

Swindon Joint Strategic Needs Assessment Bulletin

Swindon Carers 2017



Key Points:

- 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'.
- Swindon Borough Council (SBC) and NHS Swindon Clinical Commissioning Group (CCG) are committed to supporting Carers. SBC has a statutory duty to offer everyone who defines themselves as being a carer an assessment. The Swindon Carers Centre (SCC) is commissioned to deliver a range of services to carers in Swindon.
- There were an estimated 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 South West, and well above the national average of 17.7%. It is estimated the value of carers in Swindon is just under £400 million per year.
- The total number of carers in Swindon is projected to rise to 23,504 in 2021 and to 26,222 by 2031, a 33% rise overall.
- In Swindon, in 2011, 551 children aged 15 and under and 1,029 aged 16 to 24 reported providing unpaid care. 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, in 2011, 13.6% of the population aged 65 and over were providing some form of unpaid care. 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.
- An estimated 84% of carers find that caring has a negative impact on health and in particular mental 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 JSNA makes nine recommendations – these are on page 8.

What is a Joint Strategic Needs Assessment (JSNA)?

JSNA helps us to understand:

- the current health and wellbeing needs of local people;
- how their needs are being met;
- what we think their future needs are likely to be; and
- how their needs can be best met.

We want to understand Swindon's changing population, what is going on in Swindon and what makes a difference to people's health and wellbeing so that we can plan for the best care in future. Many different people from a range of organisations help to write a JSNA. The Swindon's Health and Wellbeing Board is a group that leads the development of JSNAs.

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’.

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.

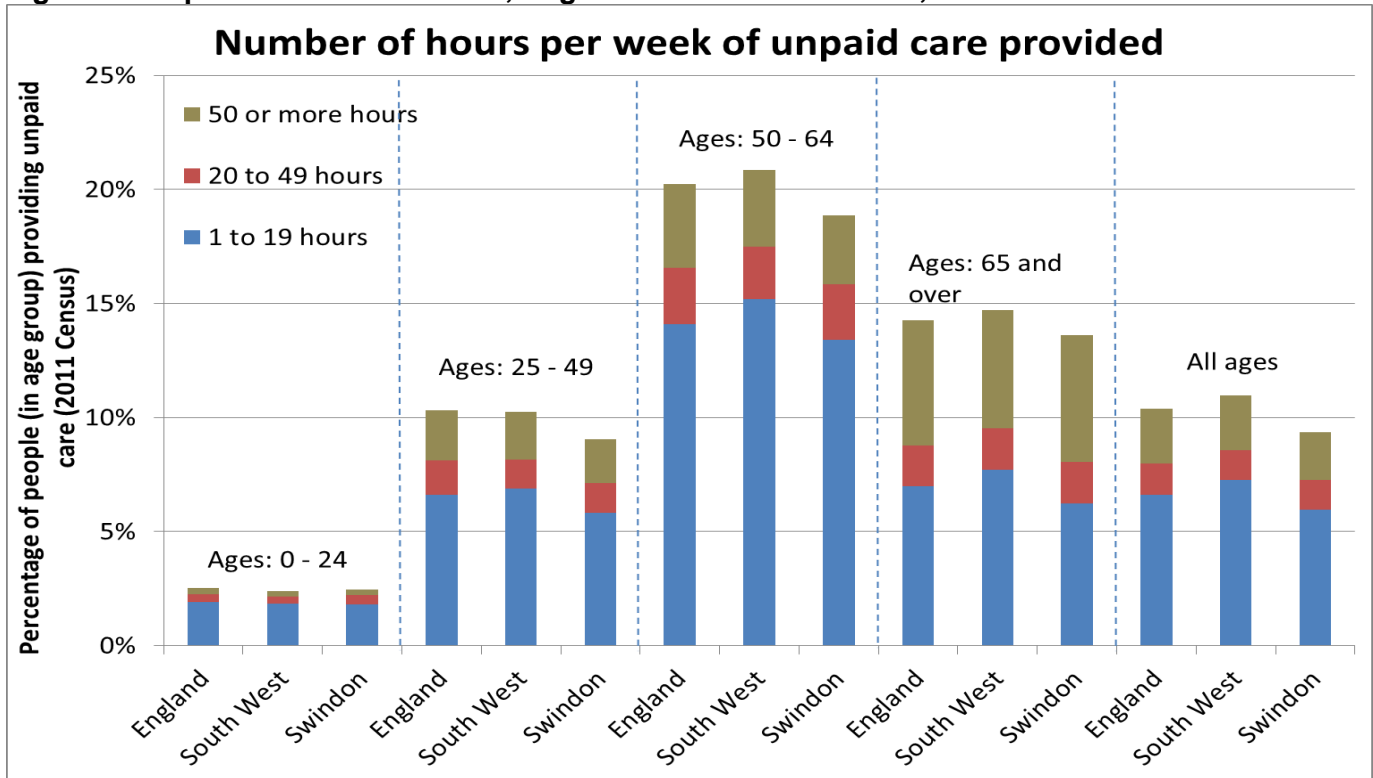
Particular attention is paid to certain groups of carers who face challenging circumstances including young carers, older carers and those caring for people with specific conditions.

