Adult Carers in Gateshead Survey Report 2017

Written and produced by Gateshead Carers Association.

We would like to thank all the Carers who took part in the Gateshead Carer Survey 2017.

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1. Purpose of the 2017 Gateshead Carers Survey

This report outlines the main findings from a major survey of the needs and issues facing carers in Gateshead. It enables comparisons to be made with the last survey of carers in Gateshead which was carried out by Gateshead Carers Association (GCA) in 2014.

This organisation has a contract with Gateshead Clinical Commissioning Group (CCG) to deliver services for carers in Gateshead.

The survey findings will shape and influence the content of Gateshead Carers Association’s Strategic Plan 2018-2021 and to provide evidence to funders and other stakeholders, particularly members of the Gateshead Carers Partnership, of carer needs, emerging trends and current issues facing carers.

It is anticipated that this report will raise the profile of carers, increase understanding of carers and ensure that carers’ needs are highly placed on the agendas of the Gateshead Health and Wellbeing Board, Gateshead CCG, Gateshead MBC and be included in the Gateshead Joint Strategic Needs Assessment (JSNA).

1.2 The Survey

The survey revisits questions asked in the last survey of carers in Gateshead carried out by Gateshead Carers Association (GCA) in 2014. Some additional questions were required to reflect updates and changes. The questions are based on and around key themes which were originally identified through consultation with carers, a review of national Carer Surveys and with reference to the National Carers Strategy and the Gateshead Carers Partnership Strategy.

For the purpose of this survey the following definition of a Carer was applied;

‘A carer is someone who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, friend or partner who is frail, disabled, ill, or has mental health or substance misuse issues.’

The survey was distributed (hard copies) to all carers on our database and electronically to members of the Carers Partnership, other partners and stakeholders for wider distribution in November 2016 and February 2017 (closing date 10/2/17). It was also accessible on-line and through Gateshead Carers Association’s website.

The survey took between 30 and 45 minutes for carers to complete and a total of 284 were returned. This compares to the 287 carers who completed the GCA Carer Survey in 2014.
Respondents were eligible to enter a £200 prize draw on completion and return of the survey.

This survey reflects the position of Adult Carers only.

1.3 About Gateshead Carers Association (GCA)

GCA is a registered charity and company limited by guarantee. Our mission is to support, advise, represent and campaign for adult carers living or working in Gateshead. We are members of the Carers Trust.

Our aims are to;

- Improve the physical and mental health of carers
- Enable carers to have more choice and control in their lives
- Increase the opportunities for carers to have a life of their own outside of caring
- Reduce the financial hardship facing carers as a result of their caring role
- Raise awareness of carers, their rights, their contribution and value amongst health and social care professionals, employers and the wider community

1.4 Profile of Gateshead

- Gateshead is a town with a population of 200,124
- There are 22,220 carers in Gateshead
- 11.1% of the population of Gateshead have a caring role which is significantly higher than the national average of 10.3% (2011 census).

The number of carers in Gateshead has increased by 5.1% over the last 10 years (around 1000 more than that recorded in the 2001 census).

Within Gateshead there are 126 smaller areas known as Lower Layer Super Output Areas (LSOAs). Twenty of these areas fall within the 10% most deprived areas in England which means that 30,716 people or 16% of the population of Gateshead live in these areas.

Extending the range of deprivation to include the 20% most deprived areas in England takes in a further 28 LSOA’s within Gateshead.

In total, 72,627 people or 38% of the population of Gateshead live in the 20% most deprived areas in England.
1.5 The Care Act 2015

Since our last survey of carers in 2014 the Care Act has come into force. The Act placed a range of new duties on Local Authorities including:

- Duty to promote wellbeing extended to include carers
- New duties for local authorities to integrate services and provide information and advice
- Local authorities must establish and maintain a care and support market and promote diversity and quality in provision of services, including sufficient provision to enable carers to participate in work, education and training
- New single duty for carers assessments based on appearance of need
- New duty to meet carers’ needs for support
- Carers should be consulted on care and support plans
- New entitlement to a personal budget and new right to request direct payments which can be paid to the carer or the adult needing care

The results of this survey, coming two years after the passing of the Act, will provide a good indicator of how well the Care Act is working for carers.
2. Key Findings

2.1 Carers Responding to the Survey

A total of 284 carers completed this survey. This compares to the 287 carers who completed the GCA Carer Survey in 2014.

2.2 Age of Carers

Carers involved in the survey ranged in age from 18 to over 80.

- In 2014 71% of carers that responded to the survey were aged over 51. This has increased to 80% in 2017. The 2011 reported figure was 63%.

2.3 Ethnicity of Carers

- The vast majority (95%) of respondents describe their ethnicity as white British.
- 5% of respondents were from other ethnic groupings including white (other) 2%, Asian or Asian British 1.5%, Black or Black British 0.5%, other ethnic groups 0.5%.
2.4 Disability of Carers

Survey respondents were asked whether they considered themselves to have a disability or long term illness. For the purpose of the survey disability is defined as ‘a physical or mental impairment that has a substantial and long term adverse effect on your ability to perform day to day activities’. Long standing means anything that ‘has troubled you over a period of time or that is likely to affect you over a period of time’.

- In 2011 36% of carers described themselves as having a disability or long term illness. This increased in 2014 to 42% and 2017 shows a further increase to 52%

Q8 Do you consider yourself to have a disability or long-standing illness/condition? If you answer NO or PREFER NOT TO SAY, please go to question 11.

