

### Why is this issue important?

The majority of care in the UK is provided by family members, friends and relatives. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

The 2011 Census shows 5.8 million people provide unpaid care in England and Wales, representing over one tenth of the population (10.3%).<sup>1</sup>

The economic value of the contribution of carers in the UK is now £132 billion per year - close to the annual cost of the total health spend in the UK.<sup>2</sup>

Across England the percentage of unpaid carers is increasing at a faster pace than population growth; people are caring for longer due to an ageing population and improved life expectancy for people with long term conditions and complex disabilities.

Carers have increasing rights under new legislation; through the Care and Support Act (2014), carers have equitable rights to those that they care for. The local authority, in partnership with health, has to ensure that there are appropriate services to support the wellbeing and needs of carers.

Those providing unpaid care were more likely to report their general health as 'not good', compared with those providing no unpaid care. Census 2011 data indicates that the general health declines as hours of unpaid care increases, for example 83% of those providing no unpaid care report "very good or good health", compared to 56% of those providing 50 or more hours for care per week.<sup>1</sup>

### Key outcomes

- **Carer-reported quality of life (Adult Social Care Outcomes Framework)**

- **Overall satisfaction of carers with social services (Adult Social Care Outcomes Framework)**
- **The proportion of carers who report that they have been included or consulted in discussions about the person they care for (Adult Social Care Outcomes Framework)**
- **The proportion of people who use services and carers who find it easy to find information about support (Adult Social Care Outcomes Framework)**
- **Social Isolation: percentage of adult carers who have as much social contact as they would like (Public Health Outcomes Framework and Adult Social Care Outcomes Framework)**

### Impact in Brighton & Hove

The 2011 Census data shows that the City has 23,967 people who identify themselves as carers, which represents 9% of the population. Although this a rise of 2,164 people since the 2001 census, proportionally it is the same (9% of the population). Of those carers:

- 68% provide 1 to 19 hours of care a week
- 12% provide 20 to 49 hours per week
- 20% provide 50 or more hours per week.<sup>3</sup>

In their report Valuing Carers 2015, Carers UK estimated the economic value of the contribution made by carers in the city to be £437 million per year.<sup>2</sup> This is an increase from £388.7million in 2011 (Table 1) and £301million in 2007.<sup>4</sup> The economic value of carers has increased for two main reasons. First, the costs of replacement care have increased. Secondly, the numbers of carers has gone up.

<sup>1</sup> Office for National Statistics. Full Story: The gender gap in unpaid care provision: is there an impact on health and economic position? May 2013

<sup>2</sup> Carers UK. (2015). Valuing Carers 2015: the rising value of carers' support. Available online: <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015> Accessed 29 Jan 2016.

<sup>3</sup> Office for National Statistics. 2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001.

<sup>4</sup> Care UK and University of Leeds. Valuing Carers 2011: Calculating the value of carers support. 2011.

## 4.2.7 Carers

Caring for someone can have a significant impact in the carer's life. Carers reported in a local survey that the areas of their lives worst affected by the caring role were 'undertaking leisure, cultural or spiritual activities' (65.5%), 'maintaining contact with people important to you' (60.4%) and 'getting out into the community' (56.7%) and most agreed that these three areas had a significant impact on their wellbeing. Furthermore, 40.0% of carers also reported that their caring responsibilities impacted on their work and employment opportunities, and 36.5% were experiencing financial difficulties. Most carers (91.4%) felt there was some risk of their mental health deteriorating, with over half (52.1%) rating themselves as being at 'significant' or 'serious' risk. These figures were similar for physical health, with 86.9% feeling that they were at some risk and 37.6% rating themselves as being at 'significant' or 'serious' risk

This survey identified three key themes that carers wanted improved locally:

- Better and more accessible information and advice
- Active and supportive communities
- Flexible and integrated care and support<sup>5</sup>

Unpaid care has increased at a faster pace than population growth, and an ageing population and improved life expectancy for people with long term conditions and complex disabilities means people are caring for longer.<sup>3</sup>

