

Adult Carers

Introduction

1. Definition of carers

‘A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.’

<http://www.carersuk.org/what-carer>

They don't get paid. Anyone of us can become a carer and it is not usually a conscious choice.

Carers are also parents or guardians of children with a disability as well as elderly people.

The Carer's Recognition Act (1995) defined a Carer as someone who:

- provides, or intends to provide, a substantial amount of care on a regular basis for another individual aged 18 or over, or
- with parental responsibility for a disabled child who provides, or intends to provide a substantial amount of care on a regular basis for the child

Carers are essentially members of the Bedford Borough community. They deliver care to people without pay for up to 24 hours a day, 7 days a week.

Many carers view themselves as a husband, wife, parent or child doing what anyone would do for a loved one rather than seeing themselves as a carer. This means there is a real challenge to identify carers and raise public awareness of the information and support that is available to them.

As a result carers are vulnerable to poor mental health experiences, particularly stress, anxiety and depression and are twice as likely to be permanently sick or disabled if they provide high levels of care.

This section of the JSNA focuses on adult carers. Young carers are a separate chapter.

2. To view the [Adult Social Care Outcomes Framework](#) (ASCOF) and other relevant frameworks listed below, click on this link.

- Annex B – Adult Social Care Outcomes Framework 2015/16 at a glance
- Annex C – NHS Outcomes Framework 2015/16 at a glance
- Annex D – Public Health Outcomes Framework 2015/16 at a glance

- Annex E – Local Authority Outcomes

What do we know?

2. National Picture

There are 6.5 million carers in the UK – one in 10 people. The number of carers is projected to grow steadily as a result of population growth, ageing of the population, and higher life expectancy. By 2037 the number of people caring will have increased to more than 9 million.² Currently:

- 1.4 million spend over 50 hours a week caring for someone
- Those providing 50 hours or more care a week are twice as likely to be in poor health as non-carers.
- The Valuing Carers report highlights the economic value of the contribution made by carers in the UK - £132 billion for the year 2014-15.
- 42% of carers are men, 58% women.
- 45% of carers give up work to care.
- 49% of carers are struggling financially because of their caring role.
- 61% of carers faced depression because of their caring role.
- 175,000 are children caring for someone
- 1 in 4 will be supporting someone with a mental health problem
- 1 in 9 of the UK's carers are looking after someone with dementia
- 70% of carers look after someone who is 65 years or over
- 60% of people with a learning disability are looked after by a carer
- Most carers (5.7 million) are aged over 18 and the peak age for caring is 50 to 59 (1 in 5 Carers)
- 3 million people combine work with caring responsibilities – more than 1 in 10 UK workers.
- Over 2 million carers work full time and 1 million part-time.
- There are 1.2million carers aged 65+.
- A quarter of all carers aged 75 and over provide 50 or more hours of informal care each week³
- There are 2.8 million people aged 50 and over, providing unpaid care in the UK, including 5% of people aged 85 and over⁴
- Less than 3 in 10 of us think we will become a carer.
- 6 in 10 of us will be carers at some point in our lives.
- 6,000 people start looking after someone each day.
- Fewer than 1 in 3 carers are using health and care technology.
- 1 in 9 employees are currently looking after someone.
- 3 in 5 carers over 85yrs are male.
- Well over a third, 39% of carers in England have waited or have been waiting for over six months for a carers assessment for someone at the end of life.
- 1 in 5 carers in England are waiting for adaptations in their home.

3. Local Picture- Bedford Borough

Bedford Borough covers an area of 476 sq. km and in mid 2014 was home to 163,924⁵ people living in approximately 67,000 households. The 2011 Census reported there were 16,084 unpaid carers in Bedford Borough, about 10% of the household population, very similar to the average for England. This represents an increase between 2001 and 2011 of 11%; it was concentrated among those providing 20-49 and 50+ hours of care a week, with a much smaller increase in those providing 0-19 hours. See Figure 1 below:

Figure 1 Hours per week of unpaid care.

