Gateshead Carer Survey
REPORT 2014

Impact of Caring on the Lives of Unpaid Carers in Gateshead.
Carer Survey Report 2014

Written and produced by Gateshead Carers Association.

We would like to thank all the Carers who took part in the Gateshead Carer Survey 2014.

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Foreword

By Dave Anderson, MP for Blaydon, Gateshead.

As someone who has been a carer and has suffered the personal tragedy of supporting and losing several family members to Muscular Dystrophy throughout my life, I know the huge contribution that carers, both family and friends make to our society. Sadly, on the whole, it goes unnoticed and unappreciated; carers are society’s unsung heroes.

That is unacceptable, but if we ever are to change attitudes then those of us who believe in carers rights have to shout longer and louder. This report is a great opportunity for us all to do just that, reflecting on the tireless contribution carers make to Gateshead and the personal sacrifices they make as a result.

In 2017 it is estimated that the population of the UK will reach a tipping point for care, where the number of older people needing care will outstrip the number of working age family members currently available to meet demand.

Most of us will look after an elderly relative, sick partner or disabled family member at some point in our lives. Ultimately we have to face our friends, neighbours and families with the reality that all of us may need to be cared for. It is very much a case of “there but for the grace of God go I.”

Over the last five years carers have suffered acutely from this Governments programme to cut benefits. The abhorrent Bedroom Tax hit carers hard and they now face the insecurity of massive delays in Personal Independence Payments. They will continue to suffer from the Local Authority cuts which leave social services hanging by a thread, carers need to be protected wherever possible.

Organisations like Gateshead Carers Association are on the coal face of this work and truly are providing a lifeline to carers in crisis.

Please read this report and engage with the great people behind it to ensure that we do the best and the right thing by those who should no longer be “unsung” and who desperately deserve our respect and need our help.

Dave Anderson
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1. Purpose of the 2014 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 2011. The report begins by setting out key national and local carer policy drivers.

This organisation has a contract with Gateshead Clinical Commissioning Group (CCG) to deliver services for carers in Gateshead. Our agreed CQUIN target (Commissioning for Quality and Innovation) for 2013 / 14 was to produce and distribute the survey, analyse responses and present the findings.

The survey findings will shape and influence the content of Gateshead Carers Association’s Strategic Plan for 2014 / 2017 and 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 2011. 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 for wider distribution in November 2013 and February 2014. 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 287 were returned. This compares to the 271 carers who completed the GCA Carer Survey in 2011.

Respondents were eligible to enter a £50 prize draw on completion and return of the survey.

No young carers (aged under 18) completed the survey. Effectively this means that the 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 Carers and the National / Local Policy Context

#### 1.5.1 The National Carers Strategy (2010)

The government is clear in its view that carers must be recognised, valued and supported. Key outcomes for carers in the strategy are;

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring
- Carers will be able to have a life of their own outside of caring
- Carers will be supported so that they are not forced into financial hardship as a result of their caring role
- Carers will be supported to stay mentally and physically well and treated with dignity.

These aims are reflected in the Gateshead Carers Strategy 2011 / 2014.

#### 1.5.2 NHS Outcomes Framework 2014 / 2015

Within this document (Annex C1; *Enhancing quality of life for people with long term conditions*) key outcomes identified are;

- Enhancing quality of life for carers
- Ensure carers can balance their caring roles and maintain desired quality of life.

Annex C3 of the NHS Outcomes Framework (*Ensuring that people have a positive experience of care and support*) states that;

- People who use social care and their carers are satisfied with their experience of care and support services
• Carers feel that they are respected as equal partners throughout the care process.

1.5.3 Gateshead Carers Partnership Strategy (2011 to 2014)

This document, produced by Gateshead MBC and partner stakeholders states that;

‘Our vision is for carers in Gateshead to be recognised and valued for the positive contribution they make to our community and the lives of the people they support. We will work to ensure that carers are empowered and enabled to take control of their own lives by recognising and identifying their own needs, by having more choice and control and through access to high quality, flexible support services’.

1.5.4 The Care Bill

It is anticipated that this will be enacted during 2014. The Care Bill simplifies, consolidates and improves existing legislation putting carers on an equal legal footing to those they care for and putting their needs at the centre of the legislation.

