the relevant information available to all carers.

Some respondents gave quite general responses and mentioned wanting “more support”, “more advice”, “better information”, “more activities” or “better communication”. Respondents listed a range of topics they would like more information, advice on support on, e.g. Alzheimers, alcohol, finance and benefits, coping skills, children with complex needs and Education, Health and Care Plans, keeping themselves healthy, what to do in emergencies and job hunting.

Another theme that came out was around the speed that things happened and carers wanted quicker assessments and medical appointments, housing adaptations to be carried out sooner and generally more responsive services. The qualifying criteria for financial benefits and allowances, blue badges, and other types of support was raised by a few respondents.

Again, respite care was mentioned by many respondents, some in terms of wanting it at all and others wanting more of it or information about how to arrange it. Respondents also mentioned the importance of time out for themselves and needing more information on how to arrange this and being confident leaving the person they cared for.

The timing of events, activities, trips and courses was mentioned by some carers, mainly those in employment who wanted more of these in the evenings.

Issues around providing services for specific groups of carers

Young carers

2011 Census

In Swindon, in 2011, 551 children aged 15 and under reported as providing unpaid care in the Census, representing 1.3% of the population. This is slightly higher than the proportion in England as a whole (1.1%). Of the population aged 16 to 24, 1,029 people (4.5%) reported providing unpaid care, lower than the average of 4.8% in England as a whole.

Table 19: Young people providing unpaid care, Swindon, 2011

Area and age group	Total pop'n	% providing unpaid care	0-19 hours	20-49 hours	50+ hours	Total
Swindon 0-15	41,382	1.3%	428	72	51	551
England 0-15	10,022,836	1.1%	90,171	11,142	10,110	111,423
Swindon 16-24	22,690	4.5%	738	182	109	1,029
England 16-24	6,284,760	4.8%	219,853	47,962	34,541	302,356

Source: ONS 2011 Census

Note: figures in this table are for all residents. Other tables contain data for those living in households only.

Needs of young carers

For over a decade, there has been considerable consultation, nationally¹⁹ and in Swindon, of the needs of young carers and their families. The main learning points from this research include:

- They want time to have fun and socialise, getting breaks from caring.
- They want more help for the person they care for.
- They need to be less isolated and have people they can turn to.
- They need more money in their families.
- They need help at school with attendance, homework, course work and bullying.
- They need to be helped to get the best from learning and work towards an independent future.
- They need to be meaningfully involved in the planning for their cared for person, and given information and knowledge about the practicalities of caring.
- They need emotional support with worry, anxiety and low self-esteem.
- They need help planning for and dealing with family crises.

¹⁹ Hidden from view: The experiences of young carers in England, Children's Society http://www.childrensociety.org.uk/sites/default/files/tcs/hidden_from_view_-_final.pdf

Characteristics of young carers and challenges faced

A recent report from Plymouth Council²⁰ highlights some of the challenges faced by young carers and an insight into their characteristics. Although Swindon is different from Plymouth in some ways these issues and characteristics are likely to apply to the Swindon young carer population in similar levels.

- 33% were caring for someone with a long term illness; 24% for someone in mental distress; 20% for someone with a physical or sensory impairment; 18% for someone with learning difficulties and 5% for someone affected by alcohol or drug misuse.
- Young carers were significantly more likely to have been the victim of violence or aggression than all other pupils in their year group.
- Young carers were significantly more likely to report witnessing violence at home than all other pupils in their year group.
- Young carers were significantly more likely to be afraid of school because of bullying but also more likely to have bullied someone themselves than all other pupils in their year group.
- Young carers were significantly more likely to say they were 'not at all' or 'not much' satisfied with life compared to all other pupils in their year group.
- Young carers were significantly more likely to say they knew where to get information about sex and contraception locally than all other pupils in their year group.
- Young carers were significantly more likely to have been drunk recently or be current smokers than all other pupils in their year group. However, there was little or no difference in dietary habit or physical activity levels or in the proportion who had taken drugs.

Swindon services for young carers

Swindon Carers Centre has developed a Young Carer Award for Schools, young carers nationally reported they were not always getting the support they needed from their school or college. There are currently 61 Swindon schools/colleges involved in the Young Carer Award, from infant's schools to FE colleges, which is ensuring that young carers receive the support they need, especially during transitions to college/new schools.

Most, if not all, schools in Swindon have a person in school to support young carers. In many cases this is usually a member of the senior team. The students are usually given extra support in school, opportunities to sit in a quiet place after or during school to complete homework etc. Counselling sessions are in place where appropriate, all teaching staff are notified so they plan support appropriately for the individual, financial support and free school meals are offered etc.

There is a section on the Healthy Schools audit which asks about the provisions in place for young carers and out of around 60 schools who have Healthy School status only one or two have said they have no provisions, that's because they have no young carers in school.

²⁰ Young Carers in Plymouth 2016, Public Health, Office of the Director of Public Health, Plymouth City Council, March 2017.

Children in need and child protection

Young carers and the needs of the person for whom they are caring may only be identified when there is a crisis. Even then, the extent of the child's caring role and the impact that it has on their own development may not be recognised quickly or fully assessed, with the result that families may not receive the services they require soon enough. Inappropriate levels of caring impact on a child's own emotional and physical health as well as their educational achievement and life chances.

The See the Adult, See the Child protocol produced by Swindon Local Safeguarding Children Board²¹ gives guidance to those working with children and adults to ensure young carers are recognised within their own rights.

There were 683 young carers/young adult carers (aged 5-22) on the Swindon Borough Council's children's database. This is a count of open 'involvements' (this could be a service offered by health visitors, SCC or other agency).

As of June 2017:

- 53 out of 683 young carers are Child in Need equating to 7.8%
- 19 out of 683 young carers are on Child Protection Plans equating to 2.8%

Overall in Swindon 2.3% in the 0-19 age range are Children in Need and 0.5% have Child Protection Plans.

Key issues

Key issues affecting young carers include:

- Young carers often take on practical and/or emotional caring responsibilities that would normally be expected of an adult. The tasks undertaken can vary according to the nature of the illness or disability, the level and frequency of need for care and the structure of the family as a whole.
- The Longitudinal Survey of Young People in England²² found that young carers are 1.5 times more likely to have a disability, long-term illness or special educational needs, 1.5 times more likely to be from a black, Asian, or minority ethnic community and twice as likely to not speak English as their first language.
- Young carers are significantly more likely to grow up in poverty, with all the associated needs and risks that this brings. The average annual income for families with a young carer is £5,000 less than families who do not have a young carer.