National and local policy

The refreshed Carers Strategy of 2010 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.

Figure 1. Unpaid carers in Swindon, England and the South West, 2011



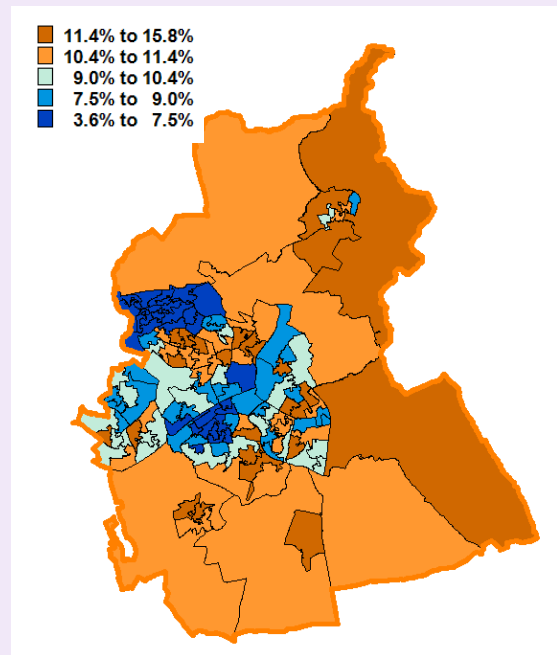
Source: 2011 Census, ONS

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 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 21,006 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 that value of carers in Swindon is currently £395 million per year (up £36 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.