In particular the Bill proposes;

• Duty to promote wellbeing extended to include Carers (clause 1)

• New duties for local authorities to integrate services and provide information and advice (clauses 3 & 4)

• 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 (clause 5)

• New single duty for Carers Assessments based on appearance of need, will now include consideration of day to day outcomes and financial assessments will only be carried out after a needs assessment (clause 10)

• Whole families can be involved in needs assessments (clause 12)
• New duty to meet carers’ needs for support (clause 20)
• National eligibility framework and standards for meeting needs of adults with...
needs and carers with care and support needs (clause 13)

- Duties for assessing needs for adults with care needs, Carers, children with care needs and Young Carers at transition have been amended to include consideration of what support and resources are already available to an individual which could meet their needs (clauses 9, 18, 10, 56 57 and 61)

- Carers should be consulted on care and support plans; Carers can prepare plans jointly with local authorities (or other organisations) (clause 25)

- Right to a support plan to help carers decide how their needs should be met; Carers can request a copy of the care and support plan (clause 25)

- 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 (clause 26 and 31).

Support for carers is therefore a priority at a national and local level. This is likely to be driven not only by a recognition of the enormous contribution carers make to lives of those they support but also by a recognition of the financial contribution carers make to the economy of the UK and locally.

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The economic value of the contribution made by carers in the UK is a remarkable £119 billion per year. This is considerably more than the annual cost of all aspects of the NHS.

It is equivalent to;

- £2.3 billion per week
- £326 million per day
- £13.6 million per hour
- £18,473pa for every carer in the UK

(University of Leeds 2011)
2. Key Findings

2.1 Carers Responding to the Survey

The survey takes between 30 and 45 minutes to complete and a total of 287 were completed. This compares to the 271 carers who completed the GCA Carer Survey in 2011.

2.2 Age of Carers

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

- In 2011 63% of carers that responded to the survey were aged over 51. In 2014 this has increased to 71%.

- The biggest change was in the 51-65 age group which increased from 30% in 2011 to 47% in 2014.
2.3 Ethnicity of Carers

- As expected the vast majority (90%) of respondents describe their ethnicity as white British.

- 10% of respondents were for other ethnic groupings including white Orthodox Jewish 1%, white (other) 3%, Asian or Asian British 3%, Black or Black British 1%, other ethnic groups 2%, which increased from 0% in 2011 to 2% in 2014 with respondents describing themselves as Japanese, Roma, Polish British and Arabic Muslim.

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 35% of respondents described themselves as having a disability or long standing illness. This has increased to 41% in 2014.

![Bar chart showing the percentage of respondents who consider themselves to have a disability or long-standing illness between 2010/11 and 2013/14.](chart.png)

- **Response 2013/14**
- **Response 2010/11**
2.5 Employment Status

- The biggest change in the period is the number of respondents describing themselves as unemployed which is up from 7% in 2011 to 15% in 2014.

- The percentage of respondents describing themselves as working full time or part time increased from 17% in 2011 to 23% in 2014.

- The majority of respondents described themselves as retired 30% which is similar to the 2011 figure of 32%.

2.6 Responsibility for Dependents

- 30% of respondents cited that they have responsibility for dependants (e.g. adult or child) in addition to the person or people they care for. The reported figure for 2011 was 20% an increase of 50%.

(See ‘Responsibility for dependants’ graph on next page)
2.7 Caring Role

- The majority of respondents care for one person 86% (2014) – compared to 83% (2011).

- 14% (2014) care for 2 or more people which shows little change from 2011 (13%).

- The vast majority of respondents are providing care for over 35 hours per week (71%) compared to 78% in 2011.

- The number of respondents providing care for between 20-34 hours per week has doubled from 6% in 2011 to 12% in 2014.
2.8 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.

Respondents identified a variety of different duties.

- The most common (69%) was practical care (prepared meals, shopping). This was followed by supervision (65%), help in dealing with benefits 64%, and help with financial matters 61%.

- The least frequently reported help was physical health (e.g. help with walking, get up/down) which was identified by 37% of respondents.

Results show a significant rise across all identified areas.

- The largest rises were in the ‘administering of medicines’ up from 32% in 2011 to 48% in 2014.