| Hours/Week Unpaid Care | Bedford Borough | | Bedford Borough | |
|------------------------|-----------------|---------------|------------------|--------------------|
| | 2001 Carers | 2011 Carers | Change 2001-2011 | % Change 2001-2011 |
| 1-19 | 10,498 | 10,838 | 340 | 3.2 |
| 20-49 | 1,497 | 2,055 | 558 | 37.3 |
| 50+ | 2,425 | 3,191 | 766 | 31.6 |
| Total | 14,420 | 16,084 | 1,664 | 11.5 |

Source, ONS 2001 Census Table CAS025 and 2011 Census, Table KS301EW

Allowing for population growth and ageing of the population since 2011, it is estimated that there are 17,100 carers in the Borough in 2015 and that by 2020 this will rise to 17,90⁶

An urban/rural divide in the distribution of carers is apparent. Eight out of ten wards with the highest levels of carers are rural, but nine out of ten wards with the lowest levels are urban.

While we wouldn't expect all carers to be in receipt of a carer's service, it seems clear we need to identify and support more carers.

There are more female carers in Bedford Borough than male carers and there is a gender gap in the numbers claiming Carer's Allowance. Almost 80% of claimants are female, which is thought to reflect the conditions attached to the benefit rather than a reluctance of males to claim; however this should be investigated further.

A recent joint report by Carers UK and Age UK, 2015, '[Caring into Later Life](#)'⁷ reveals that many older carers cannot be paid Carer's Allowance at all because it is considered to be 'overlapping' with their State Pension. Essentially, both are seen to be a payment in lieu of work so they cannot receive both benefits. The report recommends that the Government should review how the contribution of older carers can be better recognised in the social security system.

The report also shows that carers over the age of 65 are more likely to be female, perhaps reflecting the higher number of females claiming carers Allowance. However, this balance shifts as carers get older. 59% of carers over 85 are male.

Ethnicity of Carers

Analysis of variation in the provision of unpaid care by ethnicity is complicated by the differing age profiles of ethnic groups; for example, Mixed/Multiple ethnic groups have low rates of care provision but this may be due to the very young age profile of this group.

The 2011 Census does not provide any strong evidence that there are variations in care provision by ethnicity, though there are slightly higher rates of care for 50+ hours each week among the Bangladeshi, Pakistani and White Irish communities.

Provision of care among Gypsies or Irish Travellers is high with 18.6% of the population providing unpaid care compared to 10.2% among the general population, and 9.6% providing 50+ hours compared to 2.0% in the overall Borough population.⁸

However, these figures should be treated with caution since this is a very small ethnic group in the Borough numbering 115 people. Nationally, there is little difference between the proportion of Gypsies or Irish Travellers who provide care (10.7%) and the general population (10.2%), though rates of caring for 50+ hours each week (4.4%) are significantly higher than among the general population (2.4%).

4. Economic Activity

People providing high levels of unpaid care have much lower economic activity levels than those without caring responsibilities.

Among the Borough's total population aged 25-64 in 2011, 77.4% were in employment. There was little difference between those who did not provide care (78.3%) and those who provided 1-19 hours each week (78.9%). However, those who provided higher levels of care had much lower employment rates, with 64.8% of those providing 20-49 hours in employment, and only 46.5% of those providing 50+ hours¹.

Not only are unpaid carers less likely to be economically active, but a much lower proportion are in full-time employment (excludes self-employed). Of people aged 25-64 who do not provide care, 50.6% are in full-time employment, but this declines to 45.7% for those providing 1-19 hours of care, to 33.2% for 20-49 hours, and to 21.6% for those providing 50+ hours of care each week.

Furthermore, care providers are much more likely to be in part-time employment. Only 25.7% of people aged 25-64 in employment who do not have caring responsibilities work part-time, but this rises to 43.9% among those providing 50+ hours each week.⁹

5. Relationship to Deprivation

There is a general pattern of higher rates of care provision by residents of the more affluent areas. However, the average number of hours provided by carers in the less well-off areas is greater.

So, people living in the more deprived parts of the Borough are statistically less likely to be carers but when they do provide care, this is more likely to be at an intensive level.