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

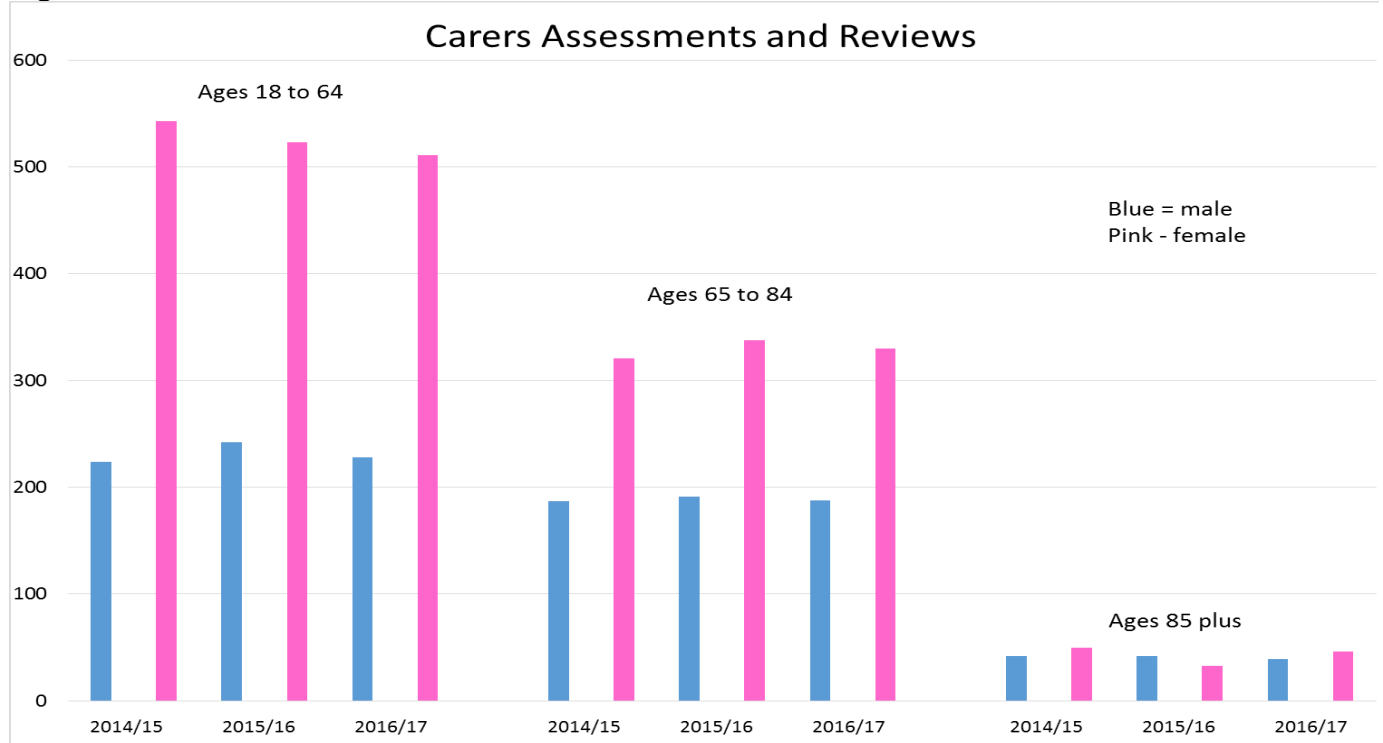


Source: 2011 Census, (ONS)
 (C) Crown copyright and database rights 100024296 2017
 Map created by Tom Frost, Senior Public Health Intelligence Analyst
 Swindon Borough Council, 2017

Social Care Services

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

Figure 3. Assessments of Carers Needs, Swindon 2014/15 – 2016/17



Source: Swindon Borough Council, 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%).

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

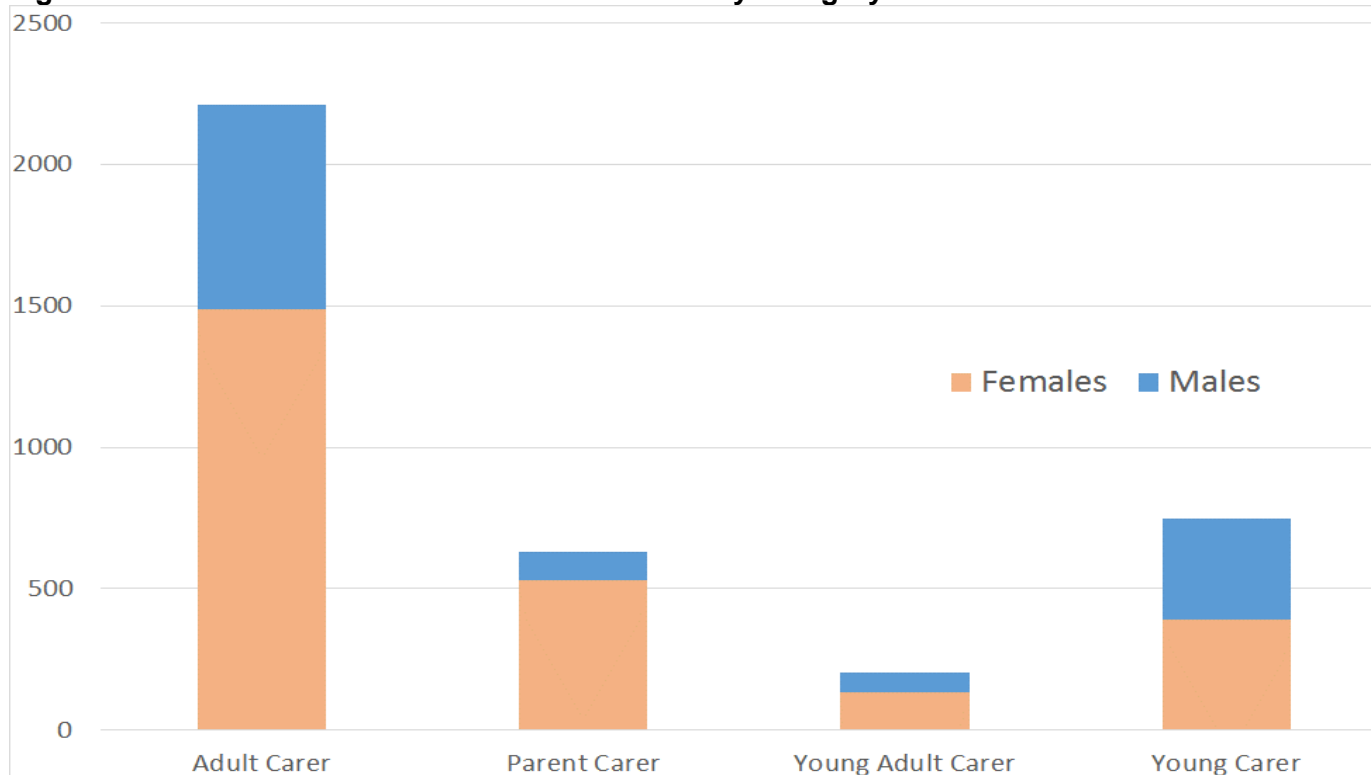
Swindon Carers Centre (SCC) is a charitable organisation, which is part of the Carers Trust Network, and was established to provide help and support to the 21,000 carers in Swindon. They work in partnership with other organisations, including local NHS services, Swindon Borough Council's Adult Social 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.