- Help with paperwork and financial matters up from 38% in 2011 to 61% in 2014

- Dealing with care services and benefits up from 42% in 2011 to 64% in 2014.
2.9 Relationship with Cared for Person

In 2011 the majority of survey respondents (45%) cared for their son/daughter (own, adopted or step). In 2014 this was still the highest recorded relationship but it had fallen to 35% of respondents.

- There was an increase in the number of respondents caring for a parent/parent in law from 15% (2011) to 21% (2014)
- There was an increase in partner/spouse/cohabitee from 24% (2011) to 34% (2014).

(See ‘Relationship with Cared For’ graph on next page)
2.10 Gender of Cared for Person

As in 2011 the majority of carers said the person they were supporting was male. There was an increase from 51% (2011) to 56% (2014).
2.11 Age of Cared for Person

There was very little change across the age bands of the cared for between 2011 and 2014 with two exceptions –

- Those caring for people aged under 16 fell from 17% (2011) to 9% (2014).
- Those caring for people aged over 56 increased from 39% in 2011 to 50% in 2014.

![Age of cared for](chart.png)

2.12 Issues Faced by Those Being Cared for

- In 2011 learning disability was identified by about half of all respondents (48%) as being the main condition of the cared for and learning disability was highest in the rank order. In 2014 learning disability was identified by 24% of respondents and it ranked 4th highest.
- The highest ranking condition of the cared for in 2014 is mobility impairment / mobility issues with 54% of respondents
- Mental Health condition is ranked 2nd highest (27%)
- Long standing illness (HIV, Cancer, and Dementia) is ranked third highest (24%)
• Substance Misuse (drug and alcohol) shows the greatest overall increase having been identified by 1% of carers in 2011 and 8% in 2014.

2.13 Benefits

• The majority of carers (81%) said that they were aware of the benefits available to the person they care for, this compares to 68% in 2011.
• 89% of respondents reported that the person they care for claims benefits, this compares to 82% in 2011.

• 80% of respondents said that they provided practical help to the person they care for in order to claim the benefits they are entitled to (77% in 2011).
• 60% of carers were aware of the benefits available to support them in their caring role. This is down from 68% in 2011.

![Bar chart showing awareness of benefits availability from 2010/11 to 2013/14.]

• Of those carers aware of the benefits available to support them in their caring role, 46% said that they claimed them. This is down from 65% in 2011.

![Bar chart showing benefits claimed from 2010/11 to 2013/14.]
• Of those not claiming benefits 44% of carers reported that they were not entitled to do so (down from 72% in 2011).

• Almost a quarter, 24% proportion of carers, did not claim because they worried it might affect the benefits of the person they care for.

2.14 Impact of Caring on Personal Finances

• In the past 12 months 50% of respondents said that their caring role had caused them financial difficulties.
• Of those 20% have had to give up paid employment compared to 10% in 2011.

• 13% felt that they had reduced promotion/training opportunities at work because of their caring role compared to 7% in 2011.

• The greatest reported change (from 17% in 2011 to 54% in 2014) was in the number of respondents who had to use their own money and savings to pay for equipment and services for the cared for.

2.15 General Health of Carer

• Overall 69% of carers reported their health as ‘average to very poor’. This compares to 58% in 2011.

• The proportion of carers reporting their health as ‘good to very good’ has fallen from 39% in 2011 to 30% in 2014.

• In 2010 58% of carers said their health was worse as a result of their caring role. This has increased to 74% in 2014.

(See ‘General Health of Carer’ graph on next page)
2.16 How Caring has Affected Health

- Feeling tired was at 78% the highest ranking response as it was in 2011 when 73% of carers indicated this.

- The biggest increase in reporting was related to the impact of the caring role on carer’s mental health and wellbeing which registered as 16% in 2011 and 43% in 2014.

- A ‘general feeling of stress’ also showed a significant increase. It was identified by 58% of carers in 2011 and by 73% in 2014.

- The number of carers describing themselves as ‘feeling depressed’ has increased from 48% in 2011 to 55% in 2014.

Reported negative health impacts have increased across all listed options.