Provision of unpaid care in Bedford Borough ¹⁰

Number of people providing unpaid care to a partner, family member or other person.

Figure 2 Provision on unpaid care.

| | Provides no unpaid care | 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 | Total number of people providing care |
|-----------------|-------------------------|---|--|--|---------------------------------------|
| Bedford Borough | 141,395 | 10,838 | 2,055 | 3,191 | 16,084 |

Source: ONS, 2011 Census, table CT0126. Crown Copyright

The population aged 65+ is projected to rise by 16% between 2014 and 2021, from 27,900 to 32,300. The population aged 80-84 is projected to rise by 9% from 4,000 to 4,350 and the population aged 85+ is projected to rise by 32% from 3,900 to 5,150¹¹.

It is likely that the predicted increase in longevity will bring more years in poor health for more people and will result in more people caring for longer. This will place an escalating pressure on health and social care and supporting carers to care will continue to be essential.

Many older people are also providers of care. In 2011 there were 3,393 carers aged 65+ in the Borough, a rise of 33% over 2001. Of these, 259 were aged 85+, with a majority (160) being male, which is also the pattern nationally.

Table showing number of adult carers applying for an NHS Carers Grant who reported that they were suffering from stress, anxiety or depression across Bedfordshire (2014-15)

Data provided by Carers in Bedfordshire (CiB)



| <u>Month</u> | <u>Number of carers awarded a grant</u> | <u>Number of carers suffering from stress, anxiety, or depression</u> | <u>Percentages of carers suffering from stress, anxiety or depression</u> |
|---------------------|---|---|---|
| <u>April 13</u> | <u>29</u> | <u>23</u> | <u>23%</u> |
| <u>May 13</u> | <u>31</u> | <u>23</u> | <u>23%</u> |
| <u>June 13</u> | <u>32</u> | <u>28</u> | <u>28%</u> |
| <u>July 13</u> | <u>31</u> | <u>24</u> | <u>24%</u> |
| <u>August 13</u> | <u>31</u> | <u>18</u> | <u>18%</u> |
| <u>September 13</u> | <u>42</u> | <u>32</u> | <u>32%</u> |
| <u>October 13</u> | <u>22</u> | <u>12</u> | <u>12%</u> |
| <u>November 13</u> | <u>33</u> | <u>22</u> | <u>22%</u> |
| <u>December 13</u> | <u>26</u> | <u>17</u> | <u>17%</u> |
| <u>January 14</u> | <u>13</u> | <u>6</u> | <u>6%</u> |
| <u>February 14</u> | <u>19</u> | <u>13</u> | <u>13%</u> |
| <u>March 14</u> | <u>22</u> | <u>16</u> | <u>17%</u> |
| <u>Total</u> | <u>331</u> | <u>234</u> | <u>71%</u> |

Data provided by CiB

6. Bedford Borough specific data (NHS Grants)

331 carers in Bedford Borough accessed a carer's grant between April 14 – March 15. The grants enable carers to take a break from their caring role, undertake a training course to help them to understand their cared for's condition or enable them to access the workplace again. 71% of carers who applied for a grant reported that they were suffering from stress, anxiety or depression.

7. Current activity & services

Current services

Care and support for carers is arranged on a personalised basis through social workers and colleagues in Adult Social Care, Children's Services, local NHS organisations, CiB and other voluntary organisations. It includes the provision of information and advice as well as the assessment of needs eligible for funded assistance and delivery of services to meet those needs.

Information and Advice

Bedford Borough Council fact sheets are available at the Borough Hall reception and other suitable premises in the community including libraries and Bedford Hospital. The factsheets, leaflets and other relevant information such as useful numbers are

also available on the Council website and can be provided in a range of languages and formats on request. NHS information and advice is also available on the Bedfordshire Clinical Commissioning Group website. It includes useful information and contact numbers for carers support services. Web addresses for carer's information and advice are provided at Appendix 1.

Results from the 2014/15 carers survey shows an increase in the proportion of carers saying they find it easy to find information about services compared to the previous survey undertaken in 2012/13. However results are marginally below the target set for 2014/15, but are reporting slightly higher than regional results in 2012/13.

