

# Strategic Review of Carers Services in Gateshead: Understanding the Needs of Unpaid Carers

**March 2017**



## **Involve North East**

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# Executive Summary

## 1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (CCG) and Gateshead Council are currently undertaking a strategic review of the provision of services available to unpaid carers in Gateshead. As part of the review process the CCG and Council want to understand how they can support the needs of unpaid carers and develop future services. The views of carers have been gathered via the Local Engagement Board (LEB), an open access online questionnaire and the engagement activities discussed within this report. This report should therefore be viewed in conjunction with the results of the online survey and LEB activity.

Ninety people shared their views as part of this specific project via participatory engagement (63) and in-depth interviews (27). The key objectives of the project were to:

- Explore what services and support carers living in Gateshead currently receive
- Explore whether these services are offering adequate support and if any needs are going unsupported
- Identify how future delivery of carers services could be developed

## 2.0 Findings

### 2.1 Identifying as a carer

All 27 carers who took part in an interview were asked at what point they identified themselves as a carer and for just over half this was after their caring role had begun. For most the trigger point to asking for support was when the health of the cared for person deteriorated whilst for a minority, financial pressures were the catalyst.

### 2.2 Support for carers

#### 2.2.1 Emotional support and counselling

Emotional support was provided through a variety of formal and informal settings such as peer support groups, run by the Carer's Trust and Gateshead Carers, school support for young carers and befriending and counselling services. Carers appreciated being able to share their feeling with peers who understood what they were going through, they reported gaining in confidence and enjoying developing interests, such as the craft group, outside of their caring role. However, a lack of information about such services was highlighted as the main issue with some people never having heard of this support whereas for others the information was not timely. Moreover, it was suggested that people should be offered the opportunity to attend courses more than once and there should be more regular contact from the Carer's Trust to discuss opportunities.

#### 2.2.2 Brokerage

Very few people had heard of brokerage support and it was reported that despite being planned, a service was never established by the Council. All three carers who had tried Direct Payments found it extremely complicated and would have benefitted from support and advice covering the legalities of becoming an employer and safeguarding mechanisms.

#### 2.2.3 Advocacy

Advocacy support completing forms, accessing financial help and gaining residence

orders for example were appreciated. However half of comments highlighted issues. Again the main concern was a lack of awareness about what advocacy services are and therefore how to access them. It was also suggested that the service lacks capacity. One person also commented on the lack of familiarity amongst carers of the term itself. A lack of continuity of support in terms of social workers was also mentioned. For kinship carers, social worker support ends as soon as full guardianship is granted and a named contact to call on if any related issue arose was requested.

#### 2.2.4 Access to health and well-being

Carers identified general support from carer organisations and specific classes they attended as well as support from hospitals and GPs to access appointments in particular. However, again about half of carers responding to this section identified issues in this respect and the joint main issue was a lack of awareness that they could receive additional support to access these services. Inflexibility in terms of accessing GP appointments was the other main issue however two people reported never being asked by their GP that they are a carer.

#### 2.2.5 Caring support and training

Eight people identified courses they had been on such as stress awareness, first aid training and moving and handling. Again however others were not aware that they could have the opportunity to access any training to help them in their caring role and requested first aid and moving and handling courses.

#### 2.2.6 Information

Despite the engagement around many of the interventions highlighting awareness of support as an issue, the majority of carers when asked directly about information, identified a variety of places to access it with most contacting organisations directly rather than being signposted. Gateshead Carers and the Carers Trust were mentioned most frequently and the information provided was felt to be thorough and was very much appreciated. Timely access to information and advice was also highlighted and is particularly important at the start of the caring role.

However, carers also commented negatively in this respect. Most felt that there was enough information available but people simply did not know how to access it or were not supported to access it by professionals. On several occasions carers made the point that “you don’t know what you don’t know”. There was also an expectation from a minority of carers that information should be provided by the Council. Others asked for a named person to contact for information and advice.

#### 2.2.7 Carers shaping policy and services

Only fourteen people felt that they had been involved in shaping policy and this was particularly true of the young carers through surveys, discussions and buddying. Others had lobbied the Council and NHS against a reduction in services or were carers champions. A lack of awareness of the opportunities to get involved was an issue whilst one carer felt that Gateshead Carers and the Carers Trust were not in a position to support any lobbying of the Council and CCG as they are funded by them.

#### 2.2.8 Young carers specific services

Whole-family support was only mentioned by three young carers. No conclusions can therefore be drawn around this intervention. In terms of education and one-to-one support the vast majority of young carers had experienced support either at school drop-ins and access to counselling or at the Carers Trust at homework catch-up sessions for

example. However, several people mentioned no or very little support or leniency at school from teachers. Activities and clubs were accessed by most young people via the Carers Trust who appreciated the space they got and the activities on offer. It was suggested however that funding cuts have led to a reduction in activities.

#### 2.2.9 Changes and transitions

Of the fifteen people who discussed this intervention only four reported positive experiences. Others felt that they had not been fully supported and this was particularly true of kinship carers at the beginning of their caring role. For another the loss of paediatrician support was particularly difficult. Transitioning to independent living was difficult for two carers who did not feel they had been supported. One was concerned about the quality of care their son was now receiving whilst another has been trying to organise independent accommodation for their son and is struggling to communicate with the Council and find suitable facilities which is impacting on family life.

#### 2.2.9 Emergency support

Only nine carers commented on support around planning for emergencies and two actually had plans in place that they were happy with. Three others had plans set up but two lacked confidence in the Mental Health Team to act on them. One carer asked for support to set up a plan.

#### 2.2.10 Breaks

When people first identified themselves as carers, breaks were the most commonly identified support they wanted, usually in the form of a few hours a week and this was more important, the longer the caring role continued. In terms of their current situation time away from their caring role was the second most valued support that interviewees received. Carers identified breaks that they had access to which ranged from a couple of hours away from the cared for person to holidays funded by Take a Break for example. They appreciated being able to take time out from their caring role to simply carry out daily chores or meet up with people with similar experiences and have fun.

Again however some identified issues with accessing breaks. A lack of awareness of how to actually access breaks was mentioned most frequently and there was some confusion over whether the Take a Break fund could be used more than once or actually still existed. It was felt that GPs were best placed to distribute information to carers on all aspects of caring. Some wanted access to more breaks particularly as they got older whilst others found it difficult to organise so far in advance. Access to suitable accommodation for the cared for person was also an issue as was physically getting to the location.

#### 2.2.11 Peer and community support

Carers generally commented positively on this intervention and identified a variety of groups they attended. They appreciated the opportunity to talk to others who had had similar experiences, share problems and relax in a trusted and non-judgemental environment. Asylum seeker support groups also gained language skills. However accessing support groups was an issue for some. A Muslim Women's Group reported that although they knew of groups they had never actually attended any despite feeling their current social group did not support their caring roles. A lack of transport and groups being on at unsuitable times were highlighted by two people.

#### 2.2.12 Access to benefits and financial support

This was particularly important for some at the start of their caring role. Support was

provided through Gateshead Carers and social workers in particular. However, about half of those commenting, highlighted concerns. A lack of information about what benefits are available and a perceived lack of support were the main issues with one carer accepting the tier they had been put on because at the time they had no support and did not know how to challenge it. Moreover it was thought that this support and financial help stopped when carers became pensioners.

#### 2.2.13 Access to work/training

Fourteen carers discussed this support with the vast majority citing support from their employers who allowed them flexibility to attend appointments for example or work outside of office hours, one NHS worker got five days carers leave per year. However half of this group did not receive any support; they had to buy extra holidays or take unpaid leave and were not assessed for stress. It was suggested that carers be allowed to take time off for their role without having to make the time back.

#### 2.2.14 Housing support

Only eight carers commented on this support with three highlighting good support that they had received around advice when moving and adaptations being installed. There was however one example of carers having to fight for adaptations, another being offered inappropriate equipment and a third citing a poor assessment experience where they got the cared for person's name wrong, rushed the assessment and have not delivered the equipment on time. One carer suggested that that the Council develop a register of vulnerable households so that they can give priority to carer's homes when for example a boiler breaks down.

#### 2.2.15 Support from Gateshead Council

Evidence above highlights positive support from social workers in particular but interviewees also highlighted issues which they had regarding support from the Council. Their responsiveness was a particular concern with two carers reporting social workers not being replaced resulting in their cases stalling, others reported having to chase the Council for referral letters and call-backs. Having to wait a considerable time for assessment reports was also mentioned. Other issues related to the quality of the service provided. One participant caring for their relative with a learning difficulty was frustrated with inappropriate communications as they were continually sent surveys even though he cannot read. Another asked for a face-to-face carer's assessment and instead the Council tried to complete it over the telephone.

### 2.3 Support for cared for people

In addition to support for themselves, interviewees were asked about the support their loved ones received. When the caring role first started, interventions for the cared for person were the things carers most wanted, for example, the right medication, therapies or a reduction in isolation and generally support for the cared for person increased with the length of time caring.

People accessed day centres, paid care at home and adaptations most frequently and day centres or activities for their loved one was the thing that carers most valued. They appreciated the peace of mind they got from this support and for the cared for person, opportunities to socialise and have a routine. However there were barriers to accessing this support. For day centres or activities sessions the length of time it took to organise and a lack of opportunities available (including those for young adults) were highlighted and control over the timing and the length of visits were issues in terms of care at home. Better communication with health and social care professionals was also requested as

was access to more medical care.

Carers also highlighted a reduction in services particularly regarding mental health support. They no longer had a named social worker or access to activities outside of the home as they were no longer part of the Outreach Team. Related to this, there was also a belief from three carers that day centres in the area were under threat of closure and they emphasised the importance of these services for both themselves and especially the cared for person.

### **3.0 Recommendations**

#### **3.1 Key recommendation**

**Information** – there is a need for greater promotion of all of the interventions available to carers in Gateshead as highlighted within the Carers' Hub tool. This should include the scope of the support or service, eligibility, and how to access it. This information should be available to carers when they are first identified as such. It is recognised that there is not a formal process of identification therefore any professional who is in contact with the carer should have access to this information for distribution. The information should also include contact numbers for Gateshead Carers and the Carers Trust to enable carers to talk through their needs. Once a year carers should receive a review from workers where they go through a checklist of all of the support available to make sure they have the most up-to-date information available to them and are accessing all the support they require.

There was an expectation from some that they should receive information from the Council. It is suggested therefore that the roles and responsibilities of the Council and any services and support that it has commissioned, is also widely publicised.

#### **3.2 Interventions**

**Brokerage** - There is a need for greater support to enable carers to manage personal budgets. As funding sits with the local authority it is suggested that there is access to dedicated support within the Council. Access to a website including all of the services could be set up but alongside this workers should be available to talk to carers through the process. This should include making clear from the outset the legalities involved such as becoming an employer and any safeguarding requirements.

**Access to health and wellbeing** - GPs should have greater awareness of which of their patients are carers and provide support accordingly. There should be a protocol in place whereby patients are directly asked whether they are a carer periodically and this should be recorded and accessible to all practice staff. Carers could be given flexibility in accessing appointments and be offered an annual health check as standard, regardless of age.

**Caring support and training** - There is demand for training around first aid and moving and handling in particular. It is suggested that all carers are offered first aid training in the first instance and at the beginning of their caring role. These and any courses should be offered at a variety of times including evenings and weekends to enable accessibility for all. Carers should also be able to attend courses more than once.

Before the cared for person returns home for the first time after their health has deteriorated it is suggested that the cared for person should be asked whether they require any specific training or advice.

**Support for young carers** - Most young carers feel supported within school but for some there is not or very little acknowledgement of their role as a carer. Schools should have a register of all young carers and flexibility should be given to them in terms of timekeeping and homework. Counsellors should be available to young carers at school outside of lesson time as should extra support from teachers.

It was felt that funding for activities had reduced. Consider providing additional funding in this respect.

**Changes and transitions** - There were requests for more support for carers during transitions which were often very stressful. In particular it is suggested that kinship carer support be reviewed to ensure that support is available from the outset and this includes any financial support.

Timely information is also needed in advance of transition periods to inform carers of what changes to support they should expect. As carers get older they should also be informed of any changes to support and particularly financial changes associated with them reaching pension age.

Information around the process for transitions should also be made available to carers at the appropriate times, for example, in advance of a carer getting to the stage where they can no longer look after the cared for person and before the transition to independent living.

**Emergency support** - It is suggested that there needs to be greater explanation around emergency plans so that carers know exactly what they mean and when to implement them.

**Breaks** - In relation to the Take a Break fund there was some confusion over whether it still existed and whether it could be used more than once. If any services end or have rules about use this information should be communicated to carers as part of the process outlined in section 4.1 above.

More support to access breaks which should also take into consideration any accessibility requirements and the needs of working carers, is also needed.

More generally the research identified the value unpaid carers place on short term respite, even if only for one or two hours per week, allowing them to carry out their own daily tasks. This should be acknowledged.