- 57% of respondents stated that this disability or illness affects or limits what they are able to do as part of their caring role. This is an increase from 48% in 2014 and 45% in 2011.
31% of carers reported Physical impairment/mobility issues, 20% mental health condition, 9% long standing illness. 29% stated ‘other’ including COPD, Diabetes, Learning disability, arthritis and heart condition.

This question was not asked in the 2011 and 2014 surveys. It will be asked in the 2020 survey

2.5 Gender of Carers

69% of respondents stated Female and 31% Male.
2.6 Postcode of Carers

The majority of respondents live in NE8 and NE9. 267 carers gave their postcode as:

<table>
<thead>
<tr>
<th>Postcode</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>NE8</td>
<td>53</td>
</tr>
<tr>
<td>NE9</td>
<td>48</td>
</tr>
<tr>
<td>NE10</td>
<td>11</td>
</tr>
<tr>
<td>NE11</td>
<td>6</td>
</tr>
<tr>
<td>NE16</td>
<td>17</td>
</tr>
<tr>
<td>NE17</td>
<td>7</td>
</tr>
<tr>
<td>NE21</td>
<td>24</td>
</tr>
<tr>
<td>NE39</td>
<td>6</td>
</tr>
<tr>
<td>NE40</td>
<td>11</td>
</tr>
<tr>
<td>DH3</td>
<td>24</td>
</tr>
<tr>
<td>Other</td>
<td>60</td>
</tr>
</tbody>
</table>

2.7 Employment Status of Carers

Q11 Which of the following MOST applies to you? (Please tick ONE only):

- The biggest change in the period is the number of respondents describing themselves as unemployed which is down from 15% in 2014 to 8% in 2017.
- The percentage of respondents describing themselves as working full time or part time has remained static at 23% (as per 2014).
- The majority of respondents described themselves as retired 35%, which is an increase from 30% in 2014.
2.8 Responsibility for Dependents

- 26% of respondents reported that they have responsibility for dependants in addition to the person or people they care for. The reported figure for 2014 was 30% and in 2011 it was 20%. Over the period 2011 to 2017 the average percentage is 25%.

2.9 Your Caring Role

- The majority of respondents care for one person 81%, a reduction from 86% in 2014. In 2011 83% of carers reported caring for one person. Over the period 2011 to 2017 the average percentage is 83%.
- 19% care for 2 or more people. This is a significant increase of 35% on 2014 data (14%).

Q15 Please tell us how many hours you spend caring for this person. If you care for more than one person, please answer only in relation to the person you spend the MOST time helping. If you spend an equal amount of time caring for two or more people, please choose one person to answer the following questions about. How many hours a week do you care for this person?

- The vast majority of respondents are providing care for over 35 hours per week (80%) compared to 71% in 2014.
- 43% are providing 100 or more hours per week.
- 23% of respondents have been caring for this person for over 5 years but less than 10 years. 21% have been caring for this person for 20 years or more.
2.10 Caring Duties

Respondents were asked ‘over the last 12 months what type of caring duties have you undertaken on behalf of the person you care for?’ Respondents were asked to identify all options that applied.

Q17 Over the last 12 months, what type of caring duties have you undertaken on behalf of the person you care for? (Please tick ALL that apply)

- **Personal care (e.g. dressing, bathing, washing, feeding)**
- **Physical help (e.g. help with walking, get up / down stairs, getting in and out of bed)**
- **Practical care (e.g. preparing meals, shopping, housework, gardening, laundry)**
- **Help dealing with care services and benefits (e.g. making appointments, phone calls, filling in forms)**
- **Help with paperwork and financial matters (e.g. writing letters, filling in forms, dealing with bills, banking)**
- **Keeping them company (e.g. visiting, sitting with, reading / talking to, playing games)**
- **Emotional support (e.g. providing a listening ear)**
- **Providing transport (e.g. taking to see friends, relative, GP)**
- **Administering medicines (e.g. ensuring medication is taken, giving injections, changing dressings)**
- **Supervision (e.g. keeping an eye on the individual, to make sure they are ok)**
- **All of the above**
- **Other (please specify)**
Respondents identified a variety of different caring duties.

- The most common (64%) was practical care (preparing meals, shopping). This was followed by 62% provide supervision (e.g. keeping an eye on the individual), 59% provide emotional support, 57% provide help dealing with care services and benefits, 54% keep them company, 53% help with paperwork and financial matters.

- The least frequently reported help was physical health (e.g. help with walking, get up/down) which was identified by 35% of respondents.

- Other responses included general communication, exercise, hospital admissions, enduring power of attorney and dealing with the police.

- Across all three surveys (2011, 2014, 2017) Practical Care, Supervision (keeping people safe), Emotional Support, Help Dealing with Care Services and Benefits have been highest ranked.

- 1 in 3 carers reported in 2017 that they provide care in all 10 areas listed.

### 2.11 Impact of Caring on Your Health

**Q18 How would you currently describe your general health?**

![Pie chart showing the distribution of health descriptions]

Overall in 2017, 75% of carers reported their health as ‘average to very poor’. When comparing with results from 2011 (58%) and 2014 (69%) there is a clear trend indicating a worsening in carer health.
Three out of every four carers (74%) reported that their caring role has made their health a little or a lot worse.

Of those that stated Yes their health has been affected, 82% said they are feeling tired (up from 78% in 2014 and 73% in 2011). 72% have a general feeling of stress, 66% have disturbed sleep and 52% stated feeling depressed.

Other responses included feeling anxious, having to leave full time employment, mental breakdown and shoplifting.