8. Web addresses for Carer's Information and Advice

Bedford Borough Council Information and Advice for Carers:

http://www.bedford.gov.uk/health_and_social_care/carers.aspx

Bedfordshire Clinical Commissioning Group Information and Advice for Carers:

www.bedfordshireccg.nhs.uk

Web address for Carers in Bedfordshire

<http://www.carersinbeds.co.uk/>

9. GP Carer's Pack

Bedfordshire Clinical Commissioning Group produced a Carer's Pack for GPs in partnership with Bedford Borough Council, Central Bedfordshire Council, Bedfordshire Rural Communities Charity, Spurgeon's, CiB and Rethink. The pack is a 103 page information folder (loose leaf for easy updating) available in doctor's surgeries. It has 12 sections including an A –Z of Carers Services, Planning for the Future and Top Tips by Carers for Carers. Each surgery in the Borough has a pack for staff and public reference. Many surgeries have nominated a carers champion and improved information for carers on notice boards and websites.

10. Identifying and Assessing Carer's Needs

Bedford Borough Council's on-line carer's assessment means that carers can self assess their needs and email their carer's assessment for a response within 2 working days. Self-assessments are then responded to by CiB staff on behalf of Bedford Borough, who contact the carer and conduct a full carer's assessment. All staff involved in carer's assessments are trained to support carers to make a self-assessment of their needs and help them find appropriate support. All staff offer carers an assessment of their needs as part of the initial assessment process concerning their service user. This is a requirement of the Care Act which was introduced on the 1st April 2014. However, prior to the implementation of the Act,

Bedford Borough Council offered assessments to carers.

Out of the 17,100¹² Of the Carers estimated to be in the Borough today 1,023 are receiving a specific Carers service funded by Bedford Borough Council (outturn performance report for NI135,2015/2-16)¹³ This is only a partial count of the total number of carers receiving a service because hundreds more receive services from the main commissioned Carers service, CiB.

The provision of carer's assessments and services is a key performance indicator (NI135).. The number of service users and carers receiving a direct payment or personal budget as a percentage of all service users and carers with community-based services was 78.2% in 2015-16. This measure constitutes key performance indicator (NI130).

The table below shows the number of service users and carers receiving a direct payment or personal budget as a percentage of all users and carers within community based services.

NI130

| | | |
|----------|-------|----------------------------------|
| 2012/13 | 70.3% | 2,338 service users and carers |
| 2013/14 | 70.5% | (2,241 service users and carers) |
| *2014/15 | 71.3% | (1,194 service users and carers) |
| *2015/16 | 78.2% | (1,468 service users and carers) |

*Please note there has been a change in statutory reporting requirements and this is reflected in the subsequent outturns.

Of the carers and service users in the table above, the table below shows the number of those carers receiving a New Carer Direct Payment.

| | |
|---------|----|
| 2012/13 | 53 |
| 2013/14 | 65 |
| 2014/15 | 78 |
| 2015/16 | 75 |

The 2014/15 National Carers Survey produced these results for Bedford Borough

- overall satisfaction of carers with social services 42.9%.included or consulted in discussion about the person they care for 77.1%.2014/15
- they had as much social contact as they would like 38.6%. who find it easy to find information about services 66.5%

11. Nationally, in 2013/14, 197,000 older carers were offered a carer's assessment and 175,000 took it up. This is a 4% increase on the number of older carers who had an assessment in 2006/7. However, this lags far behind the 35% growth in

the number of older carers (in ten years, rather than seven), suggesting that older carers were less likely to have a carer's assessment in 2013/14 than they were several years ago.

The number of older carers aged 75 and over who had a carer's assessment has not increased, despite the rapid growth in the number of carers in this age group. The Care Act has been in place since April 2015 and provides new rights for carers. All carers are entitled to a carer's assessment if they appear to have needs. This new ruling means that carers are now on an equal footing as their 'cared for' in terms of their right to an assessment of their needs. . 14

Locally, however, there has not been a notable increase in the number of carer's assessments resulting from the introduction of the Care Act. This is due to the fact that Bedford Borough already offered all carers an assessment prior to the change in legislation. Numbers have remained largely the same.