**Peer and community support** - Despite knowing of groups available at Gateshead carers a group of Muslim women carers did not access any support. It is suggested that an audit could be carried out of the support groups available, looking at the types of carers that are supported to ascertain whether there are any gaps in provision. Furthermore, further research could be carried out with this group to understand their group support needs.

**Access to benefits and financial support** - As part of the annual review

suggested in section 4.1 above, a review of the benefits carers and the cared for person are receiving should also take place.

**Access to work and training** - There is a need for greater awareness amongst employers around the number of carers they employ and the possible impact of their caring role. It is suggested that a Carer's Passport be promoted within all workplaces.

There was no evidence of support to access training. Access to this support should be reviewed to ensure that people are being offered training where appropriate.

**Housing support** - It is suggested that the Council develop a register of vulnerable households so that they can give priority to carer's homes when for example a boiler breaks down.

**Support from Gateshead Council** - The Council should put in place systems to ensure that cases are passed on to other staff when social workers leave.

It is also suggested that a protocol is established which outlines the number of days carers or their loved ones should have to wait for telephone calls, referral letters, assessment reports etc. This should be accessible to all carers.

### 3.3 Support for cared for people

Day centres and activities for the cared for person are valued most by carers. There is felt to be a lack of opportunities available in this respect and a belief amongst some that they are being reduced and are at threat of closure. It is suggested that these services are maintained where possible and the Council acts to allay carers' fears.

The scope of any paid care at home should be clearly outlined before carers set-up any support. This should include whether there is any opportunity for changing the visits.



# Section 1- Introduction

## 1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (CCG) and Gateshead Council are currently undertaking a strategic review of the provision of services available to unpaid carers in Gateshead. As part of the review process the CCG and Council want to understand how they can support the needs of unpaid carers and develop future services. The views of carers have been gathered via the Local Engagement Board (LEB), an open access online questionnaire and the engagement activities discussed within this report. This report should therefore be viewed in conjunction with the results of the online survey and LEB activity.

## 1.1 Context

A carer can be defined as anyone who provides unpaid care for a friend or family member due to illness, disability, mental health problems or addiction and whom that person could not manage without. This can be a few hours a week to round the clock care.

The type of care that carers provide varies considerably. Carers UK's 2014 State of Caring survey found that the vast majority of carers (93%) provided practical help such as preparing meals, doing laundry or shopping. In addition, 87% provided emotional support or motivation, 85% arranged or co-ordinated care services or medical appointments and 83% managed paperwork or financial matters for the person they care for. For 71% of carers help with washing, dressing, eating or using the Toilet was also provided and 57% of carers helped them with their mobility around and outside of the home.

According to the 2011 Census, there are approximately 5.4 million people who identify themselves as unpaid carers in England, accounting for 10.2% of the population. In Gateshead this proportion is slightly higher with 11.1% of residents (22,220 people) providing unpaid care.

The time Gateshead carers spend caring for family or friends varies considerably; over half spend between one and 20 hours per week.

Number of hours spent caring per week	No. of carers	Percentage of carers (%)
1-19	12,588	56.7
20-49	3,381	15.2
50+	6,251	28.1
Total	22,220	100.0

Source: Census, 2011

However more recent data from the Personal Social Services Survey of Adult Carers in England 2014-15 revealed that almost one third (30.3%) of the 500 people questioned, spent over 100 hours per week caring for a family member or friend.

<b>Number of hours spent caring per week</b>	<b>Percentage of carers (%)</b>
0-9 hours per week	12.2
10-19 hours per week	15.0
20-34 hours per week	9.1
35-49 hours per week	5.8
50-74 hours per week	5.3
75-99 hours per week	4.9
100 or more hours per week	30.3
Varies - Under 20 hours per week	3.8
Varies - 20 hours or more per week	4.9
Other	8.8

Source: Personal Social Services Survey of Adult Carers in England (2014-15)

In terms of the services and support carers in Gateshead use, the table below shows that over half had accessed information and advice in the previous 12 months and one quarter had received support from carers groups or someone they could talk to in confidence.

<b>Support or services</b>	<b>Percentage of carers using service (%)</b>
Information and advice	52.2
Support from carers groups or someone to talk to in confidence	25.3
Support to keep you in employment	3.2
Training for carers	1.7

Source: Personal Social Services Survey of Adult Carers in England (2014-15)

Four hundred and eighty people had used Gateshead Social Services within the previous 12 months and were asked about their satisfaction with the support and services they had received. Over half (54.1%) were either extremely or very satisfied and a further 31.4% were quite satisfied with this support. However, a minority of 6.9% of carers reported that they were dissatisfied (either 'quite', 'very' or 'extremely'). The remainder were neither satisfied nor dissatisfied.

When asked about support in their caring role, over half of respondents (55.6%) felt that they were given encouragement and support. However, 31.1% said that they did not have enough and 13.3% felt that they had none at all.

## 1.2 The project

Involve North East (INE) was asked to assist with the engagement activity around the strategic review.

The overall aim of this project was to understand the needs of carers in Gateshead to inform the strategic review and help develop future services.

The key objectives of the project were to:

- Explore what services and support carers living in Gateshead currently receive
- Explore whether these services are offering adequate support and if any needs are going unsupported
- Identify how future delivery of carers services could be developed



# Section 2 - Methodology

## 2.0 Methodology

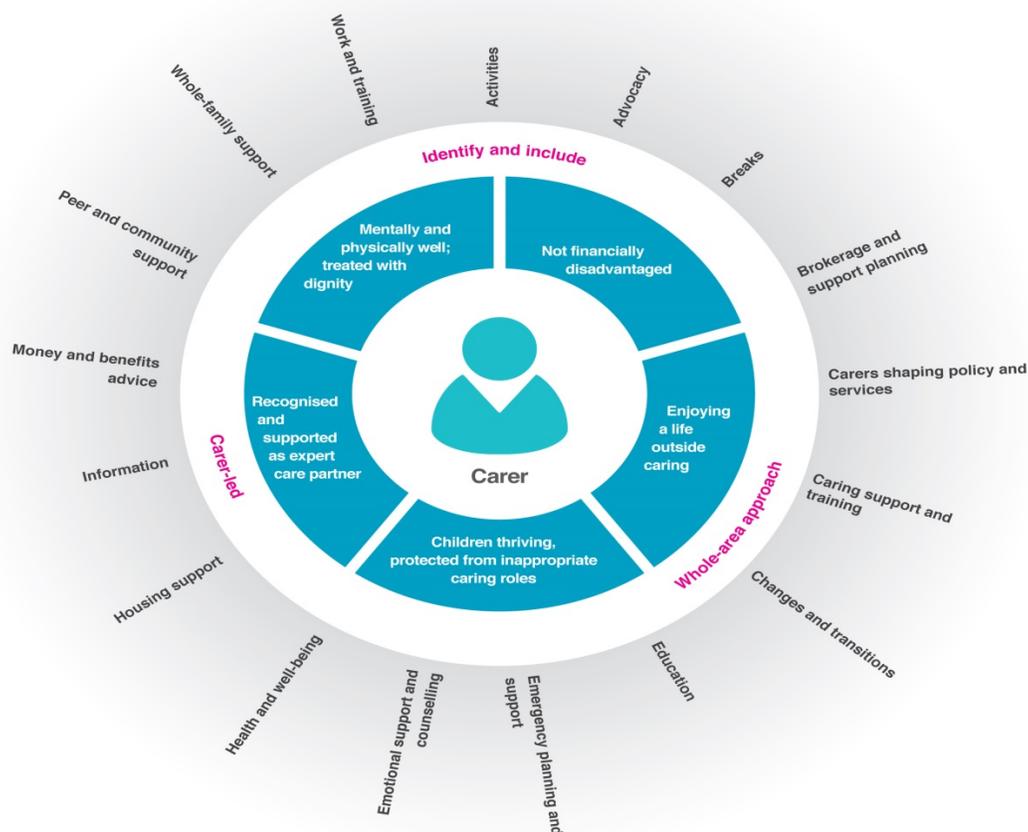
To meet the objectives of the project, two complementary qualitative techniques were required. In order to gain a depth of understanding of carers' needs and experiences a qualitative methodological approach was deemed to be the most appropriate, enabling the collection of meaningful data. Qualitative research is concerned with gaining an understanding of how people feel, their beliefs, reasoning and motivations and therefore fitted with the objectives of the research.

## 2.1 Participatory engagement

### 2.1.1 Carers' Hub commissioning tool

In order to ensure that the largest number of carers were able to give their views, a participatory engagement technique was employed. It involved INE staff facilitating interactive discussions with individuals who gave their views via eye-catching display boards and post-it notes.

The activity and corresponding questions asked of carers, was based on the Carers' Hub commissioning tool (see diagram overleaf). The Carers' Hub is a model of comprehensive carers support, developed by Carers Trust with assistance from the Association of Directors of Adult Social Services and funding from the Department of Health.



At the centre of the hub diagram are the outcomes of the National Carers Strategy for England. The white band represents a three-pronged approach that can be used to inform strategic planning, and the 17 spokes on the outside of the circle illustrate the complete range of interventions that every area needs in order to deliver the intended outcomes.

Participants were asked to attach post-it notes under each of the interventions that they have had experience of and give their views on what is good about them and where there are gaps in services and improvements could be made to help support them in their caring role.

Participatory engagement took place at:

- Pre-standing carers support groups
- Three drop-in sessions for working carers in Gateshead Civic Centre and NHS Newcastle Gateshead CCG offices
- Two organised sessions open to all, in Gateshead Civic Centre

Fifty-one carers were engaged in this way.

### 2.1.2 Young carers

A young carer is someone under the age of 18 who helps look after someone in their family, or a friend who is ill, disabled or misuses drugs or alcohol. As part of the engagement INE spoke to young carers. Those who were between 13 and 18 were able to take part using the Carers' Hub tool described above but for those under 13 years old a different method was employed.

Some young carers were asked to draw pictures and answer questions whilst others were simply asked questions. They drew pictures of their family, things they like to do generally and things they liked to do at the group (Young Carers Group at the Carers Trust). They were all asked:

- Who they help at home
- What they do to help
- Whether they can do things they like doing as much as they would like
- Who helps when they are at the group
- Whether they would like to attend more groups or activities

Sixteen young carers were engaged in this way.

## 2.2 In-depth interviews

To complement the participatory engagement and add depth to these findings, one-to-one interviews were also carried out by INE staff. Interviews allowed the exploration of issues arising from the questions asked, and the collection of richer and more detailed responses than was possible within the structure of the participatory engagement activity. The interviews also gave carers who do not usually attend support groups or services, the opportunity to share their views. For a copy of the interview questions, see Appendix 1.

Twenty-seven interviews took place (four people who took part in an interview also took part in the Carer's Hub engagement).

## 2.3 Pre-questionnaires

Everyone who took part in an interview or participatory engagement exercise was also asked to complete an individual short questionnaire which collected information specific to their situation and demographic data. See Appendix 2.

For a full participant profile see Appendix 3.

## **2.4 Participants**

Anyone who identifies themselves as an unpaid carer and is currently living or working in Gateshead was eligible to take part in the engagement including:

- Young carers
- Adult carers
- Working carers
- Parent carers
- Kinship carers
- Carers across BME groups
- Carers of a cared for person with mental health problems
- Carers of a cared for person with a disability
- Carers of a cared for person affected by substance misuse

The project also sought to engage with carers who are currently not receiving support.

## **2.5 Recruitment**

### **2.5.1 Attending pre-standing groups**

Pre-standing carer support groups were identified to take part in the project. This helped to minimise the impact on the participants' time and allow them to give their views in a setting that was familiar and comfortable to them.

### **2.5.2 Identification of individuals**

People known to workers who do not access any support groups or services or work were asked individually whether they would like to take part in an interview or attend a drop-in session.

### **2.5.3 Participatory activity**

Having completed the participatory activity, people were asked whether they would also like to take part in an interview.

### **2.5.4 Flyer**

A flyer was produced that told people about the project and invited their participation (see Appendix 4). This was distributed by the organisations:

- Gateshead Council to over 10,000 contacts on their email lists and also by their Adult Social Care and Independent Living Team
- Gateshead Healthwatch mailing list
- Stroke Association mailing list

## 2.5.5 Healthwatch Gateshead

Once defined, Healthwatch Gateshead were informed of the recruitment process and asked for guidance on any further groups or individuals they felt should be involved. They also gave advice around advertising the project.



# Section 3 - Findings

## 3.0 Findings

This section provides a summary of the findings of the engagement with carers living or working in Gateshead.

## 3.1 Carer profile

In total 90 carers took part in the research, the majority being female (77.8%). Participants were aged from under eight years old to 83 years of age. Seventy-four (82.2%) identified themselves as White British. Over one quarter (27.8%) were in employment, and 31 (34.4%) had some form of disability or limiting long-term illness themselves.

In terms of their caring role, the length of time they had been a carer varied from six months to 49 years.