There is some consistency across all three surveys (2011, 2014, 2017) in that the highest ranked health impacts are Feeling Tired, General Feeling of Stress, Disturbed Sleep, Feeling Depressed.
o 1 in 2 carers report feeling depressed
o 3 in 4 carers report feeling stressed
o 4 in 5 carers report feeling tired

Q21 If you have health problems, have these affected your ability to adequately care?

- For respondents with health problems, 54% stated that it is a little or a lot more difficult for them to provide adequate care. This compares with 48% in 2014 and 45% in 2011.

- 1 in 2 carers report that because of the impact caring is having on their health it is becoming more difficult to provide care. This equates to over 11,000 carers in Gateshead.

2.12 Accessing Healthcare Services

Q22 Do you feel that your caring commitments enable you to have time to visit your GP when necessary?

- 4 out of 5 carers report that they have the time they need to visit their GP.
2.13 Registering as a Carer

There has been a decrease in the number of carers who are aware that they can register as a carer with their GP. This is down from 54% in 2014 to 46% in 2017. In 2011 40% of carers were that they can register as a carer with their GP.

Of those who are aware that they can register only 30% have done so. This is a further decrease from 2014 when 63% had done so (in 2011 79% of carers had done so).

71% stated that they have never been asked by their GP or other staff at their surgery if they are a carer.
2.14 Impact of Caring on Your Health

Carers were asked to rate their quality of life which was defined as an ‘ability to enjoy normal activities’.

- 4 out of 5 carers (79%) report their quality of life as ‘average’, ‘poor’ or ‘very poor’ which is similar to the 2014 figure of 78%.

- 21% of carers described their quality of life as ‘excellent’ or very good’ which is similar to 2014 when 22% described their quality of life in this way.
We then asked carers if they have had to give up some aspects of their life since becoming a Carer (e.g. time socialising, training, education, hobbies, and work).

**Q27 Since becoming a carer, have you had to give up some aspects of your life? e.g. time socialising, training, education, hobbies, work.**

![Bar chart showing 79% yes and 21% no.](image)

The 2017 survey shows that 8 out of every 10 carers (79%) report that they have had to give up some aspects of their lives since becoming a carer. This is similar to the 2014 figure of 81% and is significantly higher than the 2011 figure of 68%.

**Q28. Carers were then asked to give more detail about their quality of life.**

Q. Please read the following statements about your role as a carer. For each statement, please put a tick in the box that you feel is most relevant to you (see table on page 19).
<table>
<thead>
<tr>
<th>Carer Quality of Life</th>
<th>Strongly Agree &amp; Agree 2011</th>
<th>Strongly Agree &amp; Agree 2014</th>
<th>Strongly Agree &amp; Agree 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel appreciated and valued as a carer</td>
<td>64%</td>
<td>42%</td>
<td>58%</td>
</tr>
<tr>
<td>I am able to spend my time as I want, doing things I value or enjoy</td>
<td>35%</td>
<td>19%</td>
<td>31%</td>
</tr>
<tr>
<td>I have the space and time I need to be myself</td>
<td>35%</td>
<td>21%</td>
<td>23%</td>
</tr>
<tr>
<td>I have as much control over my daily life as I want</td>
<td>35%</td>
<td>17%</td>
<td>19%</td>
</tr>
<tr>
<td>I have the time I need to look after myself (in terms of getting enough sleep, eating well etc)</td>
<td>48%</td>
<td>33%</td>
<td>39%</td>
</tr>
<tr>
<td>I have as much social contact as I want with people I like</td>
<td>42%</td>
<td>27%</td>
<td>28%</td>
</tr>
<tr>
<td>I feel I get sufficient breaks from caring</td>
<td>36%</td>
<td>19%</td>
<td>23%</td>
</tr>
<tr>
<td>I have a life of my own outside of my caring role</td>
<td>33%</td>
<td>28%</td>
<td>29%</td>
</tr>
<tr>
<td>I often feel isolated or lonely</td>
<td>24%</td>
<td>31%</td>
<td>34%</td>
</tr>
<tr>
<td>I feel I have lost my independence/freedom</td>
<td>28%</td>
<td>31%</td>
<td>35%</td>
</tr>
<tr>
<td>I feel I have sufficient time/energy to participate in training and education</td>
<td>22%</td>
<td>18%</td>
<td>15%</td>
</tr>
<tr>
<td>My caring role allows me to continue with the paid work that I’d like to do</td>
<td>22%</td>
<td>20%</td>
<td>21%</td>
</tr>
<tr>
<td>I worry about what would happen to the person I care for if I was not there</td>
<td>74%</td>
<td>66%</td>
<td>87%</td>
</tr>
<tr>
<td>I worry what would happen to me/what I’d do if/when my role as a carer ends</td>
<td>39%</td>
<td>29%</td>
<td>40%</td>
</tr>
</tbody>
</table>
• Across all indicators 1 in 2 carers report caring has a negative impact on their quality of life.

• 7 out of 10 carers report that they are unable to spend time as they want doing things they value and enjoy.

• Almost 8 out of 10 carers report that they do not have the time they need to be themselves

• 7 out of 10 carers report that they do not have as much social contact with people they like

• Almost 8 out of 10 carers report that they do not get sufficient breaks from caring

• Over 8 out of 10 carers report that they do not have sufficient time / energy to participate in training and education

• 1 in 3 carers report feeling isolated or lonely

• 9 out of 10 carers report that they worry about what would happen to the person they care for if they were not there.

• 7 out of 10 carers report that they do not have a life of their own outside of caring.

2.15 Impact of Caring On Your Personal Finances

Q29 In the last 12 months, has caring caused you any financial difficulties? If NO, please go to question 31.