12. Respite Care

Respite care is short-term care to give carers and young carers a break from caring. It is important that carers have breaks and are able to recharge their batteries. Respite care may also be needed in specific situations, for example if the carer has to go into hospital or cannot miss other important commitments. There are different options for how respite care can be made available which include breaks that run from a couple of hours to a couple of weeks.

Respite care at home

Respite care in the person's home is suitable when the person finds it preferable to remain in familiar surroundings. It usually involves adult services arranging for an agency carer to go the persons home which leaves the unpaid carer free for the allocated time. Respite for a couple of hours is typical under this arrangement although overnight or longer (one or two weeks) is possible if needed. A variation on this theme is when the person or carer has a direct payment and arranges their own paid carer.

Respite care away from home

A number of options fall under this heading. Firstly respite care in a day service. Here the person attends a day service such as Goldington Road or Conduit Road Day Centre and the carer is free for the time they are there, usually about 5hrs. The Goldington Road service has recently been extended to include Saturday opening in addition to Monday to Friday. Kempston Day Centre is a Council centre for people with learning disabilities, Beds Garden Carers and Sadlers Farm serve the same client group in the non-statutory sector. The Day Resource Centre and Barford Avenue Centre (Both South Essex Partnership Trust) are available for people with

mental illness. Oakley Day Centre is available for older people in the Oakley area. Headway is available for people who have had head injuries.

Secondly, Gadsby Street Centre for Independent Living offers a new concept compared to the typical day centre. At Gadsby Street, people with learning disabilities are able to meet up and plan their days with support from staff. The big difference is that the day is not spent at Gadsby Street but in local community facilities based on each person's developmental needs.

Thirdly, respite arrived at by the cared for person and carer undertaking an activity away from each other. Under this option the carer has free time because the cared for person receives support to be somewhere without their carer. This includes going to the gym, college or leisure activities. For young carers, CiB facilitate activities such as horse riding, bowling and go-karting where funding allows. This is important 'time out' for young carers (schoolchildren) from their caring role. It allows them to be young and promotes their social development.

Fourthly, adults with learning disabilities are able to use the Council's 'Shared Lives' service. A person with learning disabilities is matched with a family who want to offer long or short term care in their home. Shared Lives is a registered service with the Care Quality Commission, most recently inspected on 14th January 2013 and deemed fully compliant with Care Quality Commission standards in all areas inspected. 3 people with a Learning Disability use Shared Lives for respite (another 6 use it for long term care).

Fifthly, respite care in a residential care home or nursing home. This is not always easy to arrange, as it depends on a place being vacant at a specific time. However, some homes allocate places for respite care enabling carers to plan ahead. People using the same care home for regular respite get to know it and look forward to their break which usually ranges from a couple of nights to a couple of weeks. So far in 2013 – 14 we have arranged breaks like this for 579 people.

13. Carers Services

As well as services provided by adult services to individual carers on the adult services caseload, a general Carers Support Service is jointly commissioned by the Council in partnership with Bedfordshire Clinical Commissioning Group and Central Bedfordshire Council. Carers do not have to be known to adult services to be able to use the CiB services listed below, although many are.

Carers training

212 Carers have attended training courses during 2015/16, of which 557 accessed NHS Training Grants across Bedfordshire.

The courses have included:-

- Lasting Power of Attorney
- Relaxation therapy One to one
- Warmer Homes Workshop

NHS Carers Café Bedford

This Café is for carers and cared for and runs on the fourth Saturday of every month, 1pm to 5pm at Goldington Road Day Centre. The regular attendance is from 70 to 100 and all feedback is positive. Activities include creative art, chair based exercises, games and creative activities for children, health checks, chiropody and foot care, relaxation therapy, manicure, hairdressing, benefits advice and general advice is on hand all afternoon. All therapies are fully booked at each café and carers say it is a monthly lifeline. The peer support is also valued and transport provided is essential for older carers with severely disabled relatives in wheelchairs.