<b>Length of time caring</b>	<b>No. of participants</b>	<b>% of participants</b>
Less than one year	0	0.0
1-2 years	11	12.2
3-4 years	22	24.4
5-6 years	7	7.8
7-8 years	8	8.9
9-10 years	6	6.7
Over 10 years	24	26.7
Not sure	2	2.2
No response	10	11.1
Total	90	100.0

All but one person who took part in the engagement cared for a relative with some caring for up to three people and their ages ranged from 3 to 91 years of age.

<b>Number of people cared for</b>	<b>No. of participants</b>	<b>% of participants</b>
One	64	71.1
Two	14	15.6
Three	3	3.3
No response	9	10.0
Total	90	100.0

The table below shows the reasons why the person is being cared for.

<b>Reason for care</b>	<b>No. of participants</b>	<b>% of participants</b>
Dementia e.g. Alzheimer's	11	7.4
Problems connected to ageing	7	4.7
A physical disability	21	14.1
Sight or hearing loss	6	4.0
A mental health problem	19	12.8
A learning disability or difficulty	13	8.7
Long- term illness	10	6.7
Terminal illness	0	0.0
Alcohol or drug dependency	8	5.4
Autism spectrum disorder	7	4.7
Asperger's syndrome	2	1.3
Kinship	10	6.7
Other condition or reason	21	14.1
No response	14	9.4
<b>Total</b>	<b>149</b>	<b>100.0</b>

All but six of the people being cared for lived within Gateshead.

For a full breakdown of participants and their caring responsibilities see Appendix 3.

## **3.2 Participatory engagement**

As described in section 2.1, 51 carers were engaged using the Carer's Hub commissioning tool. Participants were asked to consider the services or interventions they were currently accessing as a carer, the positive aspects of the service, any issues or concerns they had and where improvements could be made.

### **3.2.1 Emotional support and counselling**

Emotional support and counselling includes services which offer ongoing emotional support, formal counselling, family/couples therapy and access to mental health services. Thirty-four people commented on emotional support that they received, most commented on the support they receive informally by attending groups or spending time with peers rather than specific counselling sessions for example.

Emotional support and counselling	No. of participants
Friends and family	5
Carers Trust (also known as Crossroads)	3
Counselling at school	3
Peer support	3
Carers Trust Facebook page	2
GP	2
Grandparents Plus	2
Marquis Way Day Centre Group	2
Support from Head of Year	2
Young Carers one-to-ones	2
Befriending service	1
Counselling	1
Gateshead Carers Craft Group	1
Online forum	1
Talking Therapies	1

### 3.2.1.1 Positive experiences

Twelve people (35.3%) highlighted positive aspects of the emotional support that they have received. Specifically, they liked being able to talk to peers who understood what they were going through or in terms of a formal counsellor, someone who was removed from the situation. Psychologically they had gained confidence and learnt not to blame themselves. Those who attended activity based groups also liked having an interest outside of their caring role. One working carer highlighted the access they had to counselling through their workplace as they were recognised as a carer and for young carers access to support in school and online was welcomed.

“Counselling has helped, I am very happy with the service. It stopped me from blaming myself. I was referred to counselling by Gateshead Carers and got seen straight away. It is a fabulous service”.

“I got a befriender at first which was a great help and a stepping stone to access. It was positive having someone to talk to. They knew the situation but they were removed”.

“I have gained confidence by coming here. The change in role from grandparent to parent is draining, and you have to keep your mental health high. It can be difficult but coming to places like this is good as there is support”.

“I get my emotional support from this group. It can be difficult to want to share your experiences at the start, but now I really treasure the company”.

“I attend counselling sessions in school; I have a Young Carers Card so if I need to leave class I can, and I can just go to see my counsellor. I don't trust my Head of Year but my counsellor always has time for me, she will get us hot chocolates from the canteen”.

### 3.2.1.2 Issues and concerns

Although many people had received good emotional support, thirteen people (38.2%) highlighted issues and concerns that they had and for the majority of this group (nine, 69.2%) a lack of information about what support was available to them was the key issue. One kinship carer said that it had taken a “few years” for them to find out about the befriending service whilst another said it took them “three weeks of looking to find the relevant support”. Six people had never formally received any information about services and two stated that they had never been asked how they are coping emotionally.

“I’ve not accessed any. I am aware of services as I have been involved with Crossroads and other voluntary and community organisations but nothing was ever flagged regarding my role as a carer”.

“As a carer I got no information about this being available or how it could help a carer – you are under a lot of stress as a carer!”

“I speak to my GP and good friends. Not sure what else I would have got that they couldn’t offer”.

Three people flagged issues with the emotional support they had received. For one it was an issue of quality of service as they felt that they had been labelled as an asylum seeker rather than a carer. Two young carers had issues in terms of the privacy of the space and having to take time out of lessons to see the counsellor. Finally one carer asked for someone to support them to attend groups.

“I felt judged as an asylum seeker when I went to counselling - the counsellor believed my Mental health issues were solely due to my AS status”.

“It is great that there is actually someone there at Young Carers, but there are always other young people there as well, so I feel insecure talking about problems with loads of other people around”.

### 3.2.2 Brokerage

Brokerage services include support when the person who receives care is offered Direct Payments/personal budgets and support for carers to access personal budgets.

Ten people commented on brokerage services. Four simply stated that they had either not heard of them or not used them whilst six people commented more specifically. All highlighted negative experiences or issues with brokerage.

#### 3.2.2.1 Issues and concerns

Three carers described how the Council had planned to set-up brokerage system but that this never developed:

“There were ideas for a Brokerage Team who would know everyone who delivered each service and operate as a central deposit. This seemed like a fairly good idea, but it never happened”.

“The energy drained away due to Council restraints; many social workers left the Council and set up their own businesses. There was an issue of limited resources”.

For two carers the idea of Direct Payments or personal budgets did not interest them as it was an “extra obligation” alongside their other caring duties. For another however who had looked into it, “it just wasn't worth it; the services were going to cost more without the Council's buying power”.

For those three who had tried Direct Payments the lack of support from the Council was an issue. The system was very complicated and resulted in them having to become an employer, arranging cover when they were on holiday and pension contributions.

“It was tricky as we decided not to buy Council services which was not an easy process. More vulnerable carers than me would find it hard if they decided not to purchase Council services”.

“You end up as an employer arranging cover and now there are pensions to consider. It becomes a real chore...I tried it for about a year.

“It's been hideous; you have to take on all legal responsibilities of employing someone, such as dismissal. We employed an individual and got no support around safeguarding issues...what to do if they spent his expenses inappropriately or went to inappropriate places”.

Two people suggested that there needs to be support within the Council to help people to use Direct Payments.

“The Council persuaded us to do direct payments. There needs to be a market place created to help people access services and opportunities”.

“You should have a person at the Council to help set up direct payments especially if people don't have internet access”.

### 3.2.3 Advocacy

Advocacy support ensures that the carer is aware of their rights; they are empowered to have their voice heard in decisions that affect them and get help with complaining. Twenty-one people commented on advocacy support which included support from a dedicated advocate and more general support from agencies.

### 3.2.3.1 Positive experiences

Eleven carers (52.4%) shared positive experiences of such support which they had received from:

- Carers Trust
- Gateshead Carers
- Hospital
- Social housing provider
- Social workers
- Young Carers at the Carers Trust

They appreciated support that they had received to complete forms and get access to financial support, kinship carers were supported by social workers to gain residence orders and others to gain access to mental health support. Advocacy support was also available to carers to help with making a complaint to the NHS.

“It all started via a welfare officer from Home Group, who provided a benefit check, they helped to fill in the paperwork and this resulted in guaranteed pension credits after visiting Age Concern, where they explained the benefits”.

“The social work assistant was great, they made sure I got support and helped me get a residence order instead of fostering, where there were too many rules. The social workers keep me informed and are easy to talk to”.

“An advocate is standing by if our meeting regarding our son, who has recently been taken into care, does not go to plan. She will advise us regarding making a formal complaint to the NHS. She has been useful in giving us straightforward advice and reminding me not to lose my temper during this stressful situation, she has been spot on”.

“The Carers Trust will speak on your behalf if you don’t feel confident. They also take a holistic approach and will help with the family issues”.

### 3.2.3.2 Issues and concerns

A further eleven (52.4%) people highlighted issues with regards to advocacy services.

Issue	No. of participants
Lack of information	5
Access to support	3
Quality of support	2
Consistency of support	1

A lack of information about what advocacy support is available was the main issue identified. Several people said that they had never heard of advocacy services and had to do things on their own. One carer had been offered services in the past and not used them but had never heard of them again.

“The lack of information regarding advocacy is a perfect example of the difficulty communicating information, and a lack of understanding as to what it could provide”.

“An advocate did offer to get us a SEN [Special Educational Needs] statement years ago; I’m not sure what’s out there now”.

“I feel even now advocacy is not widely known, even the term is unknown to people”.

Aside from information, three people highlighted an issue with actually accessing advocacy services. There was felt to be too much demand for the services, services being reduced or simply not knowing how to go about getting access to an advocate.

“The advocacy service is inundated; my son has been taken off the list as we haven't used it. It is a difficult service to access”.

“Gateshead Carers used to have a dedicated advocate, they don't anymore but they still do advocacy”.

“We don't always see eye-to-eye with the care home. We need an independent person to speak for my brother’s best interests. We were told we could nominate an advocate to speak on my behalf about what I think is best for my brother but I don't know how to access it”.

Two people had issues with the quality of support they had received from social workers and one carer with the lack of continuity of support from social workers.

“The social worker came and went; I never saw the same one”.

### 3.2.4 Access to health & well-being services

This support includes equality of access to NHS and other local services (e.g. priority access where needed, provision of alternative care arrangements to enable uptake of health services). Also, access to well-being services and health promotion/health checks and holistic approaches to reducing stress/exhaustion and promoting well-being.

Thirty people commented on services related to health and well-being.

#### 3.2.4.1 Positive experiences

Twenty-two people (73.3%) identified services or support that they had received and highlighted positives aspects of such services. The services or support discussed were:

- Carers Trust
- Gateshead Carers
- Healthy food sessions for Young Carers (Carers Trust)
- Hospital support
- GP practice support
- Swim sessions for carers (Gateshead Carers)
- Talking Therapies
- Workplace support (including Carer's Passport)

People talked generally about emotional support provided by the Carers Trust and Gateshead Carers. For Young Carers there were healthy food sessions provided where a chef comes in to the Carers Trust to talk about eating healthily and the young carers participated in cooking meals.

There were nine examples of the NHS being flexible and supporting carers to access their services. Some talked about flexibility in accessing GP appointments quickly and supportive GP practice staff, whilst others highlighted hospital support. One example of the hospital's flexibility however highlighted an issue with continuing support at home.

“My GP has lately become more responsive to me, they know I am a carer and they seem to appreciate and apply this to my health needs”.

“My husband needed to go to the doctors and said he couldn't come in at specific times due to our son. For the first time ever, the hospital made an allowance and offered different times as he was a carer”.

“The Matron at my husband's GP practice has been amazing...She has arranged everything we have got, adaptations, social services etc...I can call the Matron if we have any problems. My husband gets lots of UTI's [urinary tract infections] and chest infections. I told the Matron that if I had antibiotics I could keep him out of hospital which is detrimental to him as they don't give him his medication properly. I've had antibiotics for him for a year and since then he hasn't been in hospital. The year before he was in four times”.

“I had an operation in January to remove a tumour from my uterus. They did it by spinal rather than general anaesthetic so I could go home that day [and care for their husband who has Dementia]. But when I got home I had no extra support, so a few days later I was back in hospital with a severe chest infection”.

In terms of workplace support two carers highlighted positive experiences. One had a Carer's Passport and one worked for the Job Centre and reported having a good health and wellbeing network.

### 3.2.4.2 Issues and concerns

Fifteen people highlighted issues they had in terms of access to health and wellbeing services. Six people identified problems related to GP practice support and two,

hospital support. A further six carers were simply not aware that they could have support to access services and for one quality of support was an issue.

In terms of GP support, carers discussed issues with a lack of interpreters, a lack of flexibility in accessing appointments, not being offered an annual health check and for two people, their GP never actually asking them whether they were a carer.

“I was very stressed so visited my GP, who recommended increased medication for depression. It was hard to get an appointment with my GP although they were aware that I am a carer”.

“We do have a Carer Register but it didn't make a difference until recently. Carers and cared for people are entitled to an Annual Health Check, but this wasn't happening. I brought this up on a sub-panel and fought for it”.

“My GP knows I am a carer but has never been more accommodating or flexible with me. Due to me husbands Alzheimer's I can't leave him alone”.

“My doctor doesn't really know I am a carer, I have never really classified myself as a carer but the GP has also never asked”.

Hospital support was an issue for two people. One carer asked that their son be given one appointment where several procedures could take place instead of two so that the cared for person and carer did not have to leave the house twice. Another carer talked about how they had put off an operation as their partner would not be able to care for their son on their own.

Again a lack of information about support available to carers to access services was an issue for six people.

