Introduction

A carer has been defined as someone who ‘…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’ (National Carers strategy 2008).

The Carers Trust state that every year, over 2.3 million adults become carers and over 2.3 million adults stop being carers. Three in five people will be carers at some point in their lives in the UK.

According to Carers UK, a carer helps an ill, frail or disabled family member or friend with their day-to-day living which might include helping them to get dressed or helping with shopping or laundry. This support is provided unpaid. Someone might be in need of a carer if they have a physical or mental illness or a disability.

Carers need the right information and support to make their carers role more manageable because although caring can be rewarding, it can have a negative impact on health and wellbeing and can cause ill health (for example through back injury, backache, poor mental health, poverty and social exclusion). This is because carers are often excluded from accessing certain services or treatments because of their caring role.

Young Carers: A young carer has been defined by the directors of adult social services (ADASS) and Association of Directors of Children's Services (ADCS) as:

‘The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances… a young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child, risking impacting on his or her emotional or physical well-being or educational achievement and life chances’
What do we know?

**Number of carers:** As shown in table 1, around 14,000 people in West Berkshire provide unpaid care. This is 9.3% of the West Berkshire population. The majority of carers are of working age and are adults aged between 25 and 64.

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Provides unpaid care</th>
<th>% Provides unpaid care</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 to 24</td>
<td>834</td>
<td>6%</td>
</tr>
<tr>
<td>25 to 49</td>
<td>4,626</td>
<td>33%</td>
</tr>
<tr>
<td>50 to 64</td>
<td>5,861</td>
<td>40%</td>
</tr>
<tr>
<td>65 and over</td>
<td>3,111</td>
<td>22%</td>
</tr>
<tr>
<td>Total</td>
<td>14,232</td>
<td></td>
</tr>
</tbody>
</table>

*Source: 2011 Census, Office for National Statistics*

Over 10,000 people in West Berkshire people provided 1 to 19 hours of unpaid care a week, 1,461 provided 20-49 hours and 2,505 provided 50 hours or more unpaid care per week. The majority of carers were women (57%) and over 70% of women provided 1 to 19 hours of unpaid care per week.

In West Berkshire, there has been little change in the provision of unpaid care between 2001 and 2011. However, as the population ages, there is an expectation that more people will become a carer at some point in their lives.

<table>
<thead>
<tr>
<th></th>
<th>West Berkshire</th>
<th>England and Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provides no Unpaid Care %</td>
<td>91.6</td>
<td>90.7</td>
</tr>
<tr>
<td>Provides 1 to 19 hours Unpaid Care %</td>
<td>6.5</td>
<td>6.7</td>
</tr>
<tr>
<td>Provides 20 - 49 hours Unpaid Care %</td>
<td>0.7</td>
<td>1.1</td>
</tr>
<tr>
<td>Provides 50+ hours Unpaid Care %</td>
<td>1.3</td>
<td>2.1</td>
</tr>
</tbody>
</table>

*Source: 2011 Census, Office for National Statistics*

Unpaid care is highest for both men and women in the 50-64 age range (40% of all carers are in this age group). Women provide more unpaid care than males. The possibility of becoming an unpaid carer increases up to age 64. 19% of females and 16% of males aged 65+ provided 50 hours or more of unpaid care. This could be because they have grandchildren to care for or elderly parents.

*Figure 1: Unpaid care provision: by age and Sex in West Berkshire*

*Source: Office for National Statistics [from Nomis on 28 October 2013]*
Carers Health: Overall, almost 80% of all carers thought their own health was very good or good. Although carers aged over 65 in particular may need additional support as their own health declines, in West Berkshire, 62% of carers aged 65 and over reported to be in very good or good health and 31% of carers aged 65 and over reported to be in fair health and 7% of carers aged 65 and over reporting to be in bad or very bad health.