²¹ See the Adult, See the Child Practice Guidelines: Multi-agency Practice Guidelines for the Assessment, Support and Case Management of Families, Swindon LSCB and Swindon LSAB <http://www.swindonlscb.org.uk/procedures/Documents/See%20the%20Adult%20Practice%20Guidelines.pdf>

²² The Children's Society, 2013

- Young carers have significantly lower attendance at school and educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers e.g. the difference between nine B's and nine C's. In Swindon, young carers are not identified in routine data on educational performance. This means that the educational performance of young carers cannot be measured.
- Transitions to adulthood: Swindon Carers Centre offer a support group to young people aged 16 – 25 which addresses the specific needs of young carers as they move to adulthood.
- Approximately 19% of the young carers supported by Swindon Carers Centre care for a parent where mental health is one of the contributing cared for needs. The stigma of having a parent with a mental health problem is even greater than having the issues around parental substance misuse. The experience of Carers Trust is that young carers are happier to discuss drink/drug related alcohol problems than mental health.

Elderly carers

2011 Census

The Carers Trust reports that nationally, the numbers of older carers (aged 85+) has risen by approximately 128% in the last decade, and the 2011 Census revealed that, of the 1.8 million carers aged 60 or over, 151,674 were aged between 80 and 84 with a further 87,346 over age 84.

In Swindon, in 2011, 13.6% of the population aged 65 and over were providing some form of unpaid care, compared to 9.4% in people of all ages. These figures compare to 14.3% of people aged 65 and over in England as a whole. Of the 3,819 people aged 65 and over in Swindon providing unpaid care, 48% were male and 52% female.

Characteristics of elderly carers

It's important to remember that:

- Carers aged 60–69 often juggle caring with the demands of work and financial pressures while those aged over 70 may be more likely to find it difficult to cope with the physical demands of caring.
- Carers will be caring for people with a wide range of health conditions and disabilities, with varied emotional and physical demands and concerns for the future.
- Over 16% of older carers in research in 2011²³ were caring for more than one person. This is more common for the younger age group 60–75 where significant numbers care for a parent as well as an adult son or daughter, grandchild or someone else with a disability or long-term health condition.

²³ The Princess Royal Trust for Carers, 2011

Carers Trust: Retirement on hold: supporting older carers

Given the increasing number of people living longer and the improved life expectancy of disabled people there are likely to be more people caring for longer and much later in life. A study from the Carer's Trust set out to explore the needs of older carers, the issues they face and to identify ways of supporting them, using focus groups as a way of consulting with older carers. Six focus groups were held and 92 people participated overall. A number of key challenges were raised by the groups.

- Care coordination – navigating the health and care system and managing multiple strand of support and the associated visits and appointments with the logistical challenges they pose.
- Carers' health issues – managing and maintaining your own health, accessing exercise, alongside a caring role was made harder by the impact of the aging process
- Transport – particularly in rural areas with limited or no public transport, was a key issue. Many older carers reported a reliance on taxis, or lifts from friends, family or neighbours. Being unable, or no longer able to drive and having mobility issues that precluded walking to and from public transport stops were also raised.
- Benefits and other allowances – opinion on the availability of information and advice was divided equally with around half of carers reporting this as good, and the rest feeling they had had to find out themselves. A substantial number of participants reported not being informed about entitlements early enough and as a result had lost out on possible income.
- A duty to care – the study identified a small group of carers who spoke about having difficult or challenging relationships with the person they cared for. This group described feeling that they had a duty to care as there was no one else to do it otherwise. In addition, some participants, who had stopped caring as they were unable or unwilling to continue caring, described a lack of support in arriving at the decision and also reported judgemental attitudes of family members but also of professionals.
- Managing finances – a number of issues emerged in this theme, typically around accessing and managing the finances of the person they cared for, even with lasting power of attorney in place. These included liaising with utilities companies and having to use their own finances to fund respite or personal care as they were unable to access the finances of the cared for person or were unaware that the person has right to be assessed and potentially receive local authority funded support. A large number of carers reported having to learn how to managed finances as previously it had been the role of the cared for person. This was challenging for some but not all.

Key issues

The health and wellbeing of older carers has been highlighted as an area of significant concern. Research in 2011²⁴ found that:

²⁴ The Princess Royal Trust for Carers, 2011

- Two thirds of older carers have long-term health problems. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- One third of older carers report having cancelled treatment or an operation they needed due to their caring responsibilities.
- 50% reported that their physical health had got worse in the last year, and 70% said specifically that their caring responsibilities had a negative impact on their physical health.
- Across all of the older age groups, more than 40% said their mental health had deteriorated over the last year, with 75% of the 60–69 age-group saying that caring had a negative impact on their mental health.
- Less than 50% of carers over 70 who had to lift the person they care for, think that they do this confidently or safely.

The needs of carers of people with mental ill-health

Challenges of caring for someone with mental health needs

Caring for someone with mental health needs presents different challenges for their carer compared with a physical illness or disability. These include:

- The fluctuating nature of poor mental health. The need for, and levels of, support may therefore be unpredictable. Dependence on the carer can be really intense and prolonged at times yet minimal at others.
- Poor mental health is not necessarily as evident as a physical health problem or disability, therefore there may be less understanding or support forthcoming for the carer as there is with other health conditions.
- Because of the stigma surrounding mental ill-health, carers may be less willing to seek support or share with family members and friends. This may mean they have less of a social network to draw on themselves with a resulting risk of poor mental health in the carer themselves.
- Many people say dealing with the stigma surrounding mental health is worse than coping with the condition itself.
- Carers play a key role in the recovery of people with poor mental health conditions. This is a significant level of responsibility.
- Often mental ill-health is associated with other conditions, so this is not the only condition the carer is required to deal with.
- There are a number of legal and ethical issues surrounding mental health that can make the role of caring even harder.
- Carers need information, advice and support about carrying out their caring role, but also about understanding and coping with mental health conditions. Carers of people with poor mental health are dealing with taking on a caring role as well as learning how to respond to the behaviours and emotions associated with the condition.

As a result of these issues, caring for someone with mental health needs may be even more emotionally draining than any other caring role.

The impact of caring on social isolation and loneliness

Isolation and loneliness is something carers report experiencing, being isolated or lonely in a caring role happens when carers no longer have time or energy to maintain external friendships and hobbies. To be lonely you do not have to be alone, it can be a case of feeling alone, for many carers the world shrinks and becomes solely focused on the cared for needs.

“Alone and Caring”²⁵ by the Carers Trust highlights that eight in ten carers have felt lonely or socially isolated as a result of their caring responsibilities. The impact of caring can lead to the loss of contact with friends and family, challenges with partners, and isolation from others they work with due to pressures of the caring responsibilities. The report goes on to highlight:

- 57% of carers have lost touch with friends and family as a result of caring and half (49%) of carers say they have experienced difficulties in their relationship with their partner because of their caring role.
- 38% of carers in full-time employment have felt isolated from other people at work because of their caring responsibilities.
- Carers who have reached breaking point as a result of caring are twice as likely to say that they are socially isolated because they are unable to leave the house and are also more likely to have experienced depression as a result of caring.

Talking about caring may be especially hard for Black and Minority Ethnic (BME) carers, who, in the Carers UK study, were more likely to say that they were not comfortable talking to their friends about caring which has made them feel lonely and socially isolated. This could be because for some carers from BME backgrounds there is a cultural barrier to discussing disability openly or a stigma around particular conditions.