“Not aware of any other health and wellbeing services”.

“GPs never mentioned any help, consultant didn't either. I suppose they can see I am coping because I am a nurse”.

### 3.2.5 Caring support & training

This support covers helping carers who wish to carry on caring, safely and sustainably. They may become “Expert carers” and take part in ‘Caring with Confidence’ or ‘Looking After Me’ courses. Twenty-one people commented on this support.

#### 3.2.5.1 Positive experiences

Two young carers highlighted that they were regularly assessed by workers at the Carers Trust to ensure that they were receiving all of the support and training they needed. A further eight people (47.6% positive experiences in total) identified specific training courses they had been on:

- Emotional wellbeing/stress awareness
- First Aid
- Medical training related to care for person's condition
- Moving and handling
- Speech and language
- Understanding ADHD

“Gateshead Carers have provided emotional wellbeing training and a stress awareness course. It has been very good and informative and has provided me with new ideas”.

“I have received training linked to my grandson's behavioural condition”.

“I took a Speech and Language course; the Speech and Language Therapist came to Gateshead Carers and told us about the course”.

“I help my brother take his ADHD medication; I was taught how to do this”.

### 3.2.5.2 Issues and concerns

Thirteen carers (61.9%) highlighted issues in terms of caring and support training. Eight said that they had simply never been offered any training whilst five carers identified training that they would like to receive, namely first aid and moving and handling courses.

“It would be good to offer first aid training so we could use it not just when caring but also in general”.

“My son could choke and he cannot get out of the chair without a hoist. My wife and I are unable to get him out of his chair, only his older brother can, so we need more caring support with regard to this as I really worry about him”.

“My son has blended food as has trouble swallowing; I would like first aid training around choking”.

“I would like some moving and handling training. My son is getting heavy and my wife can no longer lift him. It's hard to get him in and out of the bath and to the [upstairs] toilet”.

One carer felt that courses were not available at times convenient to them and another that they were not particularly useful as they could not make their “son and daughter change”.

### 3.2.6 Information

Carers may receive static information such as leaflets or be signposted towards online information sources or face-to-face support. Forty-five of the 51 carers taking part in

this part of the engagement commented on the information they have received or the support they have accessed to gather information.

### 3.2.6.1 Positive experiences

Thirty-two carers (71.1%) highlighted positive experiences related to information provision. They firstly identified the sources of the information they receive:

Information source	No. of participants*
Gateshead Carers	17
Carers Trust	11
Council (including social workers)	6
Online research	5
Peace of Mind	1
Samosa Sisters	1
Parent Action Group	1
Word of mouth	1

\*Participants could give more than one information source

Nearly nine-in-ten (87.5%) carers cited specialist carer organisations as their only source of information about their caring role. Over half relied on Gateshead Carers to provide them with information, followed by the Carers Trust.

“I have got all my information from Gateshead Carers, where I have been coming for two years”.

“I had no information before Gateshead Carers. They help with everything; more in depth information about substance misuse, helps me to understand”.

“I don't use leaflets for information much. Gateshead Carers have a quarterly newsletter with some useful information. They are brilliant, they give you advice and take you through the information - they offer so much more than just booklets”.

“There's lots of information available through Young Carers on the website and there are lots of leaflets about activities. XXXX from Young Carers visited my school”.

“I get information from the Carers Trust, it is all really good. The information from the Carers Trust is always personalised and really relevant to us”.

Six people used the Council or social workers to gain information.

“The information via the social work assistant was good”.

“I get information from Gateshead Council who are getting better telling you what's on offer”.

Five people felt that information was easily accessible via their own internet research; “I use the internet, I know where to look”.

### 3.2.6.2 Issues and concerns

Despite the majority of carers highlighting accessible information sources 27 (60.0%) people also identified issues with access to information.

Issue	No. of participants*
Access to information	13
Want additional information	7
Lack of information	5
Never had any information	3
Poor quality information	3
Do not know what is available	1

\*Participants could give more than one issue

Rather than a lack of information available, nearly half of carers commented on the ability to access information; “there is lots of help out there but you need to know where to look for it”.

A lack of support from professionals was the key barrier in this respect. People were not directed to or provided with relevant information and in the case of several kinship carers, once they had full guardianship the social work support ended. For those who need additional support such as people with learning difficulties it is particularly difficult.

“If you’re currently attached to a carer support service you are kept in the loop, but if not...you don’t know what you don’t know”.

“It was hard to access information regarding guardianship myself, I managed but it was difficult. Our access to information was poor”.

“It used to be the case that a social worker told you 'these are the opportunities for you...' but now vague areas are directed to you, there is less support...There are issues with the way information is conveyed; you need people who know what they are talking about. There used to be information from people with a wider breadth of experience, but there isn't anymore”.

“The availability of information is poor; they do not direct you to information well. That's why this group is so useful, you can share experiences and gain information through word of mouth”.

Seven carers who had received some form of information asked for more to be available to them. For some, there was an expectation that they should be provided with information from the Council.

“I got nothing, the only information I got was from Gateshead Carers, I didn't receive anything from social services”.

“I haven't had any information from the Council”.

“There should be more information available generally in public places or GP surgeries”.

Five people simply felt that there was a lack of information available to them.

“There's not enough information out there”.

“I know there's still not enough information – you only see it at hospitals – it should be more visible and in places anyone would go”.

Three people stated that they had never had any information whilst a further three questioned the quality of the information. They felt that it should be more personalised, current and age appropriate.

### 3.2.7 Carers shaping policy & services

This intervention includes helping carers to participate in local planning, commissioning and service design and supporting carer-led groups. Nineteen people highlighted experiences they had had in this respect.

#### 3.2.7.1 Positive experiences

Fourteen people (73.7%) identified ways that they had been involved in shaping policy or services and seven of this group were young carers. Several were involved in a buddy system which gave them the opportunity to shape services whilst others took part in discussions and surveys through the Carers Trust. One young person also helped raise awareness of the role of carers by taking part in talks at schools in the area.

“I'm involved in the 'buddy' system, and to be a buddy you have to be responsible. We understand the services and what needs to be done”.

Other carers also had experience of helping to influence services. Three had lobbied the Council and NHS against reductions in services such as the proposed closure of a day centre, which would have negatively affected their loved ones.

“I am heavily involved in policy changing, through Deciding Together. I am also in an informal group which campaigned to keep a ward open”.

“I have been involved... I have challenged how changes will impact upon people's wellbeing and have challenged the local authority in the past over suggested changes of day care”.

One carer described being on a carer sub-panel whilst another was a carers champion within the Council.

“As a Council carer champion I feel I am able to inform the wider team with developments and information”.

Finally one participant made the point that they thought it was easier to get involved than in the past and that was partly due to a reduction in stigma associated with social services. They felt carer’s services had a part to play in that reduction.

### 3.2.7.2 Issues and concerns

Apart from this engagement, three carers reported never having had any experience of influencing policy or services. One other felt that they had taken part in consultations in the past but that they felt it was a ‘tick box’ exercise and that decisions had been made ahead of the engagement. Another felt that they had useful discussions about service issues at Gateshead Carers but could not rely on the organisation to support any lobbying as they were compromised by being funded by the Clinical Commissioning Group. Finally, one highlighted the stress of having to campaign to keep services open had put them under.

“It’s very stressful – it’s your life! The alternative is often not worth thinking about...It’s hideously stressful and affects your mental health”.

### 3.2.8 Whole-family support

This intervention covers working with the families of young carers to find alternatives to inappropriate caring roles, partnerships between children and adult services and input into safeguarding work. Only three carers commented on this type of support. One had received family support when there had been a child protection issue within the family and another said that they were currently receiving support from social services due to an “evaluation of my Dad’s side of the family”. One young carer pointed out that the Carers Trust run family days.

### 3.2.9 Education and 1:1 support

This intervention focuses on helping young carers to attend and thrive at school including mentoring and one-to-one support. All ten young carers who took part in the engagement using the Carer’s Hub tool had had experiences of support to help them receive an education.

#### 3.2.9.1 Positive experiences

Eight young carers described the support that they received and for four this support was school based. They had access to drop-ins for young carers to talk about issues concerning them whilst another said that their school was understanding if they were late or had to leave early. Another young carer had had a very supportive teacher during their GCSEs.

“There is a drop-in at school for help for young carers, it is helpful. It is not just for schoolwork, we talk about other issues such as bullying”.

Four young carers also identified support that they received from the Carers Trust. They get one-to-one support where they can “sit and talk through any problems relating to school”. They also have homework ‘catch-up sessions’, help to write CVs and are helped to gain some work experience.

### 3.2.9.2 Issues and concerns

Six young carers however identified issues relating to this support. A lack of support at school was an issue for four people with one young carer describing being bullied at school due to their caring role.

“I don’t get any support from school; they are not sympathetic to my role”.

“I get called names at school because I don't get out much because my parents are in a wheelchair”.

“At school my teachers are aware but not lenient if I am late or need extra time”.

For another, their school was supportive to an extent and it was felt that this support had reduced over time.

“The school is sympathetic but they seem to focus more on children with bad behaviour. If you push the school they will help but they are not forthcoming...They are understanding toward lateness and having to leave early but don’t support me academically”.

Finally one young person made the point that their caring responsibilities meant that they could not attend the Carers Trust homework club.

### 3.2.10 Activities and clubs

This intervention includes helping young carers to take breaks, make friends and have fun. Young carers may also be supported to access mainstream activities and online support. Nine young carers commented on this type of support.

#### 3.2.10.1 Positive experiences

Six young carers described support they received from the Carers Trust to take part in activities and have a break from their caring role.

“I come to the Young Carers and it is good because if it is getting a bit full on with some of the other Young Carers I can go out in the forest”.

“We do a lot of activities at the Carers Trust, we are going to the cinema today. There is a lot of support if I am stressed, I can come out of the house and speak to other young carers about things. There are no bad things about Young Carers”.

“I do stuff at the Carers Trust, it is good to be able to come here and have a break”.

### 3.2.10.2 Issues and concerns

Reduced funding and therefore a reduction in activities available to young carers was highlighted by two young carers. A third felt that there should be more provision.

“Funding is reducing and activities are reducing. The newsletter tells you what is available”.

“There is limited funding for activities now but I have previously attended trips to theme parks, cinema and a meal, drama, dance and theatre groups”.

### 3.2.11 Changes and transitions

This intervention provides support with the caring journey through different life stages. It includes support when carers wish or need to stop caring and bereavement. Also, support when the person who receives care goes through a transition, such as becoming an adult. Fifteen carers had experience of support in this respect.

#### 3.2.11.1 Positive experiences

Four young carers, kinship carers and parents of children with disabilities reported being well supported with regard to educational changes, moving on to adult services and involving parents who had previously been absent.

“I was initially pointed in the right direction when considering moving onto adult services. However, the age was upped from 18-25. Gateshead Carers is where I will seek further help when leaving”.

“My grandson is turning 16 and his mother is back in touch. Social services are supporting me with rights relating to my grandson. Social services helped a lot; they helped my grandson and got him sorted. It was always possible to speak to someone”.

“He’ll be joining senior school, once the right diagnosis has been made. The transition to Cedars [school in for children who have a Statement of Special Educational Need] was brilliant, they took their time and he gradually worked up to going full-time”.

#### 3.2.11.2 Issues and concerns

Ten kinship carers, people who are caring for their adult son or daughter with a disability and one bereaved carer highlighted issues with the support they had received. One said that they do get support but it is not readily available, they “have to fight for it”. A further five carers felt that they had not been fully supported during the transitions they had experienced and one carer looking after their adult son had had no correspondence about what the process will be when they are no longer able to look

after him. For kinship carers support from the very beginning of the caring role was lacking and this includes financial support.

“The grandparent to parent process is difficult, it wasn't managed properly. Their concern is the child, they don't think about you. It is like starting from scratch as a parent... They should give you more help and support, particularly financial help”.

“The situation has been poorly managed; in the early days there was no one to support you. Social services seemed to see us as the easy option and walked away...”

Another carer reported no support during any transitions for their aunt who moved from her own home to home care, then to sheltered accommodation and then to nursing care.

“I wasn't supported in this and did it all myself. Would have preferred someone to listen and help with the process”.

The stress of changes was highlighted by four people. Transitioning to independent living has been very stressful for one carer, exacerbated by issues with care provision at the accommodation.

“He is happy in care but giving up my child has been the worst experience of my life; it has been 10 months of hell. The majority of staff are great but we have had massive issues with some. We have been fighting for a suitable wheelchair for our son and this has taken over our lives. The physiotherapist said that our son might not like the chair but will 'just have to get used to it'. A staff member used our son's breathing apparatus incorrectly and did not use sterile water. We are concerned for his wellbeing. The stress is affecting our health badly”.

Another carer who is currently trying to arrange independent accommodation for their son (who is 32) reported having to facilitate everything themselves and that support from the Council has been poor and very slow. They also felt that conversations about independent living need to happen earlier.