Table 3: General health of carers in West Berkshire, 2011

<table>
<thead>
<tr>
<th>Carers age band</th>
<th>Very good or good health</th>
<th>Fair health</th>
<th>Bad or very bad health</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age 0 to 24</td>
<td>773</td>
<td>45</td>
<td>11</td>
<td>834</td>
</tr>
<tr>
<td>%</td>
<td>93%</td>
<td>5%</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Age 25 to 49</td>
<td>3,977</td>
<td>511</td>
<td>138</td>
<td>4,626</td>
</tr>
<tr>
<td>%</td>
<td>86%</td>
<td>11%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Age 50 to 64</td>
<td>4,619</td>
<td>858</td>
<td>184</td>
<td>5,661</td>
</tr>
<tr>
<td>%</td>
<td>82%</td>
<td>15%</td>
<td>3%</td>
<td></td>
</tr>
<tr>
<td>Age 65 and over</td>
<td>1,940</td>
<td>951</td>
<td>220</td>
<td>3,111</td>
</tr>
<tr>
<td>%</td>
<td>62%</td>
<td>31%</td>
<td>7%</td>
<td></td>
</tr>
<tr>
<td>All Carers</td>
<td>11,314</td>
<td>2,365</td>
<td>553</td>
<td>14,232</td>
</tr>
<tr>
<td>%</td>
<td>79%</td>
<td>17%</td>
<td>4%</td>
<td></td>
</tr>
</tbody>
</table>

Source: Office for National Statistics [from Nomis on 28 October 2013]

A carers own health can be affected by the amount of caring they do. Males and Females in West Berkshire were 0.5 times more likely to have ‘Not Good’ general health if they are providing 50 hours or more unpaid care per week than if they provide no unpaid care.

Figure 2: Ration of males and females providing 50 hours or more to no unpaid care per week with ‘Bad’ or ‘Very Bad’ general health, in West Berkshire, 2011

<table>
<thead>
<tr>
<th>Sex</th>
<th>Level of unpaid care</th>
<th>West Berkshire</th>
</tr>
</thead>
<tbody>
<tr>
<td>Males</td>
<td>No unpaid care</td>
<td>1,904</td>
</tr>
<tr>
<td></td>
<td>50 hours or more unpaid care</td>
<td>89</td>
</tr>
<tr>
<td></td>
<td>Ratio 50+ hours of care: no care</td>
<td>0.05</td>
</tr>
<tr>
<td>Females</td>
<td>No unpaid care</td>
<td>2,221</td>
</tr>
<tr>
<td></td>
<td>50 hours or more unpaid care</td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>Ratio 50+ hours of care: no care</td>
<td>0.05</td>
</tr>
</tbody>
</table>

Source: Office for National Statistics [from Nomis on 28 October 2013]

Number of young carers: In 2011, 6% of carers (834) in West Berkshire were young unpaid carers (aged 0 to 24). Of these, 52% were females and 48% were Males. A slightly higher proportion of young female carers provided longer hours of unpaid care when compared to males. It is likely that the number of young carers is an underestimate as young carers themselves do not give information themselves and some parents do not want to provide information.
Figure 3: Hours of unpaid care among carers aged 0 to 24, West Berkshire

![Bar chart showing hours of unpaid care]

Source: Office for National Statistics [from Nomis on 28 October 2013]

**Health of Young Carers**: Few young carers reported to have bad or very bad health (11 young carers). The majority reported to have very good or good health.

Figure 4: Reported health status of young carers, West Berkshire

![Pie chart showing health status]

Source: Office for National Statistics [from Nomis on 28 October 2013]

Table 4 below looks at the number of carers receiving needs assessments, receiving specific carers’ services, and receiving self-directed support in West Berkshire Local Authority (LA). There were 910 carers receiving needs assessments or reviews during 2010/11 in West Berkshire LA. 92% of these reviews or assessments led to carers receiving specific carers’ services compared to a NHS Berkshire West average of 88%. 150 carers in West Berkshire LA are receiving self-directed support/direct payments. This equates to 16% of those receiving a needs assessment of review compared to 22% across NHS Berkshire West.