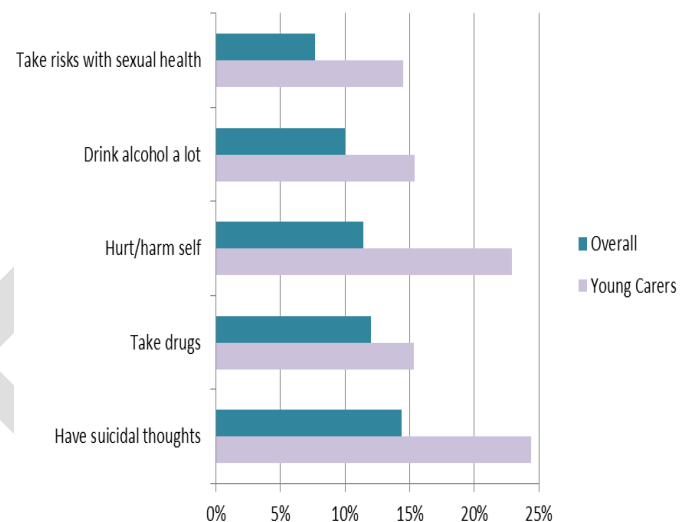
### Young carers:

Young carers are particularly vulnerable. They are more likely than non-carers to be bullied at school (14% vs 7%) and less likely to agree that they have someone to tell if they are being bullied (78% of young carers vs. 84%).

<sup>5</sup> Brighton and Hove City Council (2015). Adult Social Care. Caring for others Survey: 2014-15. Available online: <https://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/Carers%20report%20-%20May%202015.pdf> [Accessed 18 Apr 2016]

Compared to other young people, young carers are more likely to engage in risky behaviours such as trying drugs, alcohol and smoking, and to experience negative health and wellbeing<sup>6</sup>.

**Figure 3: Percentage of young carers aged 14-16 who have often or sometimes experienced these behaviours, compared to young people overall.**



Source: Safe and Well at School Survey 2015



Source: Brighton & Hove multi-agency commissioning and development strategy for carers. 2009-2012.

<sup>6</sup> Brighton & Hove Safe and Well at School Survey (SAWSS). Available at <http://www.bhconnected.org.uk/sites/bhconnected/files/SAWSS%202015%20briefing.pdf> [Accessed 02/09/2016]

### Parent carers:

Local research on parent carers, by Amaze the charity that supports parent carers locally found that:

- 69% of parents carers spend 20 hours or more additional hours of caring a week because of their child's special educational needs and disabilities, and 24% said it is an additional 100 hours a week.
- 44% of parent carers haven't had a break from their caring role in the past year
- 78% of parent carers said that they had not had their needs as a carer assessed
- 49% of parents carers reported that they don't have enough social contact, and 17% reported little or no social contact leading to isolation
- 31% reported that their caring role had stopped them being able to work
- 17% of parent carers reported having skipped meals or reduced portion sizes, as there wasn't enough money to feed the family.

A previous survey by the same organisation found that parent carers wanted more residential respite care, information/advice and counselling services. Over two thirds of parent carers said they felt that they neglected themselves, and have limited sleep due to their caring role. Almost one in five feel anxious, stressed or depressed most or all of the time. Many parent carers, within the survey, expressed being 'fearful' that services for their children may be reduced, and 82% of stated there would be a significant or devastating impact on the family if short break/respite services were reduced.<sup>7</sup>

### Where we are doing well

Through a process of joint commissioning between the Clinical Commissioning Group and the City

Council, there are an excellent range of dedicated services and opportunities for unpaid carers across the city. There is a successful mix of both statutory and voluntary sector providers, who are involved in both the direct provision of services, and strategic development, through the joint Carers Strategy Group.

The City Council has a Carers Team providing support work and assessments for carers, enabling those carers who have eligible needs to access a Carers Personal Budget (under the Care and Support Act 2014).

Within the voluntary sector there is a range of services from specialist support - for carers of people with dementia, mental health needs, and end of life care - to more generic support for all carers.

Additionally, through accessing increased funding via the Better Care Fund, we have provided a range of new services, including the provision of free alternative homebased respite to enable carers to attend health related appointments (My Health Matter, Crossroads); supporting carers to achieve agreed goals with the support of volunteers (Carers Reablement Service, Carers Centre); and dedicated Carers Support Workers based within the Royal Sussex County Hospital (Adult Social Care).

We have also invested in new approaches for supporting carers, firstly this summer we launched the Carers Digital Offer, developed by Carers UK to provide a range of local and national information, advice and learning opportunities ([www.brighton-hove.uk/CarersUK](http://www.brighton-hove.uk/CarersUK)), as well as providing dedicated support to Primary Care services to raise the awareness of carers within their services; and joining Employers for Carers enabling access to on line resources and a national network to support working carers.