“Housing for example, you express your interest and then nothing – no feedback, no offers of further support or information...They need to engage people earlier to have conversations about housing and living independently. They should showcase housing stock that is suitable to all people, they should showcase the models of support available, and how it would work. Start the conversations early and they can avoid crises”.

### 3.2.12 Emergency support

This support is to help carers and services to plan for emergencies, setting up back-up and respite provision during emergencies. Nine carers gave their views of this support.

### 3.2.12.1 Positive experiences

One carer had used the Emergency Support Scheme and felt that it worked well and knowing that it is in place gives them peace of mind. Another had an emergency care plan set up with the Council which includes access to respite.

“I used the Emergency Support Scheme last January. I thought my husband was having a heart attack. A woman was able to stay with my son so I could go with my husband to the hospital. It can be provided for up to 48 hours, and if support is needed for longer they will assess their need and put plans in place. The Scheme gives me peace of mind. You have to opt in to join, but it is free and provides support for carers. I was involved with setting it up”.

“Respite at the Grove can take him at short notice. Completed emergency care plan with Council...Logged here at Gateshead Council. Police could get a sheet”.

### 3.2.12.2 Issues and concerns

Seven (77.8%) carers had issues related to support provided in emergencies. For three, they simply had never heard of any such support and particularly the Emergency Support Scheme (the one carer who had it in place had been instrumental in setting it up). A further three carers felt that the emergency support that they had in place was ineffective and this was particularly true of the Mental Health Crisis Team.

“Social Services do know, but when I tried the Crisis Team they would not come out and I had to get the police”.

“I have issues with the Crisis Team; they are not responsive to what my son needs or wants. I have contacted them in the past when my son’s other personality came out and they just referred me to the police – the police calmed him down but that’s not their job and seeing the police just makes it worse”.

“We have a plan in place in case something goes wrong...it’s heavily reliant on friends and family so it seems meaningless. I would have confidence in his respite care provision if we needed help, they always have a free bed but I wouldn’t go to the Council, I would go straight to them.”

Finally, one carer was aware of the Emergency Support Scheme but required support and encouragement to actually put one in place.

“I have put it off because I don’t want to think about anything bad happening to me or my son”.

### 3.2.13 Breaks

This intervention provides access to breaks services and individually-tailored breaks provision for carers. It also includes planning for ways of achieving breaks where

specific services do not exist (e.g. substance misuse carers). Twenty-eight people commented upon aspects of this support.

### 3.2.13.1 Positive experiences

Sixteen carers (57.1%) described the breaks they have had access to:

- Take a Break funded holidays
- Time at Young Carers at the Carers Trust
- Day trips
- Support groups
- Overnight stays at Grove House for the cared for person

They appreciated being able to take time out from their caring role to relax, meet up with people with similar experiences and have fun.

“I get breaks at the Carers Trust which I love because I can stop feeling frustrated about what I have to do every day. I can just have fun and release my anger!”

“I use the Take a Break service and was given funding for a mini break to Amsterdam. I have also attended activities such as going to the cinema and also cook and chat which I really enjoy”.

“Last year I got a week’s holiday with my mum funded. I have also been on day trips which have been arranged through Gateshead Carers. Being in a different place with no reminders of my caring responsibilities gives me a complete mental break.”

“Respite at the Grove. We get one and a half weeks in the summer; you have to book well in advance”.

“We get 28 days a year, it’s improved recently as you can now block book – you can get two weeks. We have to book 12 months in advance but that’s okay – I think it’s really good”.

“The Young Carers give me a break. I see my friends for an hour or two. I have attended day trips down the country. We have the option of saving our fund to go away for the weekend or use it for weekly day trips”.

A further two people talked about going on holiday privately and one had support from Newcastle airport to do so.

“We do have breaks as a family. We let him decide where to go. Newcastle Airport has brought in an autism passport where they fast track you through security which is good”.

### 3.2.13.2 Issues and concerns

Thirteen carers (46.4%) identified issues with support to have breaks.

Issue	No. of participants*
Lack of information	6
Lack of breaks	4
Accessibility of breaks	2
Lack of support to access breaks	2
Logistics of accessing breaks	2
Suitability of accommodation	2
Quality of breaks offered	1

\*Participants could give more than one issue

A lack of awareness and information about how to access breaks was the main barrier to six people taking up this support. One asylum seeker questioned whether they were entitled to breaks whilst another carer questioned whether they could use the Take a Break fund more than once.

“I don't know how to access short breaks service”.

“I had to organise respite for my aunt...I only found out about respite due to a colleague at work...other people wouldn't have that connection”.

“I didn't know about the Take a Break fund. I would have taken advantage of it”.

One carer suggested that as GPs should be the first point of contact for carers. They should have a checklist and distribute information about all aspects of caring including respite care.

Four people simply felt that they needed more breaks. One carer felt that breaks were reduced as they got older and in fact they were needed more than ever. Another had been told a funded break was a “one-off” whilst a third simply wanted a couple of extra hours at a day centre for her husband who has Dementia “would make such a difference”.

“As we are getting older, we need more breaks, not less, but the Council are always wanting to cut services. They don't take into consideration the fact that our caring role is getting harder and we need more support. Breaks are always in short supply”.

“I had a break and got £400 and was told that it was a one off and I will not get another. I know that money is low but they should think about reinstating money for a decent holiday break. Breaks are essential to the wellbeing of carers”.

In terms of accessing breaks, one carer had applied and simply never heard back, whilst another was offered a week in rural accommodation with no way of getting there. Related to this two people highlighted the difficulties in arranging breaks due to having

to fit in with their working requirements and the length of time you have to book in advance.

“When we were working it was difficult to organise breaks as we had the added complication of booking holidays at work. This needs to be done well in advance and can be difficult to coordinate. You can’t book anything else until you receive confirmation”.

A further two people felt that suitable accommodation for their loved ones was in short supply.

“My son loves where he goes for respite but there is only one bed suitable for his needs. You have to book days more than 12 months in advance, it is a nightmare. I cannot do anything spontaneously”.

Two carers felt that in order to access breaks they needed more support.

“Someone at the Council used to deal with organising breaks but I think they have now left, which has meant we have had to wait longer for a response regarding breaks”.

### 3.2.14 Peer and community support

This intervention includes having access to carers’ groups and peer support schemes. Also, support to help carers to draw on more family/community resources to help with caring, participate in their communities and volunteering opportunities. Thirty-eight people commented on this support.

#### 3.2.14.1 Positive experiences

Twenty-eight people identified peer support that they received in the following settings:

<b>Setting</b>	<b>No. of participants*</b>
Carers Trust Young Carers Group	7
Gateshead Carers Craft Group	7
Gateshead Carers Asylum Seeker Drop-in	5
Gateshead Carers Grandparents Plus	4
Marquis Way Day Centre Group	3
Peace of Mind	3
School	3
Young Carer’s Group Facebook page	2
Family	1

\*Participants could give more than one setting

Characteristics of all of the groups were people appreciating being able to talk to others who had had similar experiences and were going through similar things to them. They were able to share problems, get things off their chest in a trusted and non-judgemental environment and make lasting friendships. In terms of the asylum seeker support groups they also gained language skills.

“I feel outside of Young Carers my friends don't really understand. But my friends within the Carers Trust are brilliant as they are going through very similar things”.

“At Gateshead Carers [Craft Group] I meet new people who understand. We share ideas and coping strategies. It provides me with a break from my caring role and I have made new friendships as a result of attending the sessions. The friendship has been really important as I felt isolated and so alone before attending these sessions”.

“Gateshead Carers Asylum Seeker Drop-In helps to break the isolation, gives me support; I receive translation help and generally enjoy the social aspect of it”.

“The Kinship group is a very nice group and we are all in the same situation. It is helpful and comforting and there is no judgment. I receive advice and help and have realised through attending this group that I am not the only one in this situation”.

“Nearly 100 people are signed up to Marquis Way...Overall it is very good”.

“At the Peace of Mind Group I feel comfortable, can share problems and I get help to improve language”.

“There are a lot of other young carers at school so I speak to them”.

“I have peer support through the Young Carers Facebook page”.

### 3.2.14.2 Issues and concerns

Despite a large number of positive experiences of peer support for carers in Gateshead, eight people identified aspects of this support that they felt could be improved. For carers attending the Muslim Women's Group they felt that the group was not necessarily aware of their caring status and it was not set-up specifically for carers. They were aware of other groups at Gateshead Carers but none had accessed any.

The timing of the Craft Group was an issue for one carer who worked during the day and for an attendee of the Marquis Way Day Centre Group they felt that it did not meet frequently enough and communication between group organiser and members was poor. One young carer felt that the Carers Trust was often too busy and that they wanted some privacy to explain their problems and for one parent carer of a young child they requested information about peer support in their area (South Tyneside).

### 3.2.15 Access to benefits and financial support

This intervention includes support for carers and families with benefits applications/ appeals and support to help carers manage finances as well as debt counselling. Thirty people shared their views of this support.

### 3.2.15.1 Positive experiences

Fourteen people identified the support that they had received to access benefits and financial advice.

<b>Support</b>	<b>No. of participants*</b>
Gateshead Carers	6
Social worker	4
Age UK	2
Citizen's Advice Bureau	1
Department of Work and Pensions	1
Can't remember	2

\*Participants could give more than one type of support

“Social Services sent someone to the house as I couldn't get away. They were fantastic and helped me through the process of getting Attendance Allowance. The social worker understood that not everything was black and white and advised me to put down the worst case scenario as although my husband wasn't that bad now, he would deteriorate. This was good advice as he did and it meant I didn't have to reapply”.

“We had no support until we got in contact with Gateshead Carers - thank God for them, they've been brilliant”.

“The Citizens Advice Bureau sent out some sheets for what the questions mean and how answers might be interpreted. Getting the right information and right benefits can make you feel more secure, it is one less worry”.

### 3.2.15.2 Issues and concerns

Eighteen people identified issues with support that they received around access to benefits and financial advice.

<b>Issue</b>	<b>No. of participants</b>
Lack of information	11
Lack of support	5
Lack of continuity of support	1
System barriers	1

As with a number of other interventions, a lack of information about what benefits are available and how to access them was the main issue identified. All participants from the Muslim Women's Group were unaware that they might be eligible for benefits being a carer.

“There was a gap before I received any benefits, I didn't know I could get them. I can do more with the grandchildren now as I have more monetary capacity.

“I receive child benefit, tax credits, pension credits and Carer’s Allowance but I only learned about the support from word of mouth, not social services”.

“You stumble on information by chance and share what you can”

Lack of support was also an issue for some carers. Some carers had received no support and had to do everything themselves which they found very difficult and for two, the support seemed to stop when they reached pensionable age and were no longer entitled to Carer’s Allowance.

“No support at all from social services. It has been a nightmare to get benefits”.

“You are left to your own devices, you need a point when someone can sit with you and assess if you are getting the right benefits through a discussion. There is a lot of responsibility. It is not difficult but some of the questions are unclear which makes me weary”.

“It is hard to know where to go for support. Once you get a state pension your Carer’s Allowance stops which makes things harder and harder. Things are getting more difficult anyway as you and the cared for person get older”.

A lack of continuity of support was also an issue as different social workers do not know your background. Finally, system rules were a barrier for one asylum seeker. They were supported by the cared for person’s cardiologist to apply for a concessionary travel pass for the cared for person. They were turned down and cannot afford to travel.

All cared for people should have an annual review. One carer suggested that benefits should also be reviewed at this stage to ensure that they and the cared for person are receiving all the benefits they are entitled to.

### 3.2.16 Access to work/training

This intervention covers careers advice and support for carers to get into training or employment during or after caring. Also, support for carers to maintain employment or training. Thirteen carers discussed this topic although all but two highlighted support or a lack of support from their current or previous employer rather than any support from other agencies.

#### 3.2.16.1 Positive experiences

One carer pointed out that Gateshead Carers have an Access to Work Scheme, but they had not used it whilst another had been sent training opportunities from the Carers Trust but had not accessed them.

The remaining eight people (61.5%) spoke positively about support that they had from their employers that enables them to work and care for their loved one. People cited firstly an awareness that they were a carer but also flexible working schemes, access

to a psychologist, time off to accompany the cared for person to medical appointments, and allowance for carers leave.

“I had to leave my previous job due to my caring responsibilities. My new job is more flexible, there are less responsibilities and my employer is more aware of my situation and so doesn't put pressure on me. I felt able to open up about my issues during my interview; there was no stigma which was good”.

“My wife works for NHS and get five days carers leave per year which she uses for hospital appointments”.

“We have flexi time here, which means I can start at 11 or 12 and work around my commitments as a carer”.

### 3.2.16.2 Issues and concerns

Seven people highlighted issues they had whilst working in paid employment or training and being a carer. One had simply never had any support from any agencies to help them retain employment and another who is an asylum seeker cannot access any higher education due to her current status. Four carers received no support from their employers; they had to buy extra holiday to attend appointments, were not given unpaid leave and not given a stress risk assessment as they requested.