Answered: 243   Skipped: 41

- 54% No
- 34% Yes, to some extent
- 12% Yes, to a great extent

• 1 in every 2 carers (46%) report their caring role has caused them financial difficulties. This is broadly the same as in 2014 (50%) and remains higher than 2011 (41%).
• 29% reported that they had to give up paid employment compared to 20% in 2014 and 10% in 2011.

• 47% reported that they have had to use their own money and / or savings to pay for equipment and services for the person they care for. This is down from 54% in 2014 but remains significantly higher than the 11% in 2011.

• 36% stated that carer related benefits aren’t enough to live on.

• 11% felt that they had reduced promotion / training prospects as work compared to 13% in 2014.
61% of carers are aware of the benefits available to support carers in their caring role which is broadly the same as 2014 (60%) but significantly lower than the 68% in 2011. The average figure across all 3 surveys is 63%.

Of those that are aware, 51% claim some benefits to support them in their caring role. The 2014 figure was 46% and the 2011 figure was 65%. The average figure across all 3 surveys is 54%.
When asked if you do not claim benefits to support you in your caring role, why not?

- 49% said they are not entitled to any carer related benefits.
- 16% said it is too complicated to understand or apply for.
- 19% said ‘If I did claim any, I worry it might affect the benefits of the person I care for’.
2.16 Carers Assessment

Following the Care Act 2015 the Carers Assessment questions have been changed, in some respects, from those questions asked in 2011 and 2014. In the 2017 survey questions were asked of people who had become a carer in the last 12 months and those who had been caring for over 12 months.

If you have become a carer in the last 12 months have you:

- Been offered a Carer's Assessment? 82% said No
- Asked for a Carer's Assessment? 93% said No
- Had a Carer's Assessment? 89% said No

If you have been a carer for more than 12 months have you:

- Been offered a Carer's Assessment? 77% said No
- Asked for a Carer's Assessment? 87% said No
- Had a Carer's Assessment? 82% said No

Since 2011 there has been a reduction in the number of carers reporting that they have had a Carers Assessment.

- In 2011 34% of carers reported that they had undergone a Carers Assessment. In 2014 this fell to 25%. In 2017 the number of new carers who report having had a Carers Assessment is 11%.
- The number of carers, who have been caring for over 12 months, who report having had a Carers Assessment is 18%.
- 9 out of every 10 new carers report they have not had a Carers Assessment.
- 8 out of 10 of those carers who have been caring for over 12 months, report they have not had a Carers Assessment.
- 8 out of 10 carers report that they do not get a copy of their support plan.
- Of the 42 carers who reported they had had a Carers Assessment only 1 in 4 reported that their support plan included their Personal Budget.
Of the 42 carers who reported that they have had a Carers Assessment there was a wide variation in the length of time between initial request and the assessment taking place. Whilst 4 of every 10 carers waited between 1 week and 4 weeks;

- 2 in every 10 carers reported waiting over 12 months
- 1 in every 10 carers reported waiting over 6 months
- 3 in every 10 carers reported waiting between 2 and 6 months.
1 in every 10 carers report having had a Carers Assessment as part of a joint assessment with the cared for person.

6 in every 10 carers report not having had a Carers Assessment as part of a joint assessment with the cared for person.

A high proportion of carers, 3 out of every 10, report ‘not knowing’ if they have had a Carers Assessment as part of a joint assessment with the cared for person.

Whilst the number of reported joint assessments is well below expected levels what is of further note is the high proportion of carers who are unable to say if they have had a joint assessment or not.
Under the Care Act 2015 all carers are entitled to a Carer's Assessment and this should include a personal budget.

Only 2% of carers (6 people) reported that they had taken a direct payment.
Of the small number of carers taking a direct payment, 61% thought it had helped a lot or a little.

Almost 1 in every 2 carers reported that they never felt involved or consulted or that there have been no discussions that they are aware of.
2.17 Support Services

Q.44 Have you accessed any of the following types of support in the last 12 months, to support or help you in your caring role? For each statement, please tick the box that is most relevant to you.
<table>
<thead>
<tr>
<th>Support Type</th>
<th>Yes Percentage</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>General information, advice or support</td>
<td>64%</td>
<td>222</td>
</tr>
<tr>
<td>Emotional support (e.g. talking to a friend or neighbour)</td>
<td>59%</td>
<td>219</td>
</tr>
<tr>
<td>Short breaks/support to help you take a break from caring</td>
<td>42%</td>
<td>198</td>
</tr>
<tr>
<td>Counselling / someone to talk to in confidence</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>Informal practical support (e.g. help from a family member with hospital visits)</td>
<td>38%</td>
<td></td>
</tr>
<tr>
<td>Advice on benefits for carers</td>
<td>34%</td>
<td></td>
</tr>
<tr>
<td>Membership of a carer support group</td>
<td>33%</td>
<td></td>
</tr>
<tr>
<td>Financial advice &amp; support</td>
<td>27%</td>
<td></td>
</tr>
<tr>
<td>Social events / leisure activities for carers</td>
<td>24%</td>
<td></td>
</tr>
<tr>
<td>Practical help, for example with household tasks</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Wellbeing services (e.g. complementary therapies, relaxation)</td>
<td>17%</td>
<td></td>
</tr>
<tr>
<td>Training for carers</td>
<td>10%</td>
<td></td>
</tr>
</tbody>
</table>

Q.45 Which of the following have you received this support from in the last 12 months? For each type of organisation, please put a tick in the box that is most relevant to you.