695 people claiming out of work benefits in West Berkshire LA are carers. There is an estimated 2,687 older people in West Berkshire LA proving unpaid care to a partner, family member or other person with this number projected to rise to 4,168 people by 2030. This is a rise of 55% which is steeper than the rise nationally and across NHS Berkshire West.
Table 4: Adult social care support for carers, 2010/11

<table>
<thead>
<tr>
<th>Area Name</th>
<th>Carers receiving needs assessment or review</th>
<th>Carers receiving specific carer’s services (including respite, advice and information)</th>
<th>Carers receiving Self-Directed Support/Direct Payments</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Berkshire LA</td>
<td>910</td>
<td>840</td>
<td>150</td>
</tr>
<tr>
<td>Reading LA</td>
<td>1490</td>
<td>1490</td>
<td>480</td>
</tr>
<tr>
<td>Wokingham LA</td>
<td>1010</td>
<td>810</td>
<td>40</td>
</tr>
<tr>
<td>Bracknell LA</td>
<td>805</td>
<td>800</td>
<td>280</td>
</tr>
<tr>
<td>Slough LA</td>
<td>1115</td>
<td>865</td>
<td>440</td>
</tr>
<tr>
<td>Windsor and Maidenhead LA</td>
<td>1010</td>
<td>805</td>
<td>5</td>
</tr>
<tr>
<td>Berkshire average</td>
<td>1057</td>
<td>935</td>
<td>233</td>
</tr>
</tbody>
</table>

Source: NHS Information Centre 2011

User Views

The National User Experience Survey 2012/13 collected information about carers’ experience of social care services in order to learn about whether services were supporting carers in their caring role and their life outside caring. It also asked them about their perceptions of the services provided to the cared for person. In West Berkshire, the ‘Caring for others’ survey 2012/13 was sent to 491 eligible carers and 266 carers responded. Some of the key findings were that:

- 58% of those cared for are individuals over 65, overall 27% are over 85.
- The most frequent support or services received by carers are:
  - 1. Information and Advice (128 respondents)
  - 2. Support from carers groups (62 respondents)
  - 3. One off items to help with caring role
- Only 26% of carers are able to spend time as they want and do things they value. 65% do ‘some things’ they value but not enough, with 9% saying they don’t do anything they value.
- Only 34% of carers feel they are in control over their daily life.
- Only 48% report they have as much social contact as they would like.
- Only 44% of carers felt they were encouraged in their caring role, leaving a significant proportion of carers feeling that they did not get enough support.
- 63% indicated that information was ‘very’ or ‘fairly’ easy to find.
- 75% reported that they were ‘always’ or ‘usually’ involved in discussions about the support for the person they care for. A small proportion of carers felt that they were never consulted.
- 47% of carers responding to this questionnaire were retired, 18% in full time employment. 70% of carers have been caring for over 5 years, 29% of carers have been caring for more than 20 years, 32% of carers report that they spend over 100 hours a week looking after or helping the person they care for, with many more commenting that the role is actually ‘full time’, 42% of carers are over 65 years of age.

Carers were asked to identify ‘What would improve your quality of life?’. The responses included:

- Support groups / someone to listen
- Reviews / regular contact and continuity of services
• Respite / Breaks from caring role
• Transport
• Employment support
• Financial support
• Future support for the cared for person
• Home care / practical assistance
• Good reliable carers
• Accommodation / Care Homes

What is the data telling us?

The physical health and mental wellbeing of carers is important but there is limited data and information about carers and their needs. It is also likely that there are people doing unpaid care that are not known by services, and are therefore not receiving the support they need. Given that the amount of unpaid care provided will increase, due to the ageing population, the role of the carer is pivotal in the context of reducing resources in local authorities. Carers help to ensure that people maintain their independence and stay in their own homes. To support carers, their needs must be identified and they must be supported with information and advice and be given services that support their caring role.

What are the key inequalities?

• Females provided more unpaid care than males
• The amount of unpaid care provided increased with increasing age
• Carers are often invisible and their own health needs are often neglected because their caring role has not been formally recognised.

The Princess Royal Trust for Carers (2011) found that:

• Two thirds of older carers have long term health problems or a disability themselves
• One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities
• Half of all older carers reported that their physical health had got worse in the last year
• More than 4 out of 10 older carers said that their mental health had deteriorated over the last year.