(See ‘How Caring has Affected Health’ graph on next page)
• Just under half (48%) of carers say that their own health problems have affected their ability to adequately care. This compares to 45% in 2011.
2.17 Accessing Healthcare Services

- There has been an increase in the number of carers reporting that they have time to visit their GP when necessary increasing from 69% in 2011 to 79% in 2014.

- The majority of carers 69% report that they can ask for help when they are ill which is comparative to the 2011 figure of 70%.

2.18 Registering as a Carer

- There has been an increase in the number of carers who are aware that they can register as a carer with their GP. This is up from 40% in 2011 to 54% in 2014.
• Of those who are aware that they can register 63% have done so. This is a decrease from 2011 when 79% of carers had done so.

![Graph showing percentage of carers who have registered as carers with their GP]

**2.19 Awareness of Support Services**

• Most carers (58%) are aware of where to go to access support to help them in their caring role. This is slightly lower than the 2011 figure of 61%.

![Graph showing percentage of carers who are aware of where to access support]

2.20 Type of Support Accessed by Carers

We asked Carers which type of support they had accessed over the last 12 months.

- Whilst there are differences across responses between 2011 and 2014 the overall pattern remains the same.

- For example the highest ranking was ‘general information, advice or support’ in 2011 which 48% of carers reported accessing regularly or occasionally. This compares with 2014 when again it ranked highest with 49% of carers reporting accessing it regularly or occasionally.

<table>
<thead>
<tr>
<th>Type of Support</th>
<th>% 2013/14</th>
<th>% 2010/11</th>
<th>Ranking 2013/14</th>
<th>Ranking 2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>General information, advice or support</td>
<td>49%</td>
<td>48%</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Informal emotional support (e.g. talking to a friend or neighbour)</td>
<td>44%</td>
<td>44%</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Short breaks / support to help you take a break from caring</td>
<td>32%</td>
<td>30%</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Carer support groups</td>
<td>31%</td>
<td>25%</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Informal practical support (e.g. help from a family member with hospital visits)</td>
<td>30%</td>
<td>32%</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Counselling / someone to talk to in confidence</td>
<td>27%</td>
<td>20%</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Health care / support (e.g. from your GP,PCT)</td>
<td>27%</td>
<td>32%</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Financial support (e.g. Carers Allowance)</td>
<td>23%</td>
<td>32%</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Social events / leisure activities for carers</td>
<td>22%</td>
<td>20%</td>
<td>9</td>
<td>10</td>
</tr>
<tr>
<td>Welfare Rights support (e.g. advice on benefits for carers)</td>
<td>20%</td>
<td>24%</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Advocacy for carers (helping carers to ‘speak up’ either directly for themselves or with an advocate)</td>
<td>11%</td>
<td>6%</td>
<td>11</td>
<td>14</td>
</tr>
<tr>
<td>Practical help, for example with household tasks</td>
<td>10%</td>
<td>15%</td>
<td>12</td>
<td>11</td>
</tr>
<tr>
<td>Training for carers (e.g. mental health, caring for someone who has had a stroke)</td>
<td>9%</td>
<td>10%</td>
<td>13</td>
<td>12</td>
</tr>
<tr>
<td>Wellbeing services (e.g. complementary therapies, relaxation)</td>
<td>9%</td>
<td>10%</td>
<td>14</td>
<td>13</td>
</tr>
</tbody>
</table>
2.21 Type of Organisations Respondents Received Support From

The four most significant sources of help and support remain the same.

<table>
<thead>
<tr>
<th>Organisations which carers use for regular or occasional support</th>
<th>2013/14</th>
<th>2010/11</th>
<th>Ranking</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family, friends, neighbours</td>
<td>59%</td>
<td>52%</td>
<td>1</td>
</tr>
<tr>
<td>Carers support services e.g. GCA</td>
<td>55%</td>
<td>44%</td>
<td>2</td>
</tr>
<tr>
<td>GP or practice staff</td>
<td>39%</td>
<td>41%</td>
<td>2</td>
</tr>
<tr>
<td>Local Council / Social Services</td>
<td>37%</td>
<td>41%</td>
<td>4</td>
</tr>
</tbody>
</table>

- There has been a significant increase in the number of carers reporting that they seek help and support from family and friends and carer support services (e.g. Gateshead Carers Association and Crossroads Care Gateshead)

- There has been a slight decrease in the number of carers reporting that they seek support from GP / practice staff and the Council /social Services.