Swindon Carers Centre

There are 358 carers engaged and receiving services from SCC who care for an adult with mental health problems:

Table 20: Carers providing care for adults with mental health problems by age of carer, May 2017

Age	Number
Under 18	74
18 – 25	13
26 – 64	128
65 - 74	26
75 - 84	11
85+	7
Unknown	99
Total	358

Source: SCC

²⁵ Alone and Caring, Isolation, Loneliness and the impact of caring on relationships, CarersUK

Forty four of these carers are aged over 65 of whom nine have an emergency card and one household has two carers aged 65+ in it.

The needs of Black and Minority Ethnic (BME) and Lesbian, Gay, Bisexual and Transgender (LGBT) carers

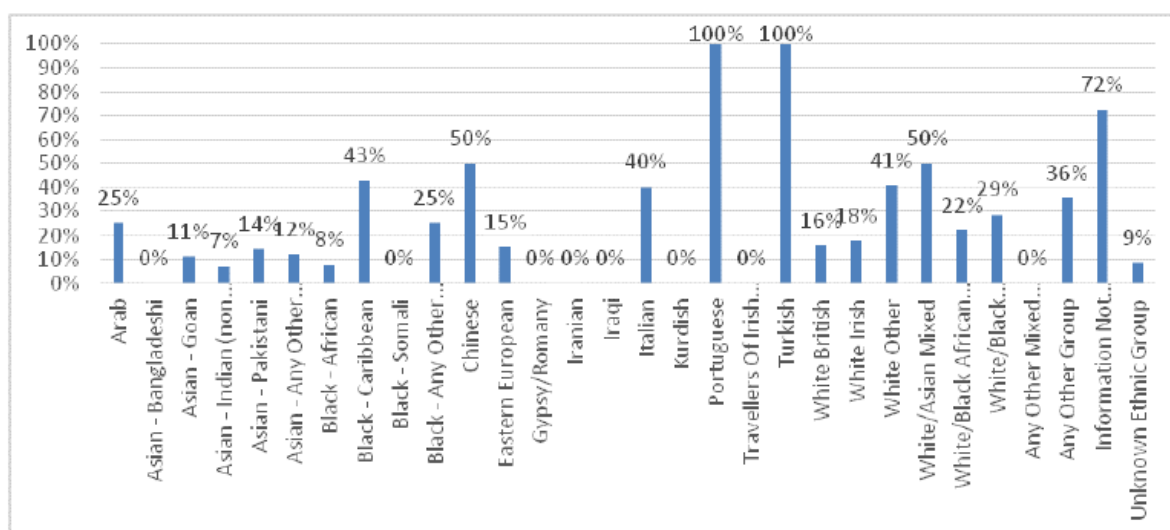
Black and Minority Ethnic (BME) carers

From the SCC data collected on the current provision there is a disproportionately high level of usage of clients from a White British background with 89% of carers registered about whom ethnicity is recorded are White British, whilst representation from BME groups is low with only 11% registered (14 – less than 1% of carers declined to say).

However, local analysis of need has identified Swindon has an increasing number of people from minority ethnic communities and backgrounds. The Citizens Advice Bureau reports that 24% of its customers and service users are from BME backgrounds.

To date SCC have undertaken an inclusion research project, and have developed a set of objectives and an action plan to support this work. From this work SCC have developed a good practice model for Carer Inclusion. This has resulted in an increase in reporting (Sept 16 – March 17) of ethnic backgrounds, religion, and sexual orientation.

Figure 17: Change in BME carers engaging with SCC Sept 16 – March 17



Source: Swindon Carers Centre 2016/17

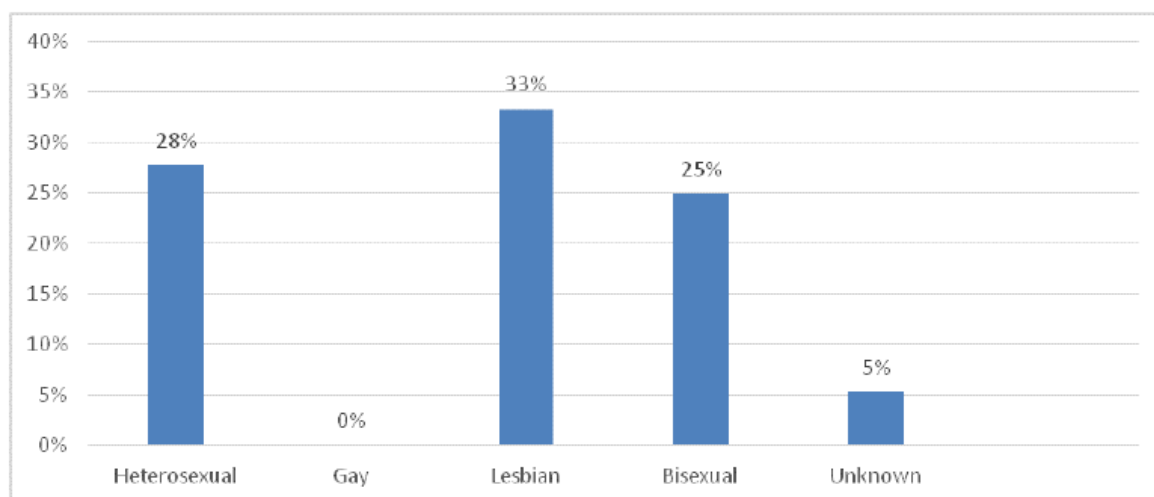
Lesbian, Gay, Bisexual and Transgender (LGBT) Carers

The LGBT website, LGBT Foundation, highlights that being a lesbian, gay, bisexual or transgender (LGBT) person and a carer can bring about additional issues. One such worry may be that existing services to support LGBT Carers and the person that they care for may not be LGBT friendly, or the Carer may feel uncomfortable about ‘coming out’ to people who can help.

The Census does not provide information on the local lesbian, gay and bisexual population (which is estimated by the Government Equality Office to be 6%), or the population of transgendered people for which there is no national estimate.

SCC data below reflects the % increase in carers engaging with the service since Sept 16 – March 17.

Figure 18: Change in carers engaging with SCC by sexual orientation, Sept 16 – March 17



Source: Swindon Carers Centre 2016/17

The needs of carers of people with learning disabilities

Elderly carers (65+) of LD children

Concerns were raised by the Carer's Trust about guardianship, power of attorney and future care implications when carers are no longer able to do their caring role.

The following analysis is based on SBC data which identified, in 2017, 118 carers aged over 65 caring for an adult with LD on the adult social care caseload. These 118 carers are looking after 102 services users with a learning disability (LD) in adult social care. Swindon Carers Centre (SCC) also holds data on carers who care for an adult with LD. There are 181 carers who care for an adult with LD known to SCC of whom 31 are aged 65 or over. It is not known whether these are also included in the SBC caseload or additional carers. Of these, 23 (74%) have an emergency card²⁶.

Of the 118 carers on the SBC caseload, 51 carers live with the cared for person and 50% of these are aged over 75.