A report from the Children's Society has found that:

• Young carers are 1.5 times more likely than their peers to have a special educational need or a disability
• Young carers have significantly lower educational attainment at GCSE level than their peers and are therefore less likely to earn a decent living
• Young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19
• Young carers are over four times more likely to live in a household where no adults are in work
• The median family income for families including a young carer was £5000 less than families without a young carer
What are the unmet needs/ service gaps?
- There is little data on carers and their needs and there are likely to be significant numbers of carers who are unknown and are not receiving support
- More carers assessments need to be conducted
- Access to emergency respite services
- Training to support the caring role
- More information and advice to carers
- More annual health checks for carers
- Young carers and their needs have to be identified
- Training to support caring role
- Planning for the future for adults with learning disability
- Information on how many Carers that are unemployed

Recommendations for consideration

1. Identification and recognition
- Support people with caring responsibilities to identify themselves as a carer at an early stage
- GPs to identify carers and offer them support. This could involve training for GPs and NHS staff
- Continue to hold an annual carers conference
- Promote and ensure carers are aware of Social Care Information Point (SCiP)
- Distribute information for carers guide widely and increase profile of Berkshire Carers Service
- Raise profile of young carers

2. Realising and Releasing Potential
- Enable those with caring responsibilities to fulfil their educational and employment potential by ensuring employers offer flexible working
- WBC/BCS to provide training for carers
- Partnership working with Job Centre Plus
- Ensure that carers can access funding for replacement care whilst on training/learning

3. A life outside of caring
- Personalised support for carers, enabling them to have a family and community life by increasing number of carer breaks
- Increase the number of carers assessments and reviews
- Improve the uptake of assistive technology

4. Supporting Carers to stay healthy
- Provision of different types of breaks or respite provision for carers, ranging from a couple of hours a week, access to day services to a holiday.
- Increase number of carers offered NHS health checks and seasonal flu vaccinations
- Carers offered access to psychological therapy services
- Promote healthy diets, regular exercise, good oral health, reduce substance misuse, offer smoking cessation, stress management
Other services and partner organisations

West Berkshire Council commission a range of services and/or provides carers grants. Some services are jointly commissioned with the NHS, Reading and Wokingham such as the contract with Berkshire Carers Service which supports unpaid carers with free information, advice and support services to help carers to care well. This might include help with benefits and grants, emotional support, finding services, meeting other carers or planning a break. Respite could be available from West Berkshire Council through the Adult Social Care department following a carers assessment.

Other services commissioned with the voluntary sector include;

Crossroads West Berkshire is a service that provides care support workers

Castle Gate outreach team provide a Young Carers Support Service. This support group helps young carers to have a break from caring, signpost to other services and listen to how they are feeling. They also provide a free Carefree Programme which is a ten week programme focused on the needs of children and young people who help care for a parent. There are separate groups for young carers whose parents have mental health problems or substance misuse and Sibs which is a programme for young carers who help care for a brother or sister.

The West Berkshire Community Mental Health Team which is part of Berkshire Healthcare NHS Foundation Trust offers support to carers and family members who have mental health difficulties. Talking Therapies is a free NHS service that carers can make use of if they are feeling down, anxious or stressed. They offer accesses to tools and therapies such as cognitive behavioural therapy (CBT). Talking Health is a new service that helps people to cope with and manage their long term health condition (such as type 2 diabetes and asthma).

West Berkshire Citizens Advice Bureau provide a professional, free, independent and confidential carers advice service. They can give specialist advice and support on a range of issues such as; disability benefits, carers allowance, consumer and legal issues.

National and local strategies

Department of Health (2010) Carers and personalisation: Improving outcomes
Children’s Society (2013) Hidden from view: the experience of young carers in England
Carers UK (2004), In poor health - the impact of caring on health
Age UK (2013) Campaigning for the needs of older carers

Other chapters you might be interested in

Safeguarding
Independence in Older Age
Access to Social Care/Personalisation
Adults with a Learning Disability
Autism in Adults
Mental Health
Parent Carers of Children with Long Term Condition

If you have any questions about this chapter, please contact Public Health and Wellbeing Team on publichealthandwellbeing@westberks.gov.uk or 01635 503437