2.22 Cultural Barriers or Difficulties in Accessing Services

We asked if respondents found any cultural barriers or difficulties when accessing support services to help carers in their caring role.

- Responses for 2011 and 2014 were identical with 95% of respondents in both years reporting they experienced no difficulties.

This is to be expected in that the vast majority of respondents are white British. Of those carers identifying cultural barriers or difficulties when accessing support a range of responses were received.

<table>
<thead>
<tr>
<th>Cultural Barriers</th>
<th>2013/14</th>
<th>2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of cultural appropriateness of the service</td>
<td>7%</td>
<td>27%</td>
</tr>
<tr>
<td>Lack of women-only services</td>
<td>0%</td>
<td>13%</td>
</tr>
<tr>
<td>Language barriers</td>
<td>14%</td>
<td>20%</td>
</tr>
<tr>
<td>Racism and prejudice on the part of the provider</td>
<td>14%</td>
<td>0%</td>
</tr>
<tr>
<td>Lack of confidentiality</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Misconceptions and stereotyping of particular ethnic groups</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Lack of awareness on the part of the service users</td>
<td>50%</td>
<td>13%</td>
</tr>
<tr>
<td>Stigma associated with certain illnesses within some communities</td>
<td>50%</td>
<td>27%</td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>36%</td>
<td>13%</td>
</tr>
</tbody>
</table>
2.23 Emergency Care

- There has been a decrease in the number of carers saying that they have an emergency care plan in place should they fall ill or be unable to continue their caring role, down from 46% in 20011 to 32% in 2014.

<table>
<thead>
<tr>
<th>Are you aware of the Emergency Care Scheme?</th>
<th>2013/14</th>
<th>2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>32%</td>
<td>46%</td>
</tr>
<tr>
<td>No</td>
<td>68%</td>
<td>54%</td>
</tr>
</tbody>
</table>

2.24 Equipment

- Just over a third 37% of carers reported that the person they care for needed special equipment (e.g. mobility/walking aids/stair lift) and this is similar to 2011 (35%).

- In terms of being able to access or receive the appropriate equipment there has been a decrease in the number of carers reporting that they are able to access it from 92% in 2011 to 72% in 2014.

*(See ‘Access to Appropriate Equipment’ graph on next page)*
Likewise there has been a significant fall in the number of carers who report that they are able to receive financial support to help access this equipment from 67% in 2011 to 41% in 2014.

### 2.25 Short Breaks from Caring

We asked carers if during the last 12 months they had accessed any support or services to help take a break from caring, excluding help from family or friends.

- 13% of carers responded that they had accessed a break lasting between 1 and 24 hours
• 20% of carers responded that they had accessed a break lasting more than 24 hours.

Of those accessing breaks;

• 72% had a break away from the person they care for compared to 79% in 2011 and 28% took a break with the person they care for compared to 21% in 2011.

Of those not accessing a break;

• the main reason given (42%) was that they ‘did not know how or where to access a break’ compared to 27% in 2011
• the number of carers responding that they ‘don’t need a break from their caring role’ fell from 42% in 2011 to 31% in 2014

• the number of carers responding that they did not ‘want to leave the person they care for’ remained steady at 34% in 2014 compared to 36% in 2011

• there was a significant increase in the number of carers who responded that ‘they cannot meet the costs associated with taking a break’ which rose from 19% in 2011 to 20% in 2014.

2.26 Carers Assessments

We asked carers if they were aware of a Carers Assessment and the fact that they were entitled to one.

• The response from 2011, when 50% of carers responded that they were aware of Carers Assessment, showed little change in 2014 with 49% of carers responded that they were aware.

(See ‘Awareness of Carers Assessment’ graph on next page)
We then asked ‘Have you had a Carers Assessment?’

- 25% responded that they had which is a significant fall from 34% in 2011.

Of those who had a Carers Assessment we asked if they had received the support / help they needed.

- In 2011 51% of respondents ‘agreed strongly’ or ‘agreed’ that they had received the support / help they needed following a Carers Assessment.
- In 2014 this had fallen to 9% of respondents.
We asked Carers if they felt involved or consulted as much as they wanted to be in discussions about the support or services the person they care for receives.