“I feel like there is not much support for working parents of disabled children. It is difficult to get time off for appointments...I have to buy extra leave. I now do compressed hours but I'm not sure whether to go part-time because I don't want to compromise the family income”

“I asked for two months unpaid leave due to my caring role. I was refused. The pressure became too much and I left the job”.

“I get nothing. I have asked for things at work such as a stress risk assessment but it hasn't happened. Employers need to be aware of their policies around carers and implement them”.

Finally, one carer asked that employers allow them to attend appointments without having to make the time back and that carers be allowed time off to attend training sessions during work time.

### 3.2.17 Housing support

This intervention includes support to maintain acceptable housing and access to adaptations and equipment. Six carers highlighted positive and negative aspects of this support. They appreciated the support they were given by the Housing Advice Centre in Newcastle, Gateshead Carers and the Carers Trust and also the adaptations they got from the Council.

“The help from Crossroads to get a property closer to my mother”

“The Council were good with putting adaptations in the house”.

However one carer had issues related to accessing adaptations.

“I have not had a pleasant experience at all getting adaptations. We needed access to both sides of the bed to change our doubly incontinent son, as we could not, we have had to put a sheet on the floor...The Occupational Therapist was not allowed to the house, we had to get a local councillor involved to see the problem. We had to give lots of detail in a huge room with councillors. It was very degrading, we had to detail dealing with my son's incontinence and my difficulties with arthritis to explain why we needed access to both sides of the bed”.

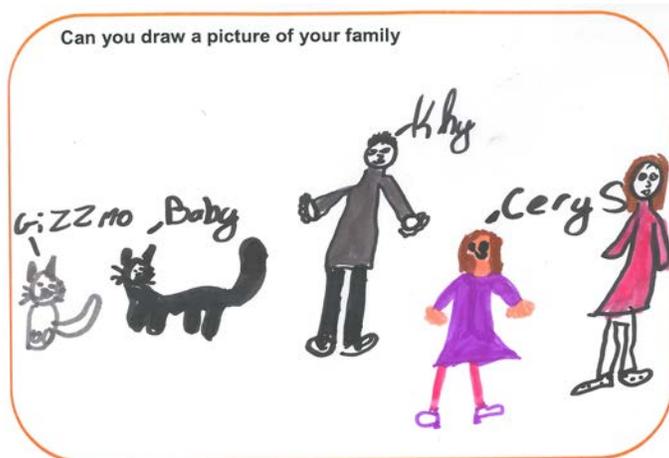
Another carer suggested that the Council have a register of vulnerable households so that they can give priority to carer's homes when for example a boiler breaks down.

### 3.2.18 Young carers' views

As described in section 2.1.2, 16 young carers aged under 13 took part in the engagement by answering a small number of questions around their caring role. Some also took part in a picture drawing activity while answering the questions.

#### 3.2.18.1 Can you draw a picture of your family?

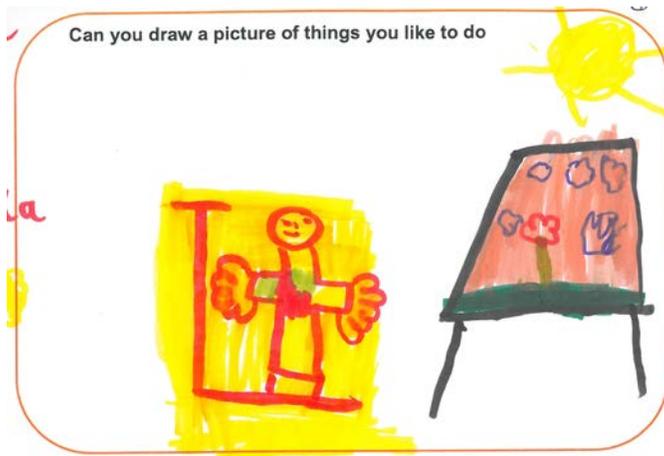
Young carers were asked to draw a picture of their family; while they were drawing they were asked to talk about their picture. The young carers were asked who they help at home and what do they do to help. The young carers helped with either their parents or siblings due to a mental or physical issue or both. The type of activities included generally helping out at home; helping tidy up, wash the dishes or cook.



“I have a fluffy cat called Gizzmo, a baby cat, a big brother and a sister. My mam has epilepsy and has fits and seizures. My mam had a blackout and four seizures in one day so I rang for an ambulance and my nana and got a neighbour who's a doctor...I might get a pride of Britain award”.

### 3.2.18.2 Can you draw a picture of things you like to do?

Young carers were asked to draw a picture of the things they like to do, while drawing their pictures they were asked if they were able to do these things as much as they would like. They drew a lot of activities they enjoy doing such as football, going to the park, playing with their dog. None of the young carers however recognised any impact upon these activities due to their caring role.



"I like to play with my friends and do art".

### 3.2.18.3 Can you draw a picture of what you like doing at this group?

Young carers were asked to draw a picture of what they liked doing at the group (Young Carers Group at the Cares Trust). While the pictures were being drawn the young carers were asked who helps at home when they are at the group and whether they would like to go to more groups or activities. Young carers drew lots of activities including going to the cinema, going to the beach, drawing, talking and skipping. While at the group young carers mentioned their parents and other siblings would help at home.



"I like playing with bubbles without popping them. It's really nice to come here".

### 3.3 Interviews

Twenty-seven people took part in a telephone interview to share their experiences of being a carer.

#### 3.3.1 Background

The initial question gathered some background information about who they cared for and how the caring role began. As shown in the table below, participants have a varied background. For example, some have cared for their children since birth whilst others have taken on a caring role for a partner who has developed an illness.

Reason for care	No. of participants
Dementia e.g. Alzheimer's	7
A physical disability	6
A mental health problem	5
Long- term illness	5
Problems connected to ageing	5
A learning disability or difficulty	4
Autism spectrum disorder	2
Alcohol or drug dependency	1
Asperger's syndrome	1
Kinship	1
Sight or hearing loss	1
Terminal illness	0
Other condition or reason	8

\*Participants could give more than one reason for care

“My oldest daughter, who is now 28, was born with a congenital abnormality. We were told it wouldn't happen again but my son, now 24, was born with the same condition... My caring role started from the birth of my oldest daughter”.

“I care for my wife, she had a series of TIAs [transient ischaemic attacks] about six or seven years ago. It affected her behaviour and she would have psychotic episodes. The TIAs had resulted in brain damage”.

“I have been a carer of my husband for 10 years. He has a degenerative back problem and fibromyalgia as well as sleep apnoea. He had to quit work due to back problems...[and then developed] severe depression and I have to watch him 24/7”.

“We look after our grandson, who is now nine. We are parents of his dad; his mum has drug and alcohol issues”.

#### 3.3.2 Identifying as a carer

Participants were also asked at what point they identified themselves as a carer.

Identifying as a carer	No. of participants
Immediately	9
After the role had begun	13
Do not view myself as a carer	5
Total	27

Half of participants did not identify themselves as carers until after their caring role had begun and for some they had been looking after their loved one for a significant amount of time (over ten years) before they recognised that they were a carer and sought some type of support. Five people were unaware of their caring role until they were put in touch with carer’s support organisations, namely Gateshead Carers or the Carers Trust.

For others their caring role began immediately either when their loved one was diagnosed with a particular condition, when they took over a caring role from someone else or at the birth of their child. Finally, five people despite taking part in this engagement simply do not like to refer to themselves as ‘carers’. They are looking after loved ones and feel the term is not representative or too formal.

“I am his wife and I don’t really like the term ‘carer’”.

“She’s my mother, it’s not a job”.

“I feel a bit of a fraud saying I am their carer but I support them in many aspects – helping them access services and support, helping them with their hygiene...”

Despite this, all but four people identified specific trigger points that had led to them reaching out for some type of support.

Trigger point	No. of participants*
Health of cared for person	11
Financial pressures	5
Carer’s health	2
Advice needed re. completing forms	1
Cared for person excluded from school	1
Friends/family concern for carer	1
Given information about support	1
Main carer deceased	1
Pressure from other caring role	1
Support provided with fostering role	1

\*Participants could give more than one answer

The main trigger for carers seeking support was a deterioration in health of their loved one and carer support was often suggested by the hospital.

“When she was having the attacks [TIAs] we would just manage but she ended up in the Tranwell and social workers got involved”.

“I work shifts and was worried – she wouldn’t eat if I wasn’t there. She ended up in hospital with a stomach problem and they wouldn’t let her come home until a care package was in place. If not for the hospital I am not sure where I would have gone or started”.

“She ended up in hospital and they wouldn’t let her return home until there was a care package in place”.

Financial pressures were also a catalyst for people looking for help.

“It was his debt, I needed help – someone to talk to”.

“We were advised by his social worker to apply for financial help. This was because he is now expected to pay towards his care, i.e. day centre, transport etc.”.

For two people their own health was being affected by their caring role whilst others had simply not known support was available until a chance meeting or a change in personal circumstances meant they had more time pressures.

“I was burnt out with work and my caring role. Work were very unsupportive and I had to go off sick, they didn’t understand mental health and told me to ‘snap out of it’...I rang Crossroads for help as I had reached breaking point”.

“I wasn’t looking for help as I didn’t realise it existed here as there is no help in my home country... We didn’t get any help until we bumped into someone whilst out shopping who told us about the Peace of Mind [Peace of Mind is a small Refugee led Community organisation based in Gateshead whose aim is to support asylum seekers and refugees integrate into new society and culture] and Samosa Sisters groups [A non-profit catering project to raise funds for the relief of poverty (destitution fund) to help vulnerable women with "No recourse to public funds"], which in turn introduced us to the Carers Centre”.

“When I was pregnant with my youngest daughter, my parents who are now both deceased were getting a lot older and they couldn’t provide as much support as they used to be able to, and so I decided to look for support...I realised that caring for a baby alongside my two children who suffer from severe learning disabilities would require extra support”.

### 3.3.3 Support at beginning of caring role

Participants were asked what help and support they wanted when they first identified themselves as a carer and three people said that at that time they felt that they did not need any support.

“I didn’t think to look for help or support as I was only concerned about XXXX, but the health professionals provided really good support and directed me to the Carers Trust”.

“I did not want help, I wanted to manage myself and care for him”.

A further three people stated that they did not know what help they needed, they just knew that they needed some sort of support and for one carer this was because they simply did not know what was available.

“I didn’t know what help I needed – I just knew I needed some help...I needed help with everything – I had no confidence and couldn’t see a way forward”.

“I didn’t really know what was available, only when we got involved with mental health teams, crisis teams and social worker did we start to look at what was available”.

Others however initially identified the following:

<b>Support</b>	<b>No. of participants*</b>
Health of cared for person	6
Breaks	5
Advice	4
Financial	4
Emotional support	3
Practical support	1

\*Participants could give more than one answer

Carers wanted additional services or support for their loved one so that they could be diagnosed and treated and live safely at home. They also wanted long term rehabilitation support and for them not to become isolated.

“I wanted to make sure he was safe, for something to be done, I couldn’t do anything”.

“I wanted the correct help and medication so [my son] could get his life back on track”.

“He didn’t get much SALT [speech and language therapy]. He got it for four to six weeks, once a week, then they left exercises”.

“We wanted his isolation to be reduced, he’s a very social person and he was become isolated and struggling to keep the house”.

A further five people had requested support to have a break from their caring role. This was predominantly for a few hours a week but sometimes included weekend breaks.

“I needed a break and the carers association offered to pay for a few weekends away”.

“I wanted respite so I would be able to carry on with normal family life”.

“I needed some space, even just a couple of hours to shower or do the shopping”.

“Just someone to cover me while I was at work and make sure she was eating – didn’t need any financial help”.

Four carers simply wanted some advice and for one refugee this related to her ability to continue to live with her mother and care for her once she reached 18. For another their request for advice resulted in accessing emotional support too.

“After XXXX’s operation I contacted Gateshead Carers. I rang them with a query about some paperwork I was completing but I was upset on the phone so they asked me to come in for a chat...I only wanted a question answering but I got much more as they referred me to their counsellor and I got six weeks of counselling”.

A further four people needed some financial support at the beginning of their caring role.

“I looked into getting a support allowance, benefits for XXXX and I’d also heard about a death grant he may be eligible for”.

“The benefits were useful – my ability to work became complicated – he wouldn’t go out so he didn’t access anything”.

For three people some emotional support had been sought to ease their caring role.

“I wanted to be able to talk to someone who understood the pressure I was under and what was going on with my son”.

“I wanted counselling as I wasn’t coping very well at that time. We also considered getting a carer for XXXX but decided against it”.

Practical support with regards to caring for someone at home was also missing for one carer.

“He came home after 12 weeks, the front door closed and I felt panicked and out of control; I hadn’t been trained and didn’t have a clue which way to start”.

#### 3.3.4 Looking for support

Carers looked for this help and support in various places and the table below shows where they initially went for help. Over one third contacted a specialist carer organisation directly and a further five contacted the Council. Others were signposted by health and social care professionals to the help they needed.