Figure 4. Carers Known to Swindon Carers Centre by Category



Source: Swindon Carers Centre

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?

Many carers find their role in supporting loved ones rewarding. For some, calling themselves a 'carer' is vitally important, as they campaigned for this and they feel that it gives value to their role and more clearly defines what they do to health and care professionals.

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 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 SCC 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.

Table 1. 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.

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. These recommendations should be taken to the established multi-agency Swindon Diabetes Transformation Board for action.

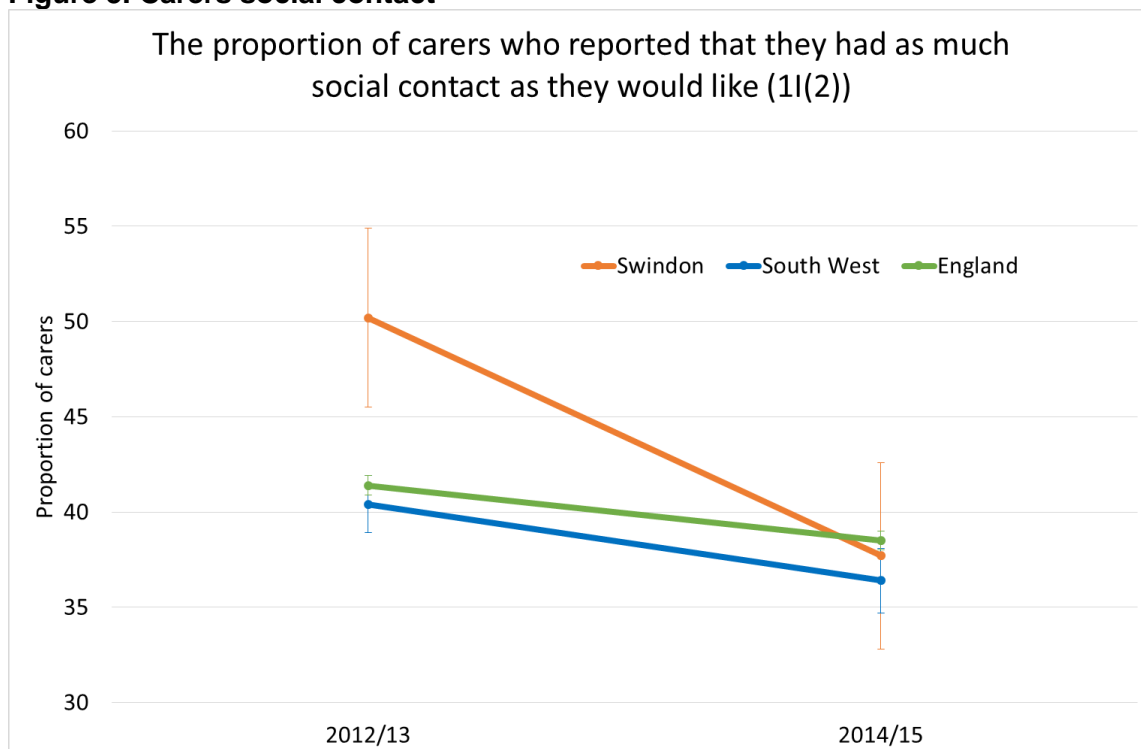
Carers of people with learning disabilities

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 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.

Figure 5. Carers social contact



Source: NHS Digital (ASCOF)

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.

Table 2: 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

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.