- 45% responded that they ‘always’ or ‘usually’ felt involved. This is similar to the 2011 response which was 43%

- 9% of carers responded that they ‘had never been involved or consulted’ which is an increase from the 5% of respondents in 2011

- 28% of carers responded that there had been no discussions in the last 12 months which is similar to the 2011 figure of 27%
2.27 Carer Quality of Life

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

- 78% of carers described their quality of life as ‘average’, ‘poor’ or ‘very poor’ which is a significant increase from the 2011 figure of 70%.

- 22% of carers described their quality of life as ‘excellent’ or very good’ which is a significant fall from 2011 when 31% 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.

- 81% of carers reported that they had done so which is a significant increase from the 2011 figure of 68%
Carers were then asked to give more detail about their quality of life. (See table below).

<table>
<thead>
<tr>
<th>Carer Quality of Life</th>
<th>Strongly Agree and Agree 2013/14</th>
<th>Strongly Agree and Agree 2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>I feel appreciated and valued as a carer</td>
<td>42%</td>
<td>64%</td>
</tr>
<tr>
<td>I am able to spend my time as I want, doing things I value or enjoy</td>
<td>19%</td>
<td>35%</td>
</tr>
<tr>
<td>I have the space and time I need to be myself</td>
<td>21%</td>
<td>35%</td>
</tr>
<tr>
<td>I have as much control over my daily life as I want</td>
<td>17%</td>
<td>35%</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>33%</td>
<td>48%</td>
</tr>
<tr>
<td>I have as much social contact as I want with people I like</td>
<td>27%</td>
<td>42%</td>
</tr>
<tr>
<td>I feel I get sufficient breaks from caring</td>
<td>19%</td>
<td>36%</td>
</tr>
<tr>
<td>I have a life of my own outside of my caring role</td>
<td>28%</td>
<td>33%</td>
</tr>
<tr>
<td>I often feel isolated or lonely</td>
<td>31%</td>
<td>24%</td>
</tr>
<tr>
<td>I feel I have lost my independence/freedom</td>
<td>31%</td>
<td>28%</td>
</tr>
<tr>
<td>I feel I have sufficient time/energy to participate in training and education</td>
<td>18%</td>
<td>22%</td>
</tr>
<tr>
<td>My caring role allows me to continue with the paid work that I’d like to do</td>
<td>20%</td>
<td>22%</td>
</tr>
<tr>
<td>I worry about what would happen to the person I care for if I was not there</td>
<td>66%</td>
<td>74%</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>29%</td>
<td>39%</td>
</tr>
</tbody>
</table>

There has been a worsening across all 14 carer quality of life indicators.

Of these, carer quality of life has worsened significantly across 5 indicators including:

- ‘Feeling valued and appreciated as a carer (64% in 2011, 42% in 2014)
- ‘Having the space and time to be myself’ (35% in 2011, 21% in 2014)
- ‘Having as much control of my daily life as I want’ (35% in 2011, 17% in 2014)
- ‘Having the time I need to look after myself’ (48% in 2011, 33% in 2014)
- ‘Having as much social contact as I want with people I like (42% in 2011, 27% in 2014)
2.28 Wider Economic Climate

Carers were asked if the recession and economic downturn has had an impact upon their own personal circumstances and their role as a carer. 33% of carers chose not to respond to this question (compared to 20% in 2011)

- There has been a significant rise in the number of respondents indicating that the recession and economic downturn had impacted on their personal circumstances (41% in 2014 compared to 30% in 2011)
- There has been a significant fall in the number of respondents indicating that the recession and economic downturn had impacted on their role as a carer (from 50% in 2011 to 26% in 2014)

Carers were then asked to provide more details about their concerns about anticipated cuts to public services which may include social care services and support for carers.