Carer's Lounge at Bedford Hospital

[The Carers Lounge](#) opened in 2012 and since then, over 5,600 unpaid family carers looking after a loved one have been contacted through the service. The Carers Lounge gives carers of any age visiting the hospital a safe, confidential, non-judgemental space where they can find support, information and advice

Support is provided through support workers by CiB, each of whom offer a different specialist skill. For example, specialist mental health support is offered on a Wednesday, another skill is available to access on another day. Many people first become carers following hospital admission of a family member and having the lounge at the hospital allows early identification and preventative help to be put in place.

CiB continue to promote the lounge on the Hospital's Dementia Awareness training program. The program highlights the support Carers give to family members living with dementia through Carer case studies. Discharge Pathway Stakeholder Events are also used as a vehicle to encourage more staff (especially ward staff) to signpost more carers to the lounge. Carers (including some hospital staff who are also carers) come to the lounge for emotional support and practical advice on issues like the hospital discharge system and form filling.

Between April 2015 and April 2016 2664 Carers living in Bedford Borough were contacted by the Carers Lounge. It is estimated that 76.5% of these were new carers. This is equivalent to approximately 1882 new carers. Of these new carers identified, 141 registered at the Lounge.

Bedford Borough Council commissions the Carer's Lounge at Bedford Hospital which is run by local charity, Carers in Bedfordshire in partnership with Bedford

Hospital. March 2016, saw the Carers Lounge win the category of Support for Caregivers, Friends and Family, and was awarded the PENN (Patient Experience National Network) award, while Bedfordshire Clinical Commissioning Group (BCCG) was runner-up in Commissioning for Patient Experience with their project to involve service users and carers in choosing a new provider of mental health and specialist learning disability services.

CiB are also involved in the End of Life Steering Group, the Safeguarding Vulnerable Adults Board and the Learning Disability Forum within the hospital. At Bedford Hospital there is a “Meet and Greet” session, where a Carers Lounge representative is introduced to student nurses to raise awareness of Carer’s support needs. This has involved 90 students so far.

In addition to this, CiB have worked closely with the hospital in producing a Carers Charter and a Carers information booklet. 15

NHS Carer Grant

Carers who have a long term health condition, or whose health is affected by caring (for example back injury or stress related illness) can apply to CiB for a NHS ‘Carers’ grant. The grant can pay for things that improve the carer’s health or ability to manage their own health needs or can fund a training course to enable the carer to return to work, for example transport to GP and hospital appointments, counselling, training, massage or other stress relieving therapy, a holiday with (or without) the person they care for to get a complete break. One application per year is allowed and the grant will not fund something that would otherwise be funded by social services or health. 702 grants were awarded across Bedfordshire. between April 2015 and March 2016.

NHS Health checks

As part of the programme, 40 to 74 year olds will be offered a free NHS Health Check that will help carers, among others, stay well for longer. Nurses in Bedfordshire offering health checks have received/been offered training in carer awareness and have attended events in Bedford such as the Carers Café to carry out health checks for carers in places which they already frequent.

Services for Ethnic Groups

Bedford Race Equality Council is encouraging people from ethnic groups to become more involved and take up services they are entitled to. A spot check of ethnic group’s engagement with CiB services showed a good take up. This is a good reflection of the diverse needs served by carer’s services in the Borough.

End of Life Services

CiB now go into hospices at Moggerhanger and Keech Cottage to help carers complete various application forms and signpost as appropriate.

CiB and other local providers commissioned by Bedford Borough Council now work in partnership with the Bedfordshire Partnership for Excellence in Palliative Support (PEPS).

Sue Ryder in partnership with NHS Bedfordshire is now delivering the PEPS service. The PEPS Coordination Centre is a team of nurses trained in specialist palliative care. Their role is to co-ordinate End of Life Care, ensuring a seamless delivery across all disciplines.

PEPS provides a single, 24-hour telephone point of access for palliative care services. It aims to improve the care experience for patients and carers.

All these services are subject to regular review. Service specifications are reviewed annually and checked to ensure services are providing good outcomes in the most cost effective manner. The commissioning of services between Bedford Borough Council and Bedfordshire Clinical Commissioning Group is increasingly co-ordinated and will continue in that direction.