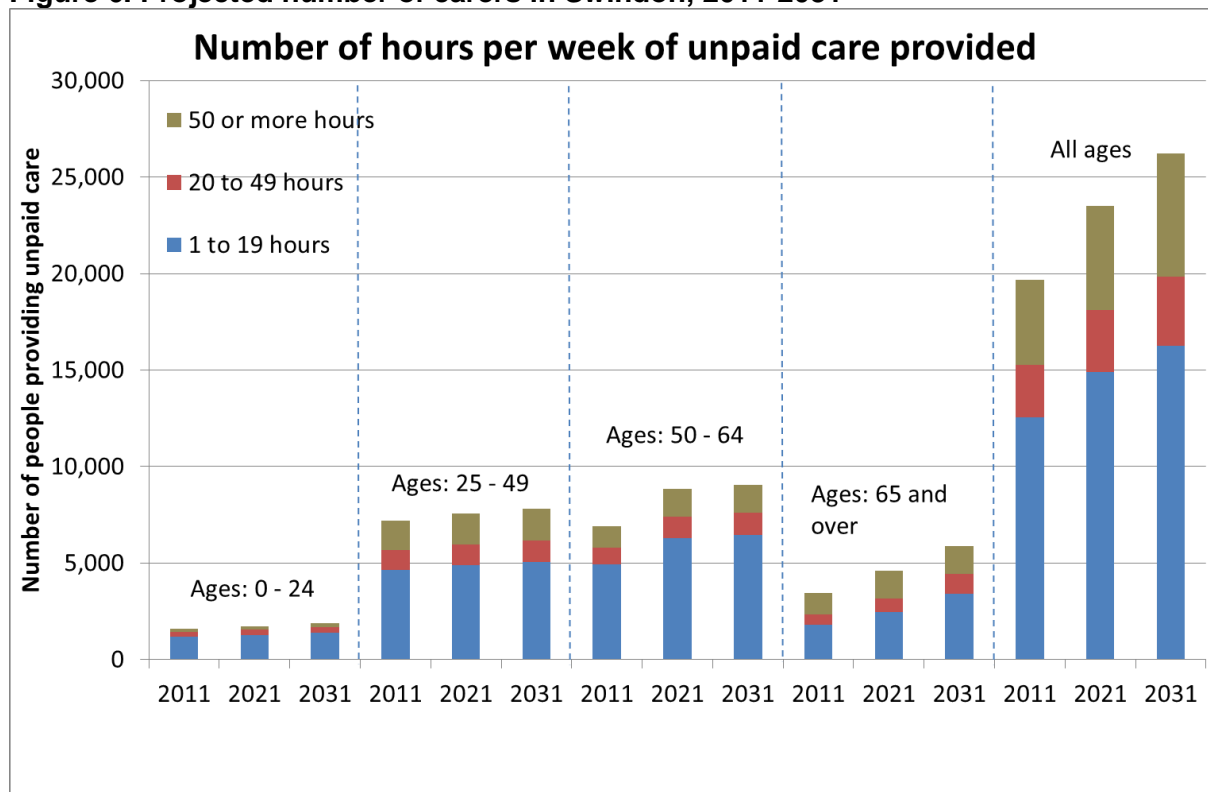
The health of carers deteriorates more quickly than that of non-carers due to the lack of support (often due to a lack of awareness of support available).

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.

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.

Figure 6. Projected number of carers in 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%).

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.



Recommendations

1. Further investment in Young Adult Carers (YAC) Services - the transition from children to adult services is challenging, YAC need recognising in their own right.
2. 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.
3. 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.
4. It is recommended that the default position should be that every carer over 65 has an Emergency Card.
5. That the Pilot employer award standards has a full follow up report on findings and next steps.
6. Promotion of the Carers Support Scheme. This is a fund that Carers can access but which is currently not being fully allocated.
7. To raise awareness of the specific needs of carers aged 85 and over and ensure services offered are appropriate and targeted.
8. Build strong links with the provider of the Reducing Loneliness and Isolation contract in order to support carers who are experiencing this.
9. To gain a better understanding of the wider offer for Carers Breaks and how these are accessed, the impact and outcomes.

Where to find more information

This Bulletin is an abbreviated version of the Carers JSNA which can be found on Swindon's JSNA website: swindonjsna.co.uk

The website contains a range of other documents about health and well-being in Swindon.

If you have any queries please contact JSNA@swindon.gov.uk

This bulletin was published in October 2017.