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Regularly</th>
<th>Occasionally</th>
<th>Never</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gateshead Carers Association</td>
<td>67%</td>
<td>33%</td>
<td></td>
<td>222</td>
</tr>
<tr>
<td>GP or Practice Staff</td>
<td>51%</td>
<td>49%</td>
<td></td>
<td>219</td>
</tr>
<tr>
<td>Other Health Services</td>
<td>38%</td>
<td>62%</td>
<td></td>
<td>198</td>
</tr>
<tr>
<td>Social Services</td>
<td>32%</td>
<td>68%</td>
<td></td>
<td>190</td>
</tr>
<tr>
<td>Other Charities and Voluntary Organisations</td>
<td>26%</td>
<td>74%</td>
<td></td>
<td>191</td>
</tr>
<tr>
<td>Other (including Gateshead Council)</td>
<td>23%</td>
<td>77%</td>
<td></td>
<td>91</td>
</tr>
</tbody>
</table>
37% of respondents said they got most of their support from Gateshead Carers Association

34% from other sources mainly friends and family

16% from their GP or Practice Staff

8% from other Health Services

4% from other charities and voluntary organisations

1 respondent stated that they get most of their support from Gateshead Council
Thinking about where you get most of your support (your answer to Q. 46), to what extent do you agree or disagree with the following statements? For each statement, please put a tick in the box that you feel is most relevant to you.

- 91% of carers reported that they have not faced any cultural barriers or difficulties when accessing support services to help them in their caring role (95% in both 2011 and 2014 surveys).

- Of the 8% (18 carers) who said they had faced cultural barriers when accessing support services, 40% said they encountered these barriers or difficulties with their local council / Social Services.
• When asked which categories did these issues fall into, 36% said lack of awareness on the part of the service users, 18% said Lack of confidentiality and 12% said lack of women-only services, lack of understanding of cultural / religious beliefs, language barriers.

2.18 Emergency Support Service

• 68% of carers are not aware of the Emergency Support Service which is the same as 2014 but significantly greater than the 2011 figure of 54%.

• Only 36% of carers reported that they have plans in place for the person they care for if they should fall ill or are unable to continue to provide care. This is significantly lower than in 2011 when 46% reported having plans in place.

2.19 Equipment

Please use this space if you would like to tell us more about any equipment that you use as part of your caring role:

Wheelchair, toilet seat & frame, wet room, shower chair, hoist, walking sticks, commode, ramp, stair lift, special mattress, bed, stair rail, bathing aids, step climber, bed positioning sheets, incontinence sheets, Zimmer frame, perching stool, elbow crutch, lazy Susan, support stockings, electric motor scooter, lifeline, riser chair.

2.20 Taking a Break from Caring

Q57 Are you aware of where to go to access support or services to help you take a break from caring? Please DO NOT include unpaid help from family and friends.

Answered: 234  Skipped: 50

<table>
<thead>
<tr>
<th></th>
<th>0%</th>
<th>10%</th>
<th>20%</th>
<th>30%</th>
<th>40%</th>
<th>50%</th>
<th>60%</th>
<th>70%</th>
<th>80%</th>
<th>90%</th>
<th>100%</th>
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</thead>
<tbody>
<tr>
<td>Yes</td>
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<td>41.45%</td>
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<td>58.55%</td>
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</tbody>
</table>

• There has been a rise in the number of carers reporting that they do not know where to access a break to 59% which shows an upward trend from 42% in 2014 and 29% in 2011.
18% of carers responded that they had accessed a break lasting between 1 and 24 hour (up from 13% in 2014).

29% of carers responded that they had accessed a break lasting more than 24 hours (up from 20% in 2014).

Q59 If YES, did you take a break: (Please tick ONE only)
Of those accessing breaks;

- 66% had a break away from the person they care for compared to 72% in 2014
- 33% took a break with the person they care for compared to 28% in 2014.

Of those not accessing a break;

- The main reason given (43%) was that they did not want to leave the person they care from with someone else. This is an increase on 34% in 2014 and 36% in 2011
- 37% did not know how or where to access this support (42% in 2014).
- 27% said they do not need to take a break from caring (31% in 2014 and 42% in 2011)
- 22% said they cannot meet the costs associated with taking a break (20% in 2014 and 19% in 2011)
ABOUT THE PERSON YOU CARE FOR

2.21 Personal Health Budget

Questions relating to Personal Health Budgets were not included in the 2011 and 2014 surveys.

Q66 Does the person you care for have a Personal Health Budget?

Answered: 195  Skipped: 89

No 91.28%
Yes 8.72%

As personal health budgets have not yet been fully rolled out in Gateshead these results are to be expected, but we will include this question in the 2020 survey.

Q67 Do you know what a Personal Health Budget is?

Answered: 246  Skipped: 68

No 86.11%
Yes 13.89%
There was a significant increase in the number of respondents caring for their Partner / Spouse / Co-habitee from 24% in 2011, 34% in 2014 to 43% in 2017.

There was a fall in the number of respondents caring for their Son / Daughter (own / adopted / step) to 28% (35% in 2014, 45% in 2011).

As in 2011 and 2014, the majority of carers said the person they were supporting was male with an increase from 51% (2011), 56% (2014) to 58% in 2017.
• The most significant change, with regards to the age bands of the cared for, between 2011 and 2017 is for those caring for someone over the age of 55, which has increased from 39% (2011), 50% (2014) to 58% in 2017.

• 54% of respondents care for someone with a Physical Impairment / Mobility issues, no change from 2014.
• 33% care for someone with a Mental Health Condition, an increase from 27% in 2014.
- 31% care for someone with a Long Standing illness, an increase from 24% in 2014.
- 20% care for someone with a Learning Disability which is down from 2011 (48%) and 2014 (24%).
- Other conditions stated included Eating Disorder, IBS, MS, Diabetes, Old Age, Heart Failure.