During 2015/16 locally a Young Carers pathway was developed, in response to the increasing awareness and needs of young carers, as well as

<sup>7</sup> Amaze, 2013. Amaze parent carer survey report. Available at <http://amazebrighton.org.uk/wp-content/uploads/2013/09/Survey2013Analysis-ReportFINAL.pdf> [Accessed on 09/11/2016]

the increased rights for young carers under both adult legislation and Children's and Families Act 2014.

The pathway includes the creation of a joint worker, who is based within the Early Help Hub and works directly with young carers, as well as effectively signposting them to a range of services. The Young Carers Strategy group ensures that the needs of young carers are addressed, through both raising awareness of young carers and providing services. The group has representatives from Children Services; Adult Social Care; School Nurses; and the Young Carers Project (part of the local Carers Centre), and provides a forum to respond to the needs of local young carers.

In July 2016 the Health and Wellbeing Board approved the new local Carers strategy – "THINK CARER, supporting Carers through an increasingly Carer Friendly City" – the strategy brings together the information gained regarding the needs of local carers through the 2016 Carers Rapid Needs Assessment,<sup>8</sup> the statutory duties and rights that carers have, and identifies five key priorities for creating a Carer Friendly City.

The Carers Commissioning Intentions, which have resulted from the Carers Strategy, focus on the need for improved access to information and advice through an integrated services approach, as well as a programme of raising carer awareness, provided by a partnership of services – the Carers Hub. Procurement for the Carers Hub will begin early 2017, and be in place by July 2017.

### Local inequalities

The 2011 Census<sup>3</sup> shows that 23,967 people in Brighton & Hove identify as carers, which represents 9% of the population, lower than the

national average (10.3%). Women make up the majority of carers (58% vs 42%). Older people are more likely to be carers, with 32.5% of people 50 years or older having caring responsibilities, and least likely to be 15 years or younger (1.2%).

Most carers self-identify as White British (82%), followed by White Other (5.5%), Asian or Asian British (4.1), Mixed (3.8%), Black or Black British (1.5%) and Other (1.5%).

Data show that the wards with the overall highest percentage of residents who are carers are Woodingdean (11.8%), Patcham (11.7%), and Hangleton and Knoll (11.6%).

Looking at the carers' population by age and ward, data show that older carers (65 years or more) concentrate in Rottingdean Coastal (28%), Withdean (24%), Hove Park and Patcham (both 23%). Conversely, carers under 25 years of age tend to concentrate in Moulsecoomb and Bevendean (16%), St.Peter's and North Laine (15%), Hanover and Elm Grove (15%), Hove Park (23%) and East Brighton (11%). **Error! Bookmark not defined.**

There is a direct link between caring for a disabled child and living in poverty (over 50% of disabled children are living in poverty).<sup>9</sup> Parent carers are much less likely to be able to return to paid work with 38% of respondents to the 2013 Parent carers survey, conducted by Amaze, saying that they can't be in paid work because of their caring responsibilities and a further 22% have had to reduce their work hours. Additionally, this continues for longer - into a child's secondary education when other parents might feel able to return to work.<sup>7</sup>

There is a paucity of data on other equality groups and caring role within the city.

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<sup>8</sup> Brighton & Hove City Council. Carers rapid needs assessment. 2016. Available at: <http://www.bhconnected.org.uk/sites/bhconnected/files/Carers%20Needs%20Assessment%202015-16.pdf> [Accessed on 09/11/2016]

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<sup>9</sup> Preston, G. with Robertson, M. (2006), Out of Reach: benefits for disabled children, London: Contact a Family/Child Poverty Action Group

### Predicted future need

Although the proportion of older people living in the City has fallen in recent years, the population aged 60 years or over is predicted to increase, particularly among the 60-64 and 75-79 age groups.<sup>10</sup>

The number of people who are older, disabled or HIV positive, or who have mental health problems, dementia, a learning disability or substance misuse problems in the city gives some indication of the likely size of future caring needs. Table 3 shows the numbers of adults aged 18-64 projected to have certain conditions by 2030. In particular the number of those with a moderate or serious physical disability is predicted to rise by over 2,000 people (12%) by 2030.