- High levels of concern remain across all 6 answer options

(See ‘Carer Concerns’ table on next page)
### Carer Concerns

<table>
<thead>
<tr>
<th>Carer Concerns</th>
<th>Strongly Agree and Agree 2013/14</th>
<th>Strongly Agree and Agree 2010/11</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am concerned about the anticipated cuts to public services</td>
<td>70%</td>
<td>77%</td>
</tr>
<tr>
<td>I worry that the anticipated cuts will put a greater strain on me as a carer</td>
<td>66%</td>
<td>68%</td>
</tr>
<tr>
<td>I worry that it will put greater financial pressure on me as a carer</td>
<td>64%</td>
<td>67%</td>
</tr>
<tr>
<td>I worry that I will not be able to get the support I need</td>
<td>65%</td>
<td>66%</td>
</tr>
<tr>
<td>I worry that the person I care for will not be able to get the support they need</td>
<td>70%</td>
<td>68%</td>
</tr>
<tr>
<td>I am concerned about cuts to specialist services, e.g. services offered to particular groups such as older people, women, BME groups</td>
<td>62%</td>
<td>68%</td>
</tr>
</tbody>
</table>

### 3. Conclusions

#### 3.1 Characteristics of Carers

The 2011 census indicated that are 22,220 carers in Gateshead which means that 11.1% of the population of Gateshead have a caring role. The number of Carers has increased by 5.1% over the last 10 years (around 1000 more than that recorded in the 2001 census)

Carers responding to the survey mainly care for one person who lives with the Carer and the vast majority (almost three quarters) are providing care for over 35 hours per week. Just under half of respondents were aged between 51 and 64.

Carers are most likely to be caring for their son, daughter or spouse / partner.

One quarter of Carers responding were aged over 65. An increasing number of Carers (44%) also consider themselves to have a disability which is significantly higher compared to the UK population as a whole which is 17.4% (2011 Census). The data suggests that most Carers are likely to describe themselves as retired. The number describing themselves as unemployed has doubled since 2011.
Carers provide a wide range of help and support with the most common caring tasks being practical care, supervision, help in dealing with financial matters. Since the last survey in 2011 there has been a significant growth in the number of Carers who helped with the management and administration of medicines and in dealing with care services and benefits.

### 3.2 The Financial Impact of Caring

Half of carers responding have said that their caring role has caused them financial hardship in the last 12 months. One in five carers has had to give up work because of their caring role and over half of carers are using their own money and savings to pay for equipment and services for the cared for. It is possible that further cuts to LA budgets will increase the financial pressures on carers.

### 3.3 Health of Carers

Caring clearly continues to impact on the health and wellbeing of carers. Almost three in every four carers – 75%, believe their health has deteriorated as a result of their caring role. The proportion of carers who describe their health as ‘average’ to very poor has grown significantly since 2011. There has been a significant reduction in the number of carers who describe their health as very good or excellent.

The vast majority of carers are reporting ‘tiredness’ and since 2011 there has been almost a threefold increase in the number of Carers reporting a negative impact on their own mental health. Over four Carers in every ten are reporting that caring is having a negative impact on their mental health. Over half of carers are describing themselves as depressed; three out of every four Carers are reporting ‘stress’.

These health impacts are affecting half of all Carers ability to adequately care.

### 3.4 Carers Quality of Life

Carers reported quality of life was poor in 2011 but in 2014 it is even worse with almost four out of every five Carers describing their quality of life as ‘average, poor or very poor’. In the survey, Carers were asked to give more detail across 14 quality of life indicators. Across all indicators the situation is worse now than it was in 2011. There have been significant falls in the extent to which carers feel valued and
appreciated, having space and time to be themselves, the amount of control they have over their daily lives, having time to look after themselves and a reduction in the time they have for social contact with people they like.

3.5 Support Services

The support Carers receive from families and friends remains strong. Increasingly, comparing survey results from 2011 with results from this survey, more Carers are turning to carer support agencies for support and fewer, although still a significant number, are turning to the LA / Social Services and GP/ Practice staff.

Worryingly, there has been a significant increase in the number of carers who do not have an emergency support plan with almost one in two Carers having no plan in place.

More Carers are aware that they can register as a carer with their GP but fewer are doing so. More Carers are reporting that they have time to visit their GP than previously. Why this should be the case is unclear but it could be related to the overall worsening of carer health outlined earlier.

In terms of support there remains a considerable need from Carers for information, advice and guidance.

3.6 Carers Assessments

With around one in two Carers reporting that they know about the Carer Assessment and their right to have one there has been little change since 2011.