Whilst no-one can predict when carers will be unable/unavailable to care the age of 46 (cared for age) has been identified as a time by when adults with a learning disability are more likely to live in residential or nursing care. The SBC data for this age range (46 plus) shows:

²⁶ <http://www.swindoncarers.org.uk/for-carers/emergency-card-scheme/>

- 58 of cared for people are aged 46 or older. Of these 58, 35 are cared for by carers over 75 years.
- 25 cared for aged 46 or older live at home with their carer. Of these, 16 (64%) are cared for by a carer over 75 year old and three receive no services at all.
- A further 12 (out of 41) cared for people aged 26 to 45 are cared for by carers aged over 75 years.

There are 45 cared for people of all ages (of whom 25 are aged 46 or older) who are being cared for by a carer or carers who live with them. These have the potential of needing new or increased services if the carer becomes unable/unavailable to care. 21 of these have carers aged over 75 years, five of whom are 85 or older. Six people cared for at home are receiving no services at all and five of these have carers aged 75 years or older.

Of the 118 carers only 36 (31%) have a current record for assessment or review at SBC. A higher percentage of cared for people had assessments, 76 out of 102 (75%). However, carers could have had assessment or review at SCC. Data at SBC and SCC would need to be cross referenced by named individual to establish this.

Key issues

It is recommended that the default position should be that every carer over 65 has an emergency card. The implications of this for SCC would be increased demand for a service. Currently there is a 21hr post to cover this area of work. It would therefore be likely that further funding to increase the hours of the post would be needed.

The needs of carers with multiple caring roles

Introduction

With the impact of an aging population, and where people are starting families later, multiple caring roles are on the rise. The term 'sandwich generation' is often used to refer to those looking after young children at the same time as caring for older parents. However, it can also be used much more broadly to describe a variety of multiple caring responsibilities for people in different generations. With an ageing population, and where people are starting families later, 'sandwich caring' responsibilities are increasing and it is women who are more likely to face the pressure of simultaneously shouldering responsibility for young and old. Research²⁷ found that, without support, the pressure of combined caring responsibilities can take a serious toll on families' health, finances, careers and relationships. It is therefore important that sandwich carers are identified in Swindon and are offered an assessment in order to receive appropriate support.

Swindon Carers Centre

Swindon Carers Centre are developing an Employer Awards Standard in partnership with carers and Swindon Borough Council, a pilot project is planned to start in 2017, several large organisations have expressed an interest in taking part in this work.

²⁷ Carers UK the voice of carers Sandwich Caring, employers for Caring

Eleven percent of carers at SCC care for 2 or more people and 21 carers are providing care for 4 or more people.

Table 21: Multiple caring roles

Number of people cared for	Number	%
1	3,471	89%
2	376	10%
3	54	1%
4 or 5	18	<1%
More than 5	3	<1%
Total	3,922	100%

Source: SCC

Some multiple caring roles involve providing care to parents (or other older adults such as grandparents or aunts and uncles) and to offspring (or other younger people such as grandchildren, nieces and nephews). SCC has 38 of these 'sandwich' carers on its database which possibly indicates we are not aware of many of these carers.

The health of carers

National surveys

Carers UK²⁸ found that 84% of carers surveyed said that caring has a negative impact on health. Nine in 10 (92%) of carers said that their mental health has been affected by caring with only 1% saying that caring has improved their mental health. 67% of carers said their GP is aware of caring responsibilities but gives them no extra help.

Carers not receiving respite are more likely to have mental health problems (36%), compared with those in receipt of respite (17%)²⁹.

The health of carers deteriorates more quickly than that of non-carers due to the lack of support (often due to a lack of awareness of support available). 64% reported a lack of practical support and 50% a lack of financial support³⁰.

The Royal College of General Practitioners (RCGP)³¹ have identified (from various sources) that:

- Carers tend to neglect their own health. The impact on a carer's own physical and mental health is worsened if they are unable to attend their own health-related appointments. They may fail to notice their own health deteriorating and miss routine appointments or check-ups with doctors or dentists. Information from Carers UK shows that two in five carers postpone their own

²⁸ Carers UK, 2013

²⁹ Hirst, 2004

³⁰ Carers UK, 2012

³¹ The Royal College of General Practitioners (RCGP) 2013

treatments due to lack of support. Care and support is also relied on to take the cared for to appointments if the carer works.

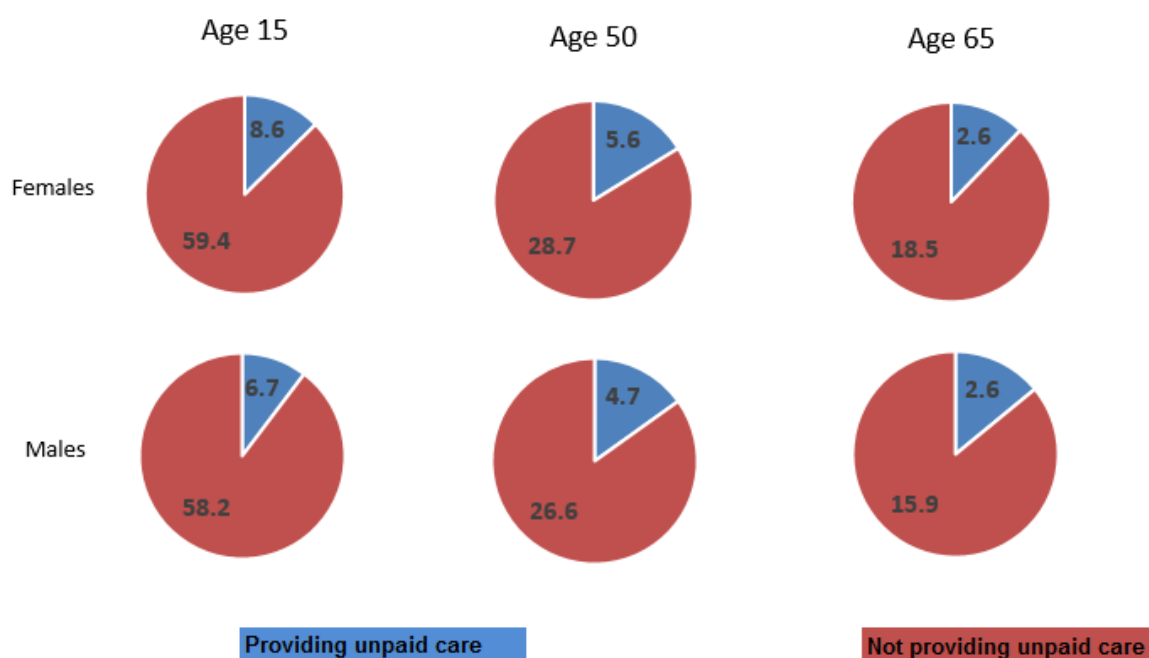
- Caring can limit carers' ability to take exercise.
- 40% of carers experience psychological distress or depression, with those caring for people with behavioural problems experiencing the highest levels of distress.
- 33% of those providing more than 50 hours of care a week report depression and disturbed sleep.
- Those providing more than 20 hours of care a week over an extended period have double the risk of psychological distress over a two year period compared to non-carers. Risk increases progressively as the time spent caring each week increases.
- 44% of carers suffer verbal or emotional abuse; 28% endure physical aggression or violence from the person they care for.
- Older carers who report 'strain' have a 63% higher likelihood of death in a four year period.
- Providing high levels of care is associated with a 23% higher risk of stroke.