Local Views

Respondents to a CiB survey, conducted in September 2015, strongly expressed the importance and effectiveness of the following services, currently commissioned by Bedford Borough Council through CiB:

- The Hospital Carers Lounge.
- Carers Grants
- Carers Magazine
- Massage therapy
- Training

The comments below show individual carer experiences.

CiB Staff are:

“compassionate and genuine”

“courteous and helpful”

“make you feel valued”

“explain things properly”

Carers Lounge

- “I’m so glad I popped in, I didn’t realise I could claim that” Carers Allowance.

Carers Café

- “People are so helpful in whatever you throw at them, if they can’t help you they will put you on to someone who can. Also to relax away from a home environment of stress etc.”

- “Greatly enjoy the comfort, company and ambience. Nice to chat with others in same book”

Carers Training

- “Found this course so helpful and will miss this. Excellent companions so helpful to listen to others (how they cope, adapt etc) SO good to know I could talk about how I was feeling without feeling guilty, uncomfortable or judged”.

Carers Breaks

“This break gave me the chance to recharge my batteries and I remain extremely grateful for this extra help.”

“I feel I am able to continue with jobs better and looking after my husband as my hands are less painful and stiff so therefore my health is better.”

“Taking a break using a grant has made me concentrate on improving my physical and mental health. This has enabled me to continue as a carer for my for my son without accumulating problems that inevitably arises from constant worry anxiety and stress”.

National & Local Strategies (Current best practices)

Recognised, valued and supported: next steps for the Carers Strategy, Department of Health, 2010

Bedford Borough Council and Bedfordshire Clinical Commissioning Group (BCCG) completely endorse the findings of the Standing Commission on Carers which prompted identification of the four national government priorities for carers

1. 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 care packages.
2. Enabling those with caring responsibilities to fulfil their educational and employment potential.
3. Personalised support both for carers and those they support, enabling them to have a family and community life.
4. Supporting carers to remain mentally and physically well.

The NHS Outcomes Framework 2014/15 Enhancing quality of life for carers

2.4 Health-related quality of life for carers (ASCOF 1D)stated that -**

Carers play a vital role in our system and must receive help and support from local organisations. Following a joint assessment of local needs, which should be published with plans, (the NHS) need to agree policies, plans and budgets with local authorities and voluntary groups to support carers, where possible using direct payments or personal budgets.

Carers Rights

Carers have the legal right to an assessment of their needs. This is contained in the Carers (Recognition and Services) Act 1995 and the Carers and Disabled Children Act 2000.

This applies to Carers in all circumstances - whether the Carer is living with, or away from the person they are caring for, caring full time or combining caring with paid work. The right to a Carers assessment still applies.

Carers have the right to an assessment even if the person they care for does not want an assessment or service.

The right to an assessment also applies to people who intend to become Carers. For example, this could happen when someone is going to be a Carer following their friend or relatives discharge from hospital.

Parent Carers of disabled children do not have to be the biological parents to have a Carers assessment. So long as they have formal parental responsibility towards the child, they have the legal right to an assessment of their own needs as Carers.

We can expect similar statements in future annual NHS Operating Frameworks.

The Care Act

The Care Act 2014, further reinforces the rights of carers, giving all local authorities a responsibility to assess a carer's own need for support. As a result, a carer no longer needs to be providing a "substantial amount of care on a regular basis" in order to qualify for an assessment. This will mean more carers are able to have an assessment. This is comparable to the legal right of the people they care for.

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[The Joint Commissioning Strategy for Carers](#) sets out the following vision for carers:

'That carers will be able to have a life of their own alongside their caring role. They will be supported to stay mentally and physically well and treated with dignity by integrated and personalised services. They will be recognised as expert partners in care and not forced into financial hardship by the caring role. Young carers will be protected from inappropriate caring and have the support they need to learn, develop

and thrive'.¹⁶

What is this telling us?