However there is a reported significant drop in the number of Carers who have had a Carers Assessment.

Of those who reported that they had been through the Carers Assessment process there are strong indications that Carers do not receive the help and support they need. In 2011 one in two Carers reported that they agreed or strongly agreed that they had received the help and support they needed following a Carers Assessment compared to around one in ten Carers in 2014.
3.7 Carer Involvement

There has been little improvement in the extent to which Carers feel involved in discussions about support or services the cared for receives with around half reporting feeling uninvolved.

3.8 Wider Economic Climate

Carers remain concerned about future cuts to the budgets of statutory organisations including social care. The economic downturn is impacting on their personal circumstances. Having said that the reported impact of cuts on their role as a Carer, whilst remaining high, has halved since 2011.

4. Summary

Whilst an enormous amount of work has been done within Gateshead, through:

- the members of the Gateshead Carers Partnership
- the commissioning of voluntary sector organisations by the Local Authority and Gateshead Clinical Commissioning Group to deliver carer support services
- the innovative work of the VSOs in delivering carer support and securing funding for carer support services from a range of other, non-statutory, sources.

The survey demonstrates that overall, life for carers’ is becoming more difficult across all areas. Since the last survey;

- The health of carers has worsened
- The mental health and wellbeing of carers has worsened
- The financial position of carers has worsened
- The quality of life for carers has worsened
4.1 Planning for Carer Support in the Future

The 2014 Gateshead Carers Survey highlights a clear and urgent need for more support for carers and that carers themselves are increasingly choosing to receive support from the voluntary sector. The complexity of the caring role and the amount of time carers are providing unpaid care is increasing. The impact of providing this care on the health and wellbeing of carers means thousands of carers are approaching the point where they will no longer be able to provide care.

At the same time increased need for care clashes with cuts in services. Age UK examined the impact of a 7% real terms cut to local authority funding and concluded it would lead to a 25% rise in the hours of personal care provided by carers.

Whilst the Care Bill is welcomed by this organisation for the extra rights it brings to Carers the implementation of it will further stretch local authority budgets and that of Gateshead CCG through joint commissioning of carer services through the Better Care Fund.

The Care Bill, when it becomes law later this year, will mean that;

The support and services for Carers arranged by local authorities will need to be increased substantially if the plans set out in the Care Bill 2013 are to be met. In 2010/2011 the government’s ‘Carers’ Grant’ allocation to local authorities totalled £256 million (plus £25 million for emergency support for Carers) (Carers UK, 2010), under arrangements first established in 1999. In 2010-2011 local authorities spent a total of £642 million on ‘other’ adult social care (DCLG, 2012: 28).

Under the planned new legislation, this expenditure would need to rise significantly to meet the likely support needs of all Carers providing 50+ weekly hours of care. Councils would need to double the support they provide to older carers (aged 75+), treble the support they give to carers aged 18-74 and increase five-fold their support for young carers. This would enable them to provide information, advice and services at the level which carers supported by local authorities received in 2010-11’.
(Local Authority Support for Carers; Implications of planned changes in the Law. Care Connect –the Social Care Innovation Hub, University of Leeds 2014).
With on-going government imposed cuts to Local Authority budgets and Gateshead CCG facing a potential cut in funding of £26 million from 2016 the economic position remains difficult and without extra support the position of carers will worsen.

The key issue is not whether carers need more support, the survey clearly demonstrates they do, but rather how statutory bodies within Gateshead, including the Local Authority and Gateshead Clinical Commissioning Group, can work with the Voluntary Sector to deliver the right carer support in the most efficient and effective way for the benefit of as many carers as possible.

**The commissioning of carer support services should;**

‘Adequately value carers’ contribution and take into account the cost of failing to support carers’

(Valuing Carers 2011- Centre for International Research on Care, Labour and Equalities – University of Leeds)

At the same time voluntary sector organisations supporting carers need to continue to source additional funding from grant making bodies to develop support services through innovative practice.

To do nothing by simply maintaining the level of support currently provided is not an option. Likewise cutting funding for the support of carers is not an option as demand for support grows at an exceptional rate. Gateshead Carers Association experienced a growth in demand for information, advice and support of 82% in the last 12 months.

**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

May 2014

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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