Life expectancy and expected provision of unpaid care

In Swindon, a 15 year old female could expect to live a further 68 years (based on 2010-12 data) and spend 8.6 of these providing unpaid care (12.6%). Whereas a 15 year old male could expect to live a further 64.9 years and spend 6.7 of these providing unpaid care (10.3%). The expected number of years of unpaid care from the age of 15 is statistically significantly lower in Swindon than England overall.

By the age of 50 females in Swindon can expected to spend 16.2% of their remaining years providing unpaid care and males 15.1%. This drops to 12.2% and 14.1% for females and males respectively by the age of 65.

Figure 19: Expected number of years providing unpaid care at ages 15, 50 and 65 in Swindon



Source: ONS, 2010-12. Swindon CCG.

The needs of carers for people at the end of life

Introduction

It is estimated there are around half a million people in the UK at any one time providing care for someone with a life-limiting illness. Inevitably, carers of people who are dying will have to face bereavement and a change in their role. Bereavement has long been recognised as a risk factor for poor psychological and physical health. In a 2007 review³², Stroebe, Schut, and Stroebe concluded that there is an early increased risk of death from a variety of causes, including suicide and 'dying from a broken heart' – meaning the psychological distress, loneliness and secondary consequences of loss such as changes in eating habits, economic status and social support. A few authors have found this risk to persist after six months.

The recently bereaved are also more likely to have physical health problems; widowed people in general consult with their GP more frequently than the non-widowed, but also may be less likely to consult when they need to. This indicates that there is likely to be significant met and unmet need in terms of the physical and mental health of the recently bereaved, particularly those bereaved of spouses.

While the needs of these carers will in many ways be similar to those of other groups of informal caregivers, there are specific issues that face people caring for someone at the end of their life, such as:

³² Health outcomes of bereavement, Stroebe, Margaret et al, The Lancet, Volume 370, Issue 9603, p1960 – 1973. [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(07\)61816-9/fulltext](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(07)61816-9/fulltext)

- Possible sudden diagnosis and onset of the caring role.
- Uncertainty as to the length of time until death.
- Likely rapidly changing care needs.
- Information needs on the dying process and associated complex medical and nursing care.
- Psychological and emotional strain of knowing that they will face bereavement.
- Practical and emotional issues at the time around the death, and in the months and years following bereavement.

In common with other groups, people caring for those at the end of life may not identify themselves as 'carers' and so may be unaware of, or reluctant to access, available support.

The National Palliative Care Policy is based around a strong preference for death at home. In order to achieve this supporting the needs of family carers is paramount.

Counselling

The evidence suggests that it is neither necessary nor desirable for all bereaved people to undergo 'bereavement counselling'. Around 85% of bereaved people will manage their own path through grief using existing social support. 5% will need specialist help to manage their extreme grief reactions, and the remaining 10% need something in between, such as a befriending or counselling service.

SCC and the end of a caring role

A carers role can come to an end for different reasons. SCC are sometimes informed and a reason can be recorded. In 42% of the 316 records the SCC hold the cared for person died and in a further 9% the carer had passed away. In 29% of cases the service was no longer required and 20% of the time the carer had moved away.

SCC continue to offer support for up to six months after the cared for person has died, and carers can continue to access groups and activities for up to 18 months. Carers who attend SCC report:

- "The support I have received since being bereaved has been really supportive"
- "They have supported me through all the stages of my journey"

Evidence of effectiveness and cost effectiveness

The Cambridgeshire Carers JSNA³³ included a literature review commissioned to investigate:

- What do we know about which interventions are effective in supporting carers to stay healthy and well?
- Is there evidence that these interventions improve outcomes for the cared for person in terms of service use?

The main findings from this literature review are summarised below.

Evidence of effectiveness of interventions to keep carers healthy and well

Overall summary

- No consistent evidence was found that interventions for carers improve carers' wellbeing or quality of life. The reason for this is likely to be that many of the individual studies on which the reviews were based are small and variable in quality. The outcomes being measured in studies were often not standard across studies e.g. ways of measuring emotional wellbeing. There were very few (particularly UK based) studies which measured cost effectiveness of interventions. This is not the same as saying that there is evidence that interventions for carers do not have benefits or are not cost effective.
- There was contradictory evidence for the impact of any type of intervention on carers' burden. However, many interventions resulted in carer satisfaction.
- The relationship between breaks from care and carers' emotional wellbeing is not straight forward. Many of the studies in reviews are small and of variable quality. There was some evidence of respite having a negative effect in some groups (because of feelings of guilt). There was suggestion that it is important that interventions are tailored to the individual family situation.
- Cognitive reframing (aims to reduce carers' stress by changing certain areas of their beliefs, such as beliefs about their responsibilities to the person with dementia, their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do) may be useful when used alongside other interventions for carers of people with dementia (reduced carer depression, anxiety and stress, but did not impact on coping or burden).
- The best evidence was that education, training and information for carers (particularly when targeted at a particular patient group) improved knowledge and caring 'abilities'³⁴.

³³ Cambridgeshire Joint Strategic Needs Assessment (JSNA) Carers 2014, Cambridgeshire and Peterborough Clinical Commissioning Group and Cambridgeshire County Council,

³⁴ Parker, G., Arksey, H., & Harden, M. (2010). Meta-review of international evidence on interventions to support carers. York: Social Policy Research Unit, University of York.

- ‘The size and complexity of the issue of providing carers with the best possible support to enable them to continue helping those they love deserves better primary research than our meta-review has uncovered’³⁵.
- There is weak UK-based evidence for carers assessment improving emotional wellbeing and access to services:
 - But subsequent uptake of services poor and carers not necessarily satisfied with services.
 - Evidence that how assessment delivered is important.