The cost of caring to the carer and the economy

- Carers save the UK economy £119 billion pound per year in health and social care costs, an average of £18,473 per carer per year.¹⁷
- The main carers benefit is £61.35 per week for a minimum of 35 hours, equivalent to £1.75 per hour which is far less than the National minimum wage¹⁸
- It is estimated that carers in the Bedford Borough area save the economy £307 million a year based on replacement care for 1 carers at £18 per hour¹⁹

Carers are affected financially, psychologically, mentally and emotionally if they are not effectively supported. It is well documented that carers already feel undervalued and unsupported for the work they carry out and without adequate carers services, many carers would no longer have the support networks or emotional support they need to cope. Breaks from their caring role are essential if they are to remain mentally and physically well themselves.

The cost to health and social care teams, if the carer then decided to stop caring, would be considerable in times of the replacement care costs.

What are the key inequalities?

- Carers can be worse off financially as a result of taking on caring responsibilities.
- Carers face difficulties accessing education and employment that fits around their caring role.
- Some carers are unable to hold down a job or attend or undertake education courses as a direct result of their caring responsibilities
- Carers can experience barriers accessing health services
- Carers are vulnerable to poor mental health experiences, particularly stress, anxiety and depression
- 40% of carers will experience significant psychological stress compared to 13.9% of women and 8.5% of men in the general population²⁰
- Carers providing high levels of care are twice as likely to be permanently sick or disabled²¹
- Carers are more prone to social exclusion
- Carers living in less well off areas are statistically less likely to be Carers but when they are, caring is more likely to be at an intensive level.²²
- The health impact amongst BAME carers is slightly worse than amongst all carers²³

What are the unmet service gaps/needs?

Data Availability

Because carers remain largely hidden in the general population, information about them is scarce. Current identification of carers needs to improve and there is a lack of local specific data particularly around BME, gypsy and traveller and veteran carers.

Access to Services

Accessing effective and appropriate services can be a major issue for carers, firstly because they do not identify themselves as carers and secondly because they are not identified by professionals. Identifying carers early on in their caring role and providing them with appropriate information, advice and support should be the priorities for action in order to prevent carers from becoming ill as a result of their caring responsibilities. Only a small proportion of potential carers are actually known to services, which means there are many more in the community who are not accessing services to which they are entitled.

It can take a number of years for carers to come forward and identify themselves and this usually only happens after the carer hits a crisis point themselves and is no longer able to cope. Service providers therefore need to take on an active role in identifying carers before they hit a crisis point.

Evidence from research shows that effective support to carers usually goes beyond a single intervention and encompasses good quality mainstream services, and sensitive and carer-aware professional practice (across health, social care, education and all local services). Importantly, evidence shows that a joint strategic approach by health, local government and voluntary organisations is needed for a local population to develop and commission a range of local services suited to the local needs of carers and people using services.

Local Evidence

Results from a survey conducted in September 2015 by CiB, from Bedford Borough respondents highlighted the following gaps:

- Difficulty accessing services if you don't drive
- Nothing in the villages
- Hours of services aren't suitable for working people.

Survey respondents made the following recommendations for consideration:

- **Transport** to appointments and other services
- Transport and sitting service
- Carers to have access to bus passes to access support
- **Support for working/younger carers**
- Out of hours support for carers who work
- Evening support groups
- Groups for carers under the age of 60

- Online chatroom

[Carers in Hertfordshire](#)²⁴ undertook research with carers in one GP practice in their area. They compared outcomes for a sample of carers who had been referred to the carers' centre for information and support with those who had not. Carers who were referred were twice as likely to feel well informed about rights and services and to know what to do in a crisis. They were more likely to have had a recent break and be more confident about accessing care services, leisure, education or work.

Cost Effectiveness

One "Understanding Stress, Anxiety and depression" course costs £650 to commission for 10 people. 4 of these carers are likely to suffer from severe psychological stress as a result of their caring role. If 4 carers were to breakdown and their cared for was to be admitted to residential care for 2 weeks for example at a cost of £920 (£460 per week as charged by BBC), then this would cost health and social care £3680 to cover the replacement care. By running courses to help carers understand and better deal with their stress and anxiety or preventing it from happening in the first place then a cost saving of £3060 can be made.

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