**Table 3: Population aged 18-64 with caring needs in 2015 and predicted population with caring needs 2020 & 2030, Brighton & Hove<sup>11</sup>**

	2015	2020	2030
Moderate or severe learning disability	1,084	1,118	1,170
Alcohol or drug dependence	18,270	18,912	19,766
Moderate or serious physical disability	17,367	18,447	19,501

Source: Institute for Public Care. PANSI [www.pansi.org.uk](http://www.pansi.org.uk)

### What we don't know

We need to improve the data collected in relation to carers from protected groups. The Carers Strategy Group is working with colleagues across the health and social care sector (including key

<sup>10</sup> Office for National Statistics. 2014 based Population Projections components of change. Available at: [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration) [Accessed 26/06/16]

<sup>11</sup> Institute of Public Care. Projecting Adults Needs and Service Information (PANSI). Available at: [www.pansi.org.uk](http://www.pansi.org.uk) (password required) [Accessed October 2016]

voluntary organisations) in order to collect more detailed information about carers within the City.

A key recommendation of the CRNA is, “Review the list of groups of carers at higher risk/with higher needs and prioritise those that more information is needed about or more specialist work is needed on. Research could be carried out with these groups to find out why they don't access services” – this work will be taken forward by the Carers Strategy Group.

Additionally, we are currently working with NHS England to develop and potentially adopt a new Carers Evaluation and Impact Tool, for carers' services (early 2017). This will enable us to know the impact on carers of the services we have commissioned.

### Key evidence and policy

The Care and Support Act 2014 places a greater emphasis on supporting carers; for the first time, carers will be recognised in the law in the same way as those they care for. The duties include providing greater information and advice, meeting assessed eligible needs of carers (which is equivalent to the duty to meet the needs of cared for people), and to have a proactive approach to supporting carers to access carers assessments, through increased identification and recognition.<sup>12</sup>

A review of international evidence on interventions to support carers found the strongest evidence of effectiveness related to education, training and information for carers.<sup>13</sup> These increased their knowledge and abilities as carers, and suggested it might also improve carers' mental health and ability to cope/resilience. This has been an increasing awareness nationally for the need to support carers, and a range of resources have been developed, including *Think Local Act Personal*; Commissioning for Carers (NHS England); and the

<sup>12</sup> Department of Health. The Care Bill. 2013

<sup>13</sup> Parker G, Arksey H, Harden M. Meta-review of international evidence on interventions to support carers. University of York; 2010.

## 4.2.7 Carers

Supporting Carers Programme (RCGP). The local Carers Strategy Group has been utilising these resources to improve local provision.

Work with carers is underpinned by two specific pieces of legislation:

- Care and Support Act 2014
- Children and Families Act 2014

Policy is also shaped by the National Strategy for Carers.<sup>14</sup>

### Recommended future local priorities

1. Services and commissioners should consider how to target services at groups identified as being under-represented within services (e.g. males, working age carers, Muslims).
2. Ensure that organisations that work with young people and with young carers specifically are aware that young carers are at increased risk of a number of poor outcomes and can respond to these risks including linking them into appropriate services such as physical and mental health services.
3. Ensure that impact of carers' services can be demonstrated by including the same questions in carer's reviews as the carer's assessment (for example, questions about the impact of caring on wellbeing and the risks to physical and mental health).
4. Ensure that the data collected by statutory services are complete and quality checked, to provide a robust source of evidence about carers and their needs.
5. Ensure that statutory services are collecting data on the protected characteristics for all carers accessing services, including religion and sexual orientation, as well as armed forces personnel.

6. Review the list of groups of carers at higher risk/with higher needs and prioritise those that more information is needed about or more specialised work is needed on. Research could be carried out with these groups to find out why they don't access services.

### Key links to other sections

- Disabled children and young people
- Adults with learning disabilities
- Adults with physical or sensory impairments
- Autistic Spectrum Conditions
- Ageing well
- Coronary heart disease
- Diabetes
- Stroke
- Respiratory disease
- Cancer
- Mental health
- Dual diagnosis
- Dementia
- Musculoskeletal conditions
- HIV/AIDS
- End of life care

### Further information

Carers' rapid needs assessment 2016

<http://www.bhconnected.org.uk/sites/bhconnected/files/Carers%20Needs%20Assessment%202015-16.pdf>

### Last updated

November 2016

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<sup>14</sup> Department of Health. Carers at the heart of 21<sup>st</sup> century families and communities. 2008