Summary of findings for carers of people with dementia

- Cognitive reframing (aims to reduce carers’ stress by changing certain of their beliefs, such as beliefs about their responsibilities to the person with dementia, their responsibilities to the person with dementia, their own need for support, and why their relatives behave as they do) may be useful when used alongside other interventions for carers of people with dementia (reduced carer depression, anxiety and stress, but did not impact on coping or burden)
- Only tentative evidence that: psychosocial support and professionally led support groups for carers of people with dementia may have a positive impact on depression.
- No evidence of benefits of respite for carers of people with dementia to carers quality of life, stress or burden. Evidence of increase in burden in one review.
- No good evidence found of cost-effectiveness of interventions for carers of dementia
- Inconclusive evidence for the benefits of respite care for mental health of those caring for frail older people (some evidence of benefit but potential negative effect)
- Some evidence of a positive effect of group psychosocial support for carers of frail elderly on coping ability, knowledge of resources and social support, but inconsistent evidence on carer burden
- Suggestion that there is a need to tailor interventions with the needs and wishes of family care-givers and integrated approaches useful

Summary of findings for carers of people with cancer or terminal illness

- Few of the studies in included reviews were UK based.
- Evidence of a small effect of interventions including cognitive behaviour therapy (CBT), education, interpersonal counselling, behavioural marital therapy and emotion-focused therapy on carer quality of life, but not enough evidence to recommend which.
- Low quality evidence that interventions to support carers to cope emotionally, reduces distress in the short term. Limited or conflicting evidence for psychological/psychosocial support interventions on measures of carer wellbeing.
- Only low quality evidence for emotional support for carers of person with terminal illness on carer distress

³⁵ Parker, G., Arksey, H., & Harden, M. (2010). Meta-review of international evidence on interventions to support carers. York: Social Policy Research Unit, University of York.

Summary of findings parent carers of young children³⁶

- Evidence that short breaks from care can improve carer wellbeing as perceived by carers themselves and allow carers time to rest and relax.
- Studies that have tried to quantify the impact on health and wellbeing are of poor quality and have found less consistent results in demonstrating a sustained effect on carer wellbeing.
- Lack of evidence on impact of short breaks on other areas of wellbeing such as employment.
- Further evidence exploring short breaks within context of other family support services needed.

Summary of findings carers of people with mental illness

- Not enough evidence to show which type of family intervention works for carers of people with schizophrenia or psychosis.
- Evidence that carer education improves knowledge but limited evidence of wider benefit.

Summary of findings carers of stroke and long term illness

- Information provision for stroke patient and their caregivers found a small but beneficial effect on caregiver knowledge, but no significant impact on carer stress. Some evidence that 'active' information provision ie followed up and reinforced was more effective than passive.
- Further research is needed on what works best to support carers with long term illness.

What improves carers' health and reduces service use?

Overall summary

- There are gaps in the limited UK-based evidence that supporting carers reduces service use in those they are caring for. This is not the same as saying there is evidence that interventions are not effective.
- There is a need for well controlled trials for specific groups, informed by pilot studies.
- Further evidence is needed for cost effectiveness of respite care.
- There was mixed evidence on impact of respite care on delaying institutionalisation with a focused review of UK literature finding delays in admission to residential care associated with home help care, day care and (for some groups) institutional day care.
- However, one well conducted systematic review found no reliable evidence that respite delays entry to residential care.
- This is not the same as saying there is evidence that services are not cost effective.

³⁶ Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., et al. (2011). The Impacts of short break provision on families with a disabled child: an international literature review. *Health and Social care in the Community*, 19(4), 337-371.

Financial impact of carers

There are a number of studies which have quantified the value of the unpaid care provided in England and the UK, these include the following.

Carers UK and Leeds University's "Valuing Carers"³⁷

New estimates show the care provided by friends and family members to ill, frail or disabled relatives is now worth a staggering £119 billion every year.

- The figure has risen by over a third since the 2007 estimate, which stood at £87 billion
- Carers' contribution now far outstrips the total cost of the NHS (£98.8 billion).
- The figure amounts to £2.3 billion per week and £326 million per day.

Royal College of GPs (RCGP)³⁸

One point two million carers spend over 50 hours caring for others, this equates to a full time workforce larger than the entire NHS. Carers are estimated to save the UK economy £119 billion a year in care costs, more than the entire NHS budget and equivalent to £18,473 per year for every carer in the UK.

RCGP has worked with Baker Tilly to identify the social return on investment which can be made when CCGs invest in services which support carers. The study³⁹ shows that this could equate to a saving of almost £4 for every £1 invested.

Department of Health – Impact Assessment (Carers)

The Impact Assessment published by the Department of Health⁴⁰ makes an estimate of the "monetised health benefits" of additional support for carers. This estimates that an anticipated extra spend on carers for England of £292.8 million would save councils £429.3 million in replacement care costs and result in "monetised health benefits" of £2,308.8 million. This suggests (as a ratio) that each pound spent on supporting carers would save councils £1.47 on replacement care costs and benefit the wider health system by £7.88.

³⁷ http://www.leeds.ac.uk/news/article/2008/unpaid_carers_save_119_billion_a_year

³⁸ <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

³⁹ <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

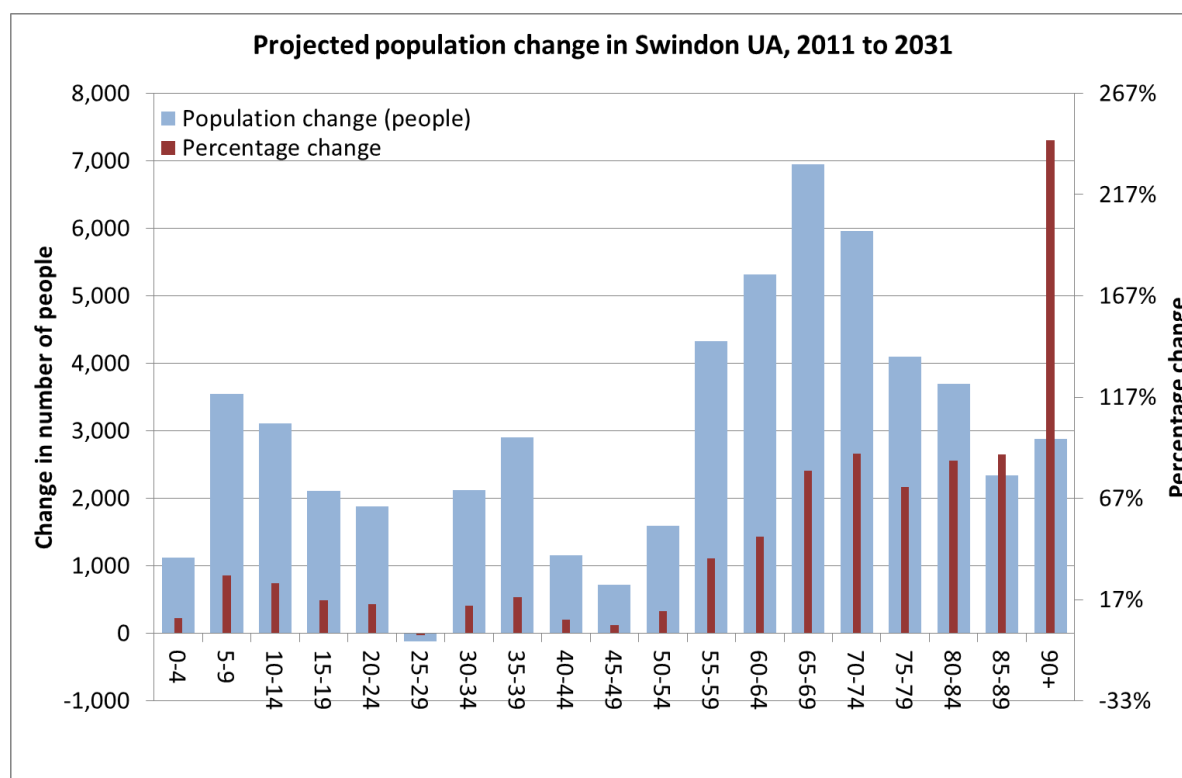
⁴⁰ <http://www.legislation.gov.uk/ukpga/2014/23/impacts>

Projections

Population projections

Nationally, the Office for National Statistics (ONS) produces population projections at local authority level based on trend data. However, these do not take planned housing developments and associated population growth into account and therefore SBC produced its own policy-led population projections in 2014⁴¹.