Where carers looked for support	No. of participants
Contacted specialist carer organisation	9
Contacted Gateshead Council	5
Signposted by hospital	3
Signposted by GP	2
Signposted by community mental health	1
Signposted by occupational therapist	1
Signposted by social worker	1
Contacted their church	1
Searched online	1

Participants were asked how easy it was to find this help and support at that time and 11 people gave their views. Eight people felt that it was easy, with health and social care professionals offering advice and signposting them to the relevant services or researching and approaching them directly.

“The hospital put me in touch with the extra services for support, I didn’t have to look for the help so it was very easy to find”.

“I began with my own church as he knew my priest was very supportive...My GP put me in contact with...a well living group that I attend...I also looked for help from a support worker. I’m very pleased with how easy the support was to find and how helpful it has been”.

“I did it all myself – was easier, just filled in a form, think I got the school to write a statement. Think it was word of mouth that made me aware of the support”.  
 “I do voluntary work for Arthritis Care so I know a lot of the local organisations. I already knew about Gateshead Carers”.

One participant who has cared for their children for 28 years commented on the difference between accessing services then and now.

“I found that it was quite easy to access services especially compared to now: they commissioned services more and it was clearer. If you needed support you were offered specific solutions, there was no personal budget or lots of options which could be confusing”.

For three people this support was not so easy to find or they simply did not know what to look for and what was available to them; as two people said, “you don’t know what you don’t know”.

“I was advised by an occupational therapist about getting a social worker for a community care assessment. I didn’t even recognise stroke as a neurological problem...I had to go through a convoluted route, word of mouth...it takes a breakthrough to initially access all areas”.

### 3.3.5 Support received

Having identified that they themselves or the person that they cared for needed some help or support, participants were then asked whether in fact they received it. Nineteen people (70.4%) felt that they did receive the support they needed with seven also commenting on the timeliness of this support.

“The mindfulness course was a great support network for everyone. They [Crossroads] also accompanied me to Tyneside Women’s Health and Clubhouse initially until I felt comfortable... Now I make sure I do things for me at different groups. I realise now that I can be a better carer if I get to do the things I enjoy and need”.

“Yes, we were given a disabled badge, a bus pass, discounted cinema tickets and I got counselling. I was also given some money from Take a Break to spend how I wished and I bought a guitar. The support was very quick; the Carers Trust is very on the ball...It took a few weeks to organise the counselling but I think this was quicker than it would have been via the doctor”.

“XXXX was diagnosed in July 2013 and Crossroads started visiting that September, so it took a few weeks for the support to come through. I was so grateful that this support had been provided; I was really tired with having to look after him all the time and keep getting up in the night, so it was a relief when they attended. I understand that it takes a few weeks to sort everything and don’t think it took too long to get the support”.

“I received respite from the Carers Trust that allowed my husband and I to do things without our children, e.g. shopping. This helped to maintain our sanity. The Pathway was clear: if you needed support, Crossroads would give you it. I think the children’s service was easier to navigate back then. We received support pretty quickly; they are keen on providing a service whenever it is best for you. We needed support in the evenings as the children were at school during the day, and when my son got older we started to need support throughout the day, and they were very amenable to this”.

However two people, one caring for a partner with dementia and another their elderly father-in-law, felt that the support they received took too long. This was due to a lack of capacity within a service and staff turnover.

“We had an assessment from Crossroads which took a while to get and then they didn’t have any carers. I had to ring to remind them and was told there were no carers available. However, I have now got a Wednesday morning carer coming in”.

“It took a while but we eventually got there. I wanted a carer’s assessment for my father in law but they just sent me the paper work to fill in...They never got back to me – apparently my case contact had left which meant I would have to start again”.

For four people, the support that they requested was not adequate. One carer who works and looks after her husband, wanted him to be able to attend centres, groups and activities. It was felt that it took too long to organise this and there are not enough opportunities for him to leave the house. For another working carer who cares for her mother who has Alzheimer's, the care package they have in place is not adequate. She also feels that she has not been offered any support as a carer.

“The care package...not really, she's on a short term care package through the Council, it was only supposed to last six weeks and it's been six months now. The girls are good but I would like to have control over their visit times...I don't really get anything – no one cares about the carer”.

Another carer who looks after her son who has a mental health condition feels the medical care she has received has been poor as her son has never been stable. A mother caring for her son with Asperger's struggled to get any financial support.

“My first application was rejected, my second was accepted. It dropped a tier in 2010, at the time he was very distressed and was dropped to the lower tier of Carer's Allowance and Disability Living Allowance. I didn't know about the charities at that point so wasn't sure how to challenge it...we just accepted the lower tier”.

Finally, one participant echoed the views of the carer above and felt that they did not know whether they had received all of the support they needed as they did not know the extent of what was available to them. Moreover, a health professional asked what help they wanted but did not provide a list of services and it was felt that it should not be left to the carer to ask for services.

“The district nurse asked what I needed and said ‘there's loads available, I don't know where to start’. I thought, how can I tell you what I need? I can tell you what he's like, then you could provide services that match”.

### 3.3.6 Current support

Having gained an understanding of how their caring role began and the services and support they had initially accessed, participants were asked about their current role:

- Whether the support has changed over time
- What, if any support they receive
- Whether there are any barriers to receiving this support
- The quality of the support
- Suggested improvements to the support they receive

In terms of whether the support they have received has changed over time, responses varied. Of the 22 people responding to this question, five felt that the support they needed had not changed significantly but two pointed out that they knew where to go for help if their situations changed. Of the remaining participants five reported that the support they or their loved one received had actually reduced over time. This was because the cared for person's condition had improved, they had moved into

independent living accommodation or the support they receive is more appropriate now.

Twelve people reported an increase in the provision of care since the start of their caring role and for eleven, this was for the cared for person. They spend more time in day care, need more support within the home or needed adaptations. Two carers also reported needing more respite breaks and one, more emotional support. However for six participants there have been difficulties accessing this additional support. This was due to the length of time people have had to wait to hear back from the Council or health professionals about the additional support or simply not being able to access the support they needed. For one mother who cares for her son who has a congenital abnormality, the transition from children's to adult services has also negatively affected the family.

“Well we now have four days at a day centre instead of two, my wife's needs have changed... When she moved from two days to four at the day centre it took an age to organise, it was a battle. I went to the doctor and asked if we could see the psychiatrist again and she recommend five days but I only wanted four. We then went to the Council and had to chase them to get referral letters. I know there are cuts happening but if it goes [day care and respite support] I am not sure how I would cope...”

“He's getting old and I wanted a shower so he could wash easier – I was scared he would fall and hurt himself – I wanted a wet room. I went to the Council and they told me I could have a rail! I have a friend with a bad knee and they gave him a wet room when he went to his GP!...I also get respite. Before Christmas I spoke to social service to see if I could get 16 or 17 days instead of 14 as 14 days holiday wasn't really 14 days it was 16 or 17 to me. I was told they would get back to me that was 7 weeks ago”.

“Yes, his condition has progressed. He is now slower and can't do anything for himself which means I need more help but I've found it difficult receiving help from the doctor, they've been very slow and couldn't do anything”.

“I had a very good paediatrician for my son until he was 18, when we lost the support of the paediatrician. I have a supportive GP and my son has a cardiologist but we have lost the 'middle man': the paediatrician dealt with all the issues initially as a general medic which meant he knew my son well and recognised his needs...I have 32 hours of agency support to allow me to work part-time. My son has excluded himself as his autism has become more pronounced; he refuses to attend day centres. He needs to go into supported living to better meet his needs and for the sake of my family, but Gateshead Council are not offering any reasonable solutions. It is really difficult to access this new level of support as they are not recognising my son's needs and only offering unsuitable living arrangements. I employed a childminder for my youngest daughter and she also gets support from the Young Carers Service. My daughter has recently been diagnosed with clinical depression and this has been exacerbated by my son's behaviour. I have told social services about this

issue but they haven't taken this on board. The focus on the 'holistic family' is really ineffective and I'm really concerned for my daughter".

"I would like a full day respite a week but there are no carers available".

### 3.3.7 Barriers to support

Seven people felt that there were no barriers to them accessing support for themselves or the person they care for. However the remaining participants identified things that made it difficult for them to get the support they needed.

Barriers to support	No. of participants*
Reduction in services	4
Lack of time	4
Lack of information	3
Lack of transport	2
Refusal to access services	2
Timeliness of response	2
Asylum status	1
Employer issues	1
Family concerns	1
Lack of adaptations	1
Lack of support from Council	1
Staff changes	1

\*Participants could give more than one answer

The joint most commonly mentioned barrier was a reduction in the services that they had previously received. This includes services being taken away completely or a reduction in the quality of a service.

"We don't get any help or support now from social services. Once we got guardianship all this help ceased – it literally stopped as we walked out of court with the social worker – she said 'this is where I stop' and said goodbye to our grandson".

"The social worker was a great help but as with mental health services, the reduction in resources means her name is constantly being dropped off the list, so if you call up you don't get a named contact who knows you".

"I used to get the 'Take a Break' fund but this stopped last year...I used to rely on it for a break".

"My son used to be part of the outreach team; they would take him out which made it easier for me but that's gone, he doesn't have a social worker...he's very lonely. I am trying to sort out his PIP [Personal Independence Payment] but there's so much paperwork".

Not having the time to access services (two of this group are working carers) was also an issue for four carers.

“Time is the main thing. Also the other family commitments that I have. I help my mum with her shopping one day a week and help with all her household bills etc. I also look after my granddaughter two days per week”.

“It’s just time, working full time, my husband works away. We try to go to appointments but it’s difficult”.

“The [carers support] groups aren’t on at the times I can attend”.

A lack of information about the services and support available was also an issue for some.

“I don’t know what help’s available, he may want more help if he realised what was available to him”.

Not having the ability to physically get to services such as day care for the cared for person or support groups for the carer, was also highlighted by two people.

“I also took him to the Hardman Centre but the minibus doesn’t come to our house, we are in Wardley, it only goes to Leam Lane. I think he would like the Hardman Centre because they have activities and he is still active enough to take part”.

For two people, the cared for person’s refusal to attend centres and activities was a barrier and for one, has resulted in additional stress for the mother.

“My son’s refusal to attend the services has made it more difficult to access the support. Personal budgets work well if the person will engage with the services, but if not you will be left to struggle on your own. Sometimes I have to leave the house at midnight and sit in my pyjamas in McDonald’s car park because I just can’t cope anymore”.

As mentioned in section 3.2.6 having to chase up services or wait a considerable time for a response was also an issue.

“They [Gateshead Council] don’t make it easy...it’s complicated. I have to look services up, I called them but they haven’t called back”.

The fact that they are an asylum seeker is an issue for one carer as they are unable to access financial support apart from the £5 per day they get to live on. Another participant felt that their employer was not understanding or compromising and did not take into consideration that she was a carer, making it very difficult to both work and care. For another carer, her adult children have refused to let her put their father into respite so she is unable to take a break and another was unhappy that the doctor caring for her son had not yet been replaced after moving to another job. Finally, for one carer, the quality of support from the Council was an issue.

“I was quite frustrated with Gateshead Council when they did the assessment...When they phoned him [the main carer] they tried to do the assessment over the phone even though I had said I needed to be there as Dad plays down the things he does as a carer. They also tried to exclude XXXX [Gateshead Carers worker] from the process”.

### 3.3.8 Current support

As shown in the table below, both carers and the cared for person accessed support.

Type of support	No. of participants*
Support for carer	19
Support for cared for person	14
Financial support	9

\*Participants could receive more than one type of support

The table below shows the support or services that carers currently receive with support to enable the carer to take a break from their caring role, most frequently mentioned.

Support for carer	No. of participants
Respite care/Take a Break	9
Gateshead Carers groups	4
Gateshead Carers one-to-one support	4
Carers Trust one-to-one support	2

In terms of support for the cared for person, people accessed the following:

Support for cared for person	No. of participants*
Attendance at a day centre	5
Paid care at home	4
Adaptations	2
Cleaner	2
Independent living	2
Activity sessions	1
Church group	1
Free taxi service	1
Meals on wheels	1

\*Participants could receive more than one type of support

Finally, participants also highlighted financial support that they or their loved one receives.

<b>Financial support</b>	<b>No. of participants*</b>
Carer's Allowance	4
PIP/DLA	3
Child benefit	1
Child tax credits	1
Fostering allowance	1
Employment Support Allowance	1
Council tax relief	1
Personal Independence Payment	1

\*Participants could receive more than one type of support

### 3.3.9 Looking for support

Participants were asked how they find out about the support they are currently receiving. Of the 22 people responding to this question the most commonly mentioned method was being signposted by the hospital followed by word of mouth.