<table>
<thead>
<tr>
<th>Condition of the person you care for</th>
<th>Ranking from Highest (1) to lowest (10) 2011</th>
<th>Ranking from Highest (1) to lowest (10) 2014</th>
<th>Ranking from Highest (1) to lowest (10) 2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Impairment / Mobility Issues (1)</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Sensory Impairment (e.g. blind, deaf, hearing, vision impairment) (2)</td>
<td>5</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Speech Impairment or without Speech/Voice (3)</td>
<td>10</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Social Communication Impairment (e.g. Aspergers, Autism Spectrum Condition) (4)</td>
<td>7</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Learning Disability (5)</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Specific Learning Disability (e.g. ADHD, Dyslexia, Dispraxia) (6)</td>
<td>8</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Long Standing Illness (e.g. HIV, Alzheimer's, Cancer, MS, Parkinson's) (7)</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Mental Health Condition (e.g. Depression, Schizophrenia, Anxiety) (8)</td>
<td>3</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Substance Misuse (e.g. Drugs, Alcohol) (9)</td>
<td>8</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Other (please specify) (10)</td>
<td>6</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>
The ranking shows most frequently reported condition of the cared for (1) to least frequently reported (10) across all 3 surveys.

- The most notable change is Learning Disability which has fallen from the most frequently reported condition of the cared for person in 2011 to the 5th most reported in 2017.

Q72 If the person you care for is in one of the categories above have they asked for or been offered a Personal Health Budget?

Answered: 205  Skipped: 79

- Yes 8.78% (18)
- Don't know 34.22% (64)
- No 60.00% (123)

This question has not been previously asked in 2011 and 2014. It will be included in the 2020 survey.
2.22 Benefits for the Person You Care For

• 54% of carers said that they were aware of the benefits available to the person they care for, this is a significant drop from 81% in 2014 and 68% in 2011.

• 85% of respondents reported that the person they care for claims benefits, this is a slight drop from 89% in 2014 (82% 2011).
Disability Living Allowance was the most commonly claimed benefit by the cared for with 48% of those aware of it, claiming it. Attendance Allowance is claimed by 30%.
Q78 Thinking about the total amount received in benefits over the last 12 months, would you say they have:

- Reduced 0.72% (21)
- Increased 17.13% (37)
- Stayed the same 73.15% (158)

This question was not included in the 2011 and 2014 surveys

Q79 Do you feel you know what financial assistance and benefits are available for you as a carer and for the person you care for?

- Yes 32.46% (74)
- No 67.54% (154)
• 7 in every 10 carers (67%) reported that they do not know what financial assistance and benefits are available for them as carers and for the person they care for.

**Q80** Do you provide practical help (e.g. to complete a benefit application) to the person you care for in order to claim the benefits they are entitled to?

Answered: 227  Skipped: 57

- Yes 70.93% (161)
- No 29.07% (66)

• There has been a fall in the number of carers reporting that they provide practical help to the person they care for in claiming benefit from 80% in 2014 to 71% in 2017.
1 in every 2 carers report receiving practical help with benefits claims.

Of those carers receiving practical help 6 out every 10 (58%) received the most support from Gateshead Carers Association.
2.23 Community Care Needs Assessment

- 6 out of every 10 carers (58%) report that the person they care for has not had a needs assessment from social services.
• Of those who reported that the cared for person had received a needs assessment 42% of respondents said this was within the last 12 months, with 22% reported that it was 3 or more years ago.

Q85 Did the person you care for receive a support plan?
Answered: 247  Skipped: 77

- 1 in every 3 carers (29%) reported that they did not know if the person they care for has received a support plan. This links to question 64 where almost 1 in every 2 carers reported that they never felt involved or consulted or that there have been no discussions that they are aware of.

Q86 If YES, did the support plan of the person you care for include his / her personal budget (an amount in pounds showing the cost of meeting his / her support needs)
Answered: 112  Skipped: 172

- 1 in every 2 carers (46%) of reported that they did not know if the support plan for the person they care for included his/her personal budget.
1 in every 3 carers (33%) reported that they did not know if the person they care for had chosen to take the personal budget as a Direct Payment.

Of the small number of people who responded to this question (37) the majority (25) reported Direct Payments as being helpful.
2.24 Public Funding Cuts to Services

Q89 Have the cuts to public services had an impact upon the following? For each statement, please put a tick in the box that is most relevant to you.

Answered: 191  Skipped: 93

- **My personal circumstances**: 30.56% Yes, 69.44% No
- **My role as a carer**: 35.71% Yes, 64.29% No

1 in every 3 carers (30%) reported that cuts to public services have had an impact upon their personal circumstances, with 36% saying cuts have impacted upon their role as a carer.
Of those respondents who have experienced a reduction in services the single most reported experience of a reduction in services was in respect of Social Worker Support (14%).

This was followed by Respite (10%), Health Services Support (10%) and Housing Support (10%).

Areas mentioned under ‘other’ included, DLA, Take a Break Holidays, Transport to Hospital, Mental Health support.
The majority of carers (6 out of every 10) reported that council services used by themselves or the person they care for had not been reduced or withdrawn in the last 24 months.

1 in every 10 carers reported that services had been reduced or withdrawn.

This question was not asked in our 2011 and 2014 surveys. It will be included in the 2020 survey.
Respondents rated the above either important or extremely important (4 & 5).
• General information, advice and support is the most valued reported support service, followed by short breaks, financial support including benefits advice and someone to talk to in confidence.