Figure 20: Population projections, Swindon, 2011 - 2031



Source: SBC Population Projections, 2011 based

The population of Swindon by mid-2011 was estimated to be 209,700, an increase of approximately 29,600 persons from 2001 representing a growth rate of 16%, the highest in the South West.

The SBC projections estimate that Swindon's population could increase to 240,000 persons by 2021, and 265,400 by 2031, equivalent to growth of approximately 14% from 2011 to 2021, and a further 10% from 2021 to 2031.

The largest increase in persons will be in the 65 to 74 age group, projected to be 12,900 more by 2031. However, the 85+ age group will have the largest growth rate at approximately 136%. By 2031 the population aged over 65 is projected to grow by 25,900 persons to reach a total of 55,000 by 2031, accounting for 46% of total population growth.

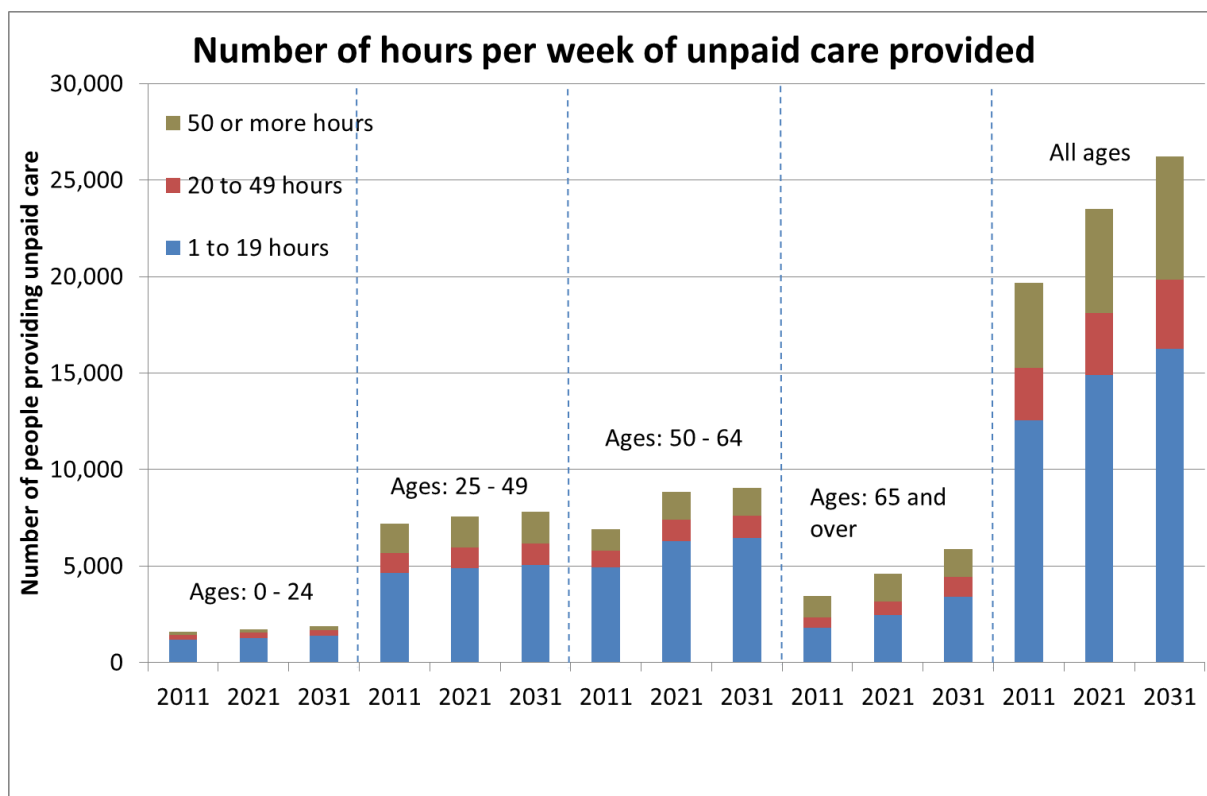
⁴¹ <http://swindonjsna.co.uk/Files/Files/Population-Projections-to-2031.pdf>

The working age population (16-64) is also projected to grow by approximately 21,600 persons to reach a total of 160,800 by 2031, accounting for 39% of total growth. Overall, the age structure of the population is projected to change with significantly higher growth in the older age groups than in the younger groups. This will result in an increase in the ratio of children and older people to working age people so that by 2031 for every one person under the age of 16 or aged 65+ there will be 1.5 persons of working age instead of 2 persons of working age in 2011.

Carers projections

The percentage of carers in each age group according to the 2011 Census have been applied to the SBC population projections to forecast the number of carers in Swindon in future years.

Figure 21: Projected number of carers, Swindon, 2011 - 2031



Source: ONS 2011 Census, SBC Population Projections, 2011 based

The total number of carers is projected to rise to 23,504 in 2021 and to 26,222 by 2031, a 33% rise overall. Because the over 65 population is projected to increase the most, the number of carers in this age group is also projected to increase the most, up from 3,960 in 2011 to 7,500 in 2031 (up 89%).

The number of people who need caring for is likely to rise in line with population projections which means there will be more elderly people with physical and mental health conditions. For example the number of people with dementia is projected to roughly double between 2014 and 2030⁴², whereas the number of 18-64 year old

⁴² www.poppi.org.uk

adults with Learning Disabilities is forecasted to rise more slowly, by around 8% over the same period⁴³.

Possible alternative scenarios

Swindon is growing in size and population, SBC has a Local Plan target to deliver 22,000 new homes between 2011 and 2026. This will inevitably lead to an increase in the number of Carers needing support in Swindon.

There is no current evidence of further funding from Government to support Carers.

⁴³ www.pansi.org.uk

Conclusions and recommendations

Summary of key points

Key issues for carers

National survey data tells us that carers report that caring has an impact on their physical, emotional and economic wellbeing. Carers may also not prioritise their own health for and may miss routine health appointments, like influenza vaccinations or check-ups, with doctors or dentist.

Carers may give up work as a result of their caring responsibilities. This is significant given the importance of 'meaningful activity' (such as employment) to maintaining an individual's positive mental health. Such activity also reduces social isolation.

This JSNA has identified the importance of local community networks and services in supporting the health and wellbeing of carers. Carers in new communities may, therefore, be at risk of having fewer opportunities for support.

In addition, young carers are more likely to grow up in poverty, have poorer school attendance and attainment, to be not in education, employment or training (NEET) and to be bullied and see physical aggression at home. All of these issues may impact on future life chances into adulthood.

Carers from BME groups are likely to be under-identified in Swindon. Services for carers are not necessarily culturally sensitive in relation to the Gypsy and Traveller community. This community is at particular risk of missing out on Carers Allowance because of the impact of travelling and may be forced to move away from established community networks to be able to access equipment and adaptations.

Key trends

The number of carers in Swindon increased between 2001 and 2011, the proportionate increase was greater than for the general population. There will be further population growth in Swindon, including new developments, which means the number of carers are expected to increase. The population in Swindon is ageing, which will result in a larger number of adults with care needs.

Gaps in knowledge/services – all carers

The Care Act 2014 requires services to prevent and reduce future needs through the early identification and support of carers. Considering the large number of carers identified in the census work, is needed to understand how best to support carers who do a small amount of caring, especially those who are likely to go on to care more intensively for someone whose needs are increasing over time, with staying healthy and well. Given the low level of evidence available on what works best to keep carers healthy and well, building in evaluation of interventions will be crucial.

The survey carried out as part of the JSNA process yielded some useful information, but further work is needed to systematically capture the views of carers. This could include use of reference groups or known distributions groups (for example receiving carers' magazine) or better use of information collected at contact points with carers (e.g. carers' assessment).

NICE guidance and good practice documents recommend that carers involved in patient care are identified as soon as possible and supported appropriately. This includes having information sharing and confidentiality protocols in place. In addition, national carer policy points to the need to take a holistic approach to assessing the needs of the carer and cared-for person together. It is important that carers are recognised and supported within acute hospitals and that their needs are identified at hospital discharge. Work in the Great Western Hospital has shown the capacity to recognise and support carers and link to community based support, emergency planning and referral to GP carer registers where they exist. It is currently not possible to measure whether carer status is being recorded in the multidisciplinary team record at discharge in Swindon.

In Swindon not all carers providing high intensity care (as identified in the 2011 census) have a plan in place to deal with an unexpected emergency that stops them being able to carry out their caring role. However, some carers may have nominated a friend or family member in this role. It is also important to ensure services and the wider community are able to support carers with lower level, 'urgent' issues, including supporting carers out of hours. Planning is also important for transitions in care e.g. child to adult, death of carer.

Accurate data are not available on the number of carers registered in primary care in Swindon. The GP surgery is often the first point of call for carers and most want to use surgeries as a source of support or referral.

National surveys suggest that GPs could do more to support carers. Further work is needed to understand the provision of services to carers in Primary care in Swindon.

The majority of carers who are recently bereaved do not require specific 'bereavement counselling'. It is important that professionals recognise when a referral is needed to such services. There are a number of bereavement services in Swindon, including Cruse Bereavement Care, who are a leading national charity, offering face-to-face and telephone support. However, the availability and quality of these services is not known.

Gaps in knowledge/services – young carers

Joint working between services specifically working with young carers and mainstream preventive services for children and young people is needed to ensure that young carers are seen as a vulnerable group, their needs identified early and seen in the context of the whole family (for example through ensuring good parenting support).

National data tells us that young carers have poorer educational outcomes than their peers. Information from local focus groups tells us that children are worried about meeting deadlines and managing homework at school. However, at a population level it is not possible to identify numbers of young carers in Swindon schools or to look at local educational outcomes for this potentially vulnerable group. Support at transition to adulthood (from age 14) is needed to ensure young carers continue in education or training and to ensure good health outcomes. A multidisciplinary approach is needed to ensure each child or young person is able to access

education and fulfil their educational potential. Data on the referrals of young carers to organisations like SCC suggest that adult services need to do more to identify young carers and take action to support their needs, particularly mental health, and drug and alcohol services. There is poor take up of young carers' services by black and ethnic minority communities.

There are few dedicated services for young adult carers in Swindon although the Swindon Carer Centre has self-funded a temporary post to help support this group. This suggests that this group of carers may be missing out on advocacy, information and advice on issues such as finance and employment as well as emotional support and opportunities to socialise. However, currently the way data on service use by young adults, is recorded makes it difficult to identify the support this group is receiving from adult services. With a lack of engagement, young adult carers have no voice. They need mechanisms to be heard and involved in the planning, review and evaluation of Carers Services.

Swindon young adult carers have identified the following gaps:

- Limited access to Information and Advice for young adult carers.
- Poor access to Carers Assessments for young adult carers.
- Poor access to support to access social and leisure activities for young adult carers.
- Limited access to participation opportunities and chances to be heard for young adult carers.

Recommendations

- Further investment in Young Adult Carers (YAC) Services – the transition from children to adult services is challenging, YAC need recognising in their own right.
- To develop a Swindon Carers Strategy and action plan based on the findings and key messages from this report aligned to the Memorandum of Understanding.
- Sign up by the Carers Leads group to implement and monitor the Swindon Carers Strategy – including key priorities such as: ill health, social isolation and crisis, retirement, bereavement, changes in caring role, coming home from hospital and first access of formal care and support and ensure interventions are targeted towards these.
- It is recommended that the default position should be that every carer over 65 has an Emergency Card.
- That the Pilot employer award standards has a full follow up report on findings and next steps.
- Promotion of the Carers Support Scheme. This is a fund that Carers can access but which is currently not being fully allocated.
- To raise awareness of the specific needs of carers aged 85 and over and ensure services offered are appropriate and targeted.
- Develop education, training and information sessions for carers across all age ranges through working with specialists in specific fields (Mental Health, Dementia etc.).
- Build strong links with the Health Ambassadors and Community Navigators to support the work in highlighting carers' needs.
- Ensure Young Carers are engaged in the Member of Youth Parliament and Youth Council work, specifically campaigns that support emotional health and wellbeing.
- Build strong links with the provider of the Reducing Loneliness and Isolation contract in order to support carers who are experiencing this.
- To gain a better understanding of the wider offer for Carers Breaks and how these are accessed, the impact and outcomes.

Appendix A - Census definitions

The 2001 and 2011 Census forms asked whether you provided unpaid care to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age and for how many hours per week.

Carer

Provision of unpaid care

A person is a provider of unpaid care if they look after or give help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age. This does not include any activities as part of paid employment. No distinction is made about whether any care that a person provides is within their own household or outside of the household, so no explicit link can be made about whether the care provided is for a person within the household who has poor general health or a long-term health problem or disability.

The following Carer categories are available:

- All categories: Provision of unpaid care
- Provides no unpaid care
- Provides unpaid care: Total
- Provides 1 to 19 hours unpaid care a week
- Provides 20 to 49 hours unpaid care a week
- Provides 50 or more hours unpaid care a week

General Health

General health is a self-assessment of a person's general state of health. People were asked to assess whether their health was very good, good, fair, bad or very bad. This assessment is not based on a person's health over any specified period of time.

The following categories of General Health are available:

- All categories: General health
- Very good or good health
- Fair health
- Bad or very bad health