• The areas with the lowest reported importance is employment matters. This is unsurprising when only 23% of carers report being employed either fulltime or part time and with 55% describing themselves as retired or permanently sick or disabled.

3. Summary and Emerging Trends

The Gateshead Carers Survey provides the most comprehensive information on the lives of carers in Gateshead. It was introduced in 2011 and is repeated every 3 years. This being the third survey we are now able to identify trends which are developing over time in key areas of carer’s lives. The 2017 survey also provides an opportunity to develop our understanding of the impact of the Care Act 2015.

There are other findings which are significant and should not be overlooked and these include;

Mental Health and Wellbeing

Across all three surveys there is consistency in relation to the most frequently reported impacts of the caring role on carer’s wellbeing. These are;

• Feeling Tired
• General Feeling of Stress
• Disturbed Sleep
• Feeling Depressed

The figures are stark with 1 in every 2 carers report feeling depressed, 3 in every 4 carers report feeling stressed, 4 in every 5 five carers report feeling tired.

Emerging Trends

By emerging trends we mean an aspect of carer’s lives which shows an increase or decrease in each survey.
1. Carers reporting that they have a long term disability or long term health condition

The percentage of carers who report that they have long term disability or long term health condition has increased by 44% since 2011. Older carers (those aged 55 plus) is the fastest growing age community of carers and it is likely that this will continue to be the case in the coming years based on demographic projections.

2. Carers providing care for more than 35 hours per week

Whilst the time spent caring has grown significantly the 2017 survey results also show that 4 in every 10 carers (42%) are providing care for over 100 hours per week. This equates to over 8,800 people in Gateshead
3. Impact of caring on general health

After considering the growth in the number of hours of care provided it is unsurprising but of great concern that increasing numbers of carers are reporting that caring is having a negative impact on their health. This equates to 16,575 carers which is up from 12,818 in 2011.

4. Carers reporting that health problems are affecting their ability to care

When considering that carers are caring for longer (hours per week), that 1 in 2 carers has a disability or long term health condition, that the fastest growing age community of carers is 55 plus it is perhaps unsurprising that there has been a sustained increase in the number carers reporting that health problems are affecting their ability to care. 1 in every 2 carers is now in this position which, in Gateshead, equates to 11,000 people.
5. Carers reporting their quality of life as average, poor or very poor

Quality of life is a strong indicator of carer wellbeing. The principle of wellbeing is core to the Care Act. Carer quality of life across a range of indicators has remained consistently reported as poor across all three surveys. Over the past surveys increasing numbers of carers are reporting that;

- They have less time to participate in training and education
- Less time to look after themselves (in terms of getting enough sleep, eating well etc.)
- They are increasingly feeling socially isolated or lonely
- They have less control over their lives
- 8 out of every 10 carers are reporting their quality of life as average to very poor which equates to 17,000 people in Gateshead.
6. Carers who have had to give up paid employment to care

There has been a sustained and significant increase in the number of carers who report that they have had to stop working to provide care. This has an impact not only on the financial position of individuals and families in Gateshead but it are also likely to impact on the health and wellbeing of the carer and the Gateshead economy.

7. Carers reporting that they have had a Carers Assessment

The Care Act 2015 gave carers a statutory right to a Carers Assessment. The expectation was that this would inevitably lead to a significant increase in the number of carers assessments carried out.
The 2017 survey indicates that the opposite has happened. The number of assessments carried out has fallen not only since 2015 but from the numbers reported in the 2011. The trends identified above indicate the need for carer support is clearly increasing. There are warning signs (e.g. number of carers reporting that it is becoming more difficult to provide care because of their own disability or long term condition, the growth in carers aged 55 plus) that unless there is an urgent and sustained increase in carer assessments which, as a result, leads to actual support for carers there will be a crisis across the health and social care system.

It is well documented that each carer, by providing care to family members and friends save the UK economy and health and social care services, on average, over £18000pa.

8. Involvement and consultation with carers

The Care Act 2015 is very clear that the care and support planning process is there to help decide the best way to meet a person’s needs and that the planning process takes place with the local authority and the person and any carer they have.

It is both surprising and disappointing to note that the number of carers reporting that they are usually consulted or involved in discussions about support or services provided for the cared for person has fallen since the implementation of the Care Act.
The increasing number of carers aged over 51 is in line with demographic projections. The number of older carers is growing at a staggering rate. There are nearly 1.2 million carers aged 65 and over in England – an increase of 35% in just ten years, compared to an 11% rise in the number of all carers, and a 4% rise in the number of carers aged 25-64 in the same time period. The fastest growing group is carers aged 85 and over, whose numbers have more than doubled, growing by a huge 128% in ten years to over 87,000 (Census 2011).

There is a gap between life expectancy and healthy life expectancy which means that as people live for longer they are also likely to need care and support for a bigger proportion of their lives. For boys born between 2008 and 2010, healthy life expectancy is 63.5 years compared with a life expectancy of 78.1 years, so they are expected to be in poor health for 14.6% of their lives. For girls, healthy life expectancy is 65.7 years compared with a life expectancy of 82.1, so although women are expected to live longer they are also expected to live a fifth (20%) of their lives in poor health.

There is a clear and urgent need to provide more support to older carers.

4. **Looking Ahead**

As an organisation which exists solely to provide support to carers it is vital that our work reflects what carers are telling us. As outlined above there are significant trends emerging in relation to the impact caring is on having on the physical and mental health of carers with high levels of carers reporting of anxiety, stress and depression.

There is also evidence within the surveys which indicates that the quality of life which carers experience is becoming increasingly worse. More and more carers are having to give up work to care, carers are increasingly socially isolated and increasingly find
it more difficult to do the things they want to do on a personal level such as social activities, education and training and return to or stay in employment.

As an organisation we need to refresh our support to carers to ensure that we are best placed to enable carers to meet the demands and challenges they are facing. However in doing that we must also consider what we know is happening across the health and social care system which include clear and unambiguous statements from the Care Act 2015 and key strategic and consistent messages from Gateshead Council / Newcastle Gateshead Clinical Commissioning Group (CCG), Association Of Directors of Adult Social Care (ADASS), the Department of Health, the Social Care Institute for Excellence (SCIE) and other key strategic bodies across the UK.

For example:

**The Care Act 2015 aims to;**

‘Consider the person’s own strengths and capabilities, and what support might be available from their wider support network or within the community to help in considering what else other or alongside the provision of care and support might assist the person in meeting the outcomes they want to achieve’

Meeting needs rather than providing services is integral to the Care Act as is the wellbeing principle. This means promoting individual aspirations, enhancing independence and wellbeing and maximising autonomy – supporting people to live their lives in the way that they choose.

**The Social Care Institute for Excellence sees a need to move from;**

‘A paternalistic care management viewpoint rooted in a deficit model to a focus on what the organisations and citizens of an area can do with their assets and potential’

**Gateshead Council and Gateshead Newcastle CCG have identified that one of its aims for supporting carers is;**

‘To help carers to develop and learn new skills to maintain independence and build confidence. We want to support carers to look after their own physical health, emotional health, mental health and general wellbeing’.

**NHS England is saying that the NHS should be;**

‘Helping people build their confidence, skills and knowledge, these approaches include:

- Self-management education
- Peer support
- Health coaching
- Group based activities to support health and wellbeing
- Asset based approaches in the health and wellbeing context’
The Association of Directors of Adult Social Care (ADASS) has identified a need for;

'A new type of personalised conversation is taking into account the strengths and resources of the individual service user, their friends, families and the wider community. This enables a much more innovative asset based approach to addressing needs'.

'Assets, strengths or resilience based approaches help people and communities to come together to achieve positive change using their own experience, knowledge and skills. These approaches recognise the personal, social and physical capital that exists within local communities'.

Self-care, asset / strength based approaches, building confidence, skills and knowledge, peer support, community support and enhancing independence and wellbeing and maximising autonomy of carers are essentially responses to the reality that health and social care is changing.

We have, prior to the results of the survey, been mindful of the direction in which health and social care is heading and have been considering what we need to do as an organisation to continue to support carers in the light of what is being said nationally, regionally and locally. We know that over the last two years the number of people being assessed as eligible for community care support has fallen nationally by 200,000. This trend is likely to continue over the next 3 to 5 years. The reality is that carers will, of necessity, have to care for longer and with less (or different) support from local authorities as government imposed cuts to their budgets continue.

At the same time we know that the number of carers coming to GCA for support has increased from an average of 11 new carers per month in 2012 to an average of 94 per month in 2016. In February of this year 131 carers sought support from this organisation. At a time of static and potentially reducing income this upward rise in demand is unsustainable and we need to prevent the development of long waiting lists.

As a result of the national messages, our surveys and the increase in demand for our support we need to develop our offer to carers in a way which will enable us to meet demand and ensure that our offer to carers focuses not just on their present need or challenge but also to be future focussed. Future focussed approaches respond, when appropriate, to the current presenting need but also aim to leave the carer stronger, more confident, better connected and more resilient in the future.

Being future focussed is not just about a carer’s presenting needs but also about their strengths, developing their resilience, realising their potential and enabling carers to have the skills, knowledge and resources they will need to meet new, growing and different challenges.
We will be working with carers to identify the life they want and the skills, knowledge and personal development they need to move towards getting there. Our focus needs to be on empowering carers to be stronger and more confident, especially in controlling their life, claiming their rights, realising their potential, achieving their goals, staying healthy mentally, physically and financially.

We plan to have a revised initial offer to carers in place from December 2017 which will be further developed in 2018. It will include a range of facilitated support groups and peer support groups which will provide opportunities for carer’s across these areas;

- Emotional Resilience
- Personal Development
- Making Connections
- Health

We will do this through the development of a range of themed ‘Carer Cafes’ which will provide an opportunity for informal conversations with tea / coffee and healthy nibbles, on a range of topics including;

- Managing Stress
- Assertiveness
- Handling conflict
- Mindfulness
- Guilt
- Confidence building

We will work with partner organisations to have a rolling programme of health related Carer Cafes on a range of topics including;

- Smoking, Alcohol and Weight reduction
- 5 Ways to Wellness
- Healthy Eating

We will work to ensure that carers are less socially isolated through increased activity within communities and the continuation of our social groups.

Our approach to carer wellbeing will be strengths based and this will be reflected in all aspects of our work including our social groups, peer and facilitated support groups and in one to one case work.

We will continue to work to ensure that carer’s contribution to the lives of those they care for is recognised and valued across health and social care services, employers and other stakeholders and we will continue to challenge our own practice and any systemic barriers in health and social care, work, education and training which are working against the ability of carers to live the life they wish to live.
In the words of carers;

“We are people in our own right with responsibility for another life. We need financial help and back up, to help us live our lives and care for sick and disabled people.”

“Society would collapse without carers, don't ignore us. All we are asking for is a fair deal.”

Steve Cowen  
Chief Executive Officer  
Gateshead Carers Association

August 2017

For further information about this report and the Gateshead Carers Survey, please email: enquiries@gatesheadcarers.com or Telephone: 0191 490 0121.

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