<b>Where carers looked for support</b>	<b>No. of participants</b>
Signposted by hospital	4
Word of mouth	3
Information provided by specialist carer organisation	3
Contacted Gateshead Council	2
Another carer	1
Approached by support service	1
Chance meeting	1
Leaflets through the door	1
No change in support	1
Searched online	1
Signposted by GP	1
Work for Gateshead Council	1
Don't know	2

### 3.3.10 Positive aspects of support

Carers commented on what they liked about the support they or the person they care for receives. As shown in the table below, the social and emotional support carers receive was most frequently mentioned followed by the opportunities to take time out of their caring role.

<b>Positive aspects of support</b>	<b>No. of participants*</b>
Social and emotional support for carer	11
Time away from caring role	6
Advice and information	5
Support at home for cared for person	5
Activities for cared for person	4
Financial support	2
Timeliness of support	2
Access to free transport	1
Flexibility in support	1

\*Participants could give more than one answer

In terms of social and emotional support, carers cited being able to have time to themselves, feeling listened to and being able to share common concerns.

“Gateshead Carers is somewhere I can go to get a break from my caring role when my siblings are home or when my mother is at college – I appreciate this time to myself”.

“Grandparents Plus, we value all of it. We feel heard and you can be yourself and express how you feel. You can stop being a carer for a while”.

“Gateshead Carers are great. XXXX is warm, empathetic, approachable, professional and my dad has confidence in her”.

“When you starting going along to the groups and you realise how much people are going though. It’s good to talk, you find things out”.

Six people also appreciated the services that were in place to enable them to have time away from their caring role although all were referring to short term respite which allows them to carry out everyday tasks such as shopping.

“The respite care on a Wednesday morning is a lifeline for me”.

“I get time to do the everyday tasks. The day care and respite mean I can wind down a little, sort the garden, go to appointments”.

“Time to myself and it allows me to do the weekly shopping for two hours on a morning. It also means I get to see and help out with my daughter”.

“The respite care is excellent as it gives both carer and cared for person a break”.

For five people, the advice and information they have access to was important and all cited Gateshead Carers in this respect. For one carer who is an asylum seeker, the advice around being recognised as a carer was invaluable.

“The best thing Gateshead Carers did was recognise me as a carer and make that official...until I was introduced to the Carers Centre, I didn’t realise I was a carer. I just felt I was doing my duty as a daughter....I was told the carer status would help our asylum case; at 18 I could have been separated from my mother which I was worried about. Having the carer label is actually very positive thing for me as it means I will not be separated from my mother”.

“They are just at the end of a phone. They help you access other information and support – help you navigate the system. I have been able to go on training and courses on different conditions”.

“For me it’s knowing that if I need any advice I can call them [Gateshead Carers] and they always call back”.

A further five people cited the support their loved one receives in their own home; two mentioned services directly whilst two highlighted the peace of mind they got from using the services.

“For me it’s peace of mind as we can’t take care of them as much as we would have wanted to”.

“It’s the reassurance that someone is looking after XXXX; without Crossroads I would not leave XXXX at home for more than half an hour. He gets to chat with someone new, and the staff are always helpful and friendly”.

“The care company we use is excellent – we have never had a bad carer and we always get the same carers which means we don’t constantly have to explain how to use his wheelchair and they can build up a relationship”.

“Meals on wheels is essential otherwise my husband would starve as I’m at work and it helps to control his insulin dependency”.

Activities that are available for the cared for person to participate in, such as spending a period of time each day at a day centre or weekly task based groups, were also appreciated.

“Blaydon Care Centre is a godsend...he goes to Blaydon three days a week... The person who runs the Centre is very amenable. They have collected him early before so I could go to my hospital appointment”.

“The day centre for my brother it’s his life, it’s part of his set routine”.

“For my father-in-law it’s the break and the opportunity to socialise”.

### 3.3.11 Suggested improvements to support

In terms of the current support or services they are receiving, 10 of the 26 carers felt that there were no improvements that could be made. However the remainder suggested improvements to the following:

Suggested improvements	No. of participants*
Support from Gateshead Council	6
Information provision	5
Activities for the cared for person	4
Emotional support	3
Respite/breaks for carers provision	3
Care at home	2
Access to support	1
Carers Trust capacity	1
Communication between services	1
Training for carers	1
Transport support	1

\*Participants could give more than one answer

Six people made suggestions for improvements to the support or specific services they received from Gateshead Council. People wanted a named person they could contact at the Council and ideally this contact would be face-to-face rather than over the telephone.

“Just give people a person to speak to. Contacts need to be face-to-face, a phone is no good and machines are even worse”.

Three people also asked for better quality support from the Council citing a poor experience with an Occupational Therapy assessment and the timeliness of assessment reports. One participant who cares for their relative who has a learning difficulty was also frustrated with inappropriate communication from the Council.

“We had a recent assessment for adaptations. They got my mum’s name wrong and were like a whirlwind and couldn’t wait to be away. They said would deliver adaptations yesterday but they didn’t arrive...Dad now has no confidence in them, not a good experience”.

“My brother has an assessment each year; it took three months to get the report from this last year and this year I received the same report as last year! He also gets a survey in the post from social services - he can’t read or write!”

“It took a very long time to get a Carers Assessment. The social worker we had been assigned was on long term sick and no-one had picked up our referral”.

Finally, one carer felt that the care package in place for their son who has a learning difficulty was not fit for purpose as he needed to go into supported living. However she was struggling with the Council to get a resolution which has been compounded by a lack of communication from the organisation.

“With regard to Gateshead Council, my son’s care package is around £70,000 per year but is not meeting his needs aside from his safety, and allowing me to work. This is not the best use of money, and as a carer they are not considering the needs of my family. I never get a full night’s sleep unless my son is at respite...Gateshead Council have offered four housing options, but they have been really inappropriate. It has been implied that I am being awkward by not accepting one of them, but I know my son would not last there and his needs would definitely not be met. This struggle has been ongoing for 15 months... There have been difficulties in communication – the Council told us they would respond on 15th February and still haven’t today [2nd March], despite my husband leaving three voicemails. This adds even further stress”.

Carers also requested additional or more timely information. Two people simply wanted more information to be “readily available” about the services on offer. For one carer the timeliness of the information was particularly important and they requested that information be available as soon as it became clear that the individual would need to provide a caring role for their loved one.

“Somewhere you can ring when it first happens, someone who has wide knowledge and can signpost, help to complete the forms and ring people. I’m not a shrinking violet but it’s not the same when you’re in that situation – you need an advocate to lift the stress”.

Four people simply requested access to more day activities for the cared for person with one carer who looks after her brother with a degenerative physical disability, more one-to-one support.

“I would like more activities available and trips out for XXXX which would give more time to myself. I would also like care packages to involve more one-on-one support”.

“I know there have been funding cuts for day trips but I would like more so he is not stuck in the house. There should be more activities/groups and social things he can part take in and I would like the current activities to be longer”.

Considering respite care, all three carers wished that they could have more and one specifically requested support via Take a Break which they previously had access to but no longer receive. Another wanted some “in- house respite...someone to stay with XXXX may solve some problems”.

Another three people felt that there was a need for improved access to emotional support. One carer described telling their GP they were feeling suicidal and the GP “just gave me a leaflet and asked if I still wanted my prescription”. Another sung the praises of their clinical psychologist but felt that they knew of a number of other people caring for someone who had had a stroke who would also benefit from such support.

Two people who have paid carers who come into their home felt that the quality of the services is poor.

“Just the time of the visits – I wish I could control them or space them out better or perhaps longer visit so they talk to her”.

“The quality of the care provided...I feel like the girls who come are not fully trained and rush through to get to their next appointment. The staff are changed without asking or us being notified and are often late. They should spend more time with XXXX to get through his list of needs”.

One person also mentioned a lack of capacity at the Carers Trust as they had waited a period of time before getting support as there were no carers available and another requested “earlier access to support”.

One participant who cares for her husband who has had a stroke and has Alzheimer’s asked for training to help her care for her husband in their own home. As mentioned earlier, another wanted transport to get her husband to a day centre.

### 3.3.12 Services most valued

Carers were asked to think about the support they or the person they care for receives and identify what services or supports they value the most. Some people simply mentioned the name of a service whilst others talked about what support it offered.

Valued service or support	No. of participants*
Day centres/activities for cared for person	8
Respite/breaks for carers	8
Emotional support	6
General support from specialist carer organisation	5
Care at home	4
Advice	3
GP surgery staff	1

\*Participants could give more than one answer

Eight people valued the facilities and activities available to the cared for person and several felt strongly that this needed to continue.

“Blaydon – if they closed I don’t know what I would do”.

“Kites Rise and The Grove has been brilliant as a temporary solution – my youngest daughter can relax, and we have a calm house”.

“Shadon House as it provides company for my husband and he gets to see other people”.

“The day centre is my brother’s life; it is what he lives for, what he gets up in the morning for. He has a set routine and the day centre is his routine. I purposely moved house so my brother could walk there”.

“Inspired Support [an organisation that supports people with autism spectrum conditions and learning disabilities], for my son”.

A further eight valued the respite care they received; they have time to go and socialise, go shopping and have support to take the cared for person out.

“We also have respite hours with our care company as part of our package; up to 240 hours per year. This means I can ask for extra help when needed. For example we had a family christening and a regular carer came with us to look after XXXX so I didn’t have to worry about him”.

Six people identified that the emotional support they received was most important to them and cited the following services:

- Grandparents Plus
- Carers Trust
- Gateshead Carers

Support from a specialist carer organisation in whatever form was important to five people; three people stated that the Carers Trust was very good and two valued Gateshead Carers. For four people the provision of care services in the home was the most important; having carers coming into the home, meals provided or a cleaning service were all mentioned. A further three people valued the advice they could call upon from Gateshead Carers.

### 3.3.13 Additional services or support

Finally, carers were asked whether they felt that there were any additional services or support they or the cared for person needed. Fifteen people responded to this question and the following were suggested:

<b>Additional services or support</b>	<b>No. of participants*</b>
Respite/breaks for carers	4
Emotional support	3
Information	3
Communication with health and social care professionals	2
Employer support	2
Services for cared for person	2
End of life care	1
Independent living support	1
Simplified paperwork	1
Total	19

\*Participants could receive more than one type of support

Four carers wanted more opportunities to take time out from their caring role although funding cuts, a lack of transport and poorly thought out support were barriers to this.

“My father-in-law [the carer] is taking part in a befriending scheme, where for 10 weeks someone comes along and takes him out but the issue is the travel – by the time he’s organised and out the house most of the session is lost”.

“I used to attend creative writing and singing groups for carer’s which I think the funding has been pulled for. I would love there to be more groups to join so I can switch off and leave my worries at home for an hour or so”.

In terms of emotional support one person wanted more support for carers of people with substance misuse. Another asked for more opportunities to talk and share their thoughts whilst a third requested:

“Access [to] counselling services again and a mindfulness group. I would also like more consistent contact from the Carers Trust such as bi-weekly ‘cause I feel like this has cooled off too much due to me not needing their support as much”.

More accessible information for carers about what services are available for them and the cared for person from the outset was also suggested.

“There should be someone you can contact to talk to and support to get the help you want...someone who can signpost you to the services to get the help as carers are vulnerable”.

“For me it’s about the coordination of information to help people access support and services right. My husband is a social care trainer and I work in the Council and we struggled to access help”.

Two people highlighted a lack of communication with health and social care professionals and asked to be better involved in the decisions around the care of their loved ones. A further two carers, although having understanding employers, felt that they could be offered more support in this respect.

“I would like more recognition for carers, particularly at work...I want to work and my employer is good to me but carers don’t get recognised”.

“For me, more time from my employer to go to appointments. My employer is good, we work flexible hours but it’s still hard”.

In terms of services for the cared for person, one mother asked that their daughter see a health psychologist more frequently than the five monthly appointments they currently get, whilst another wanted access to day time activities for young adults with learning difficulties.

One carer felt that there should be more encouragement to help people into independent living and another called for more simplified systems for carers.

“The paperwork at the beginning is very frustrating. Even the paperwork for the Carers Assessment was ridiculous. Things need to be made as simple as possible for carers as you feel like you’re constantly chasing things up”.

Finally, one participant who cared for her mother with Dementia before she died asked for greater awareness from care workers around caring for people at end of life.

“I would like to see more help to keep family members at home towards end of life. There should be more acknowledgement about end of life and re-education for staff members treating patients coming towards their end of life pathway as my mother was treated as having Alzheimer’s rather than a woman coming to the end of her life”.

In addition to these suggestions four people raised concerns that services were going to close with three people highlighting day centres. They emphasised the importance of these services in terms of themselves and the person they care for.

“I am grateful for what I have – I just don’t want it to be cut back or cut altogether. I would end up having a breakdown. I have contemplated suicide a few times, the stress is relentless”.

“Councils need to save money and I’m concerned it will close...I know this is a survey about how to save money but I need Blaydon; it’s a life saver – the staff are so lovely”.

“The day centre is good, they do a lot of activities my only issue is the possible closure, I have been told by a social worker that the closure of the day centre would be detrimental to my brother’s health. My brother sees it as his school. If it closes I would have to give up my job...which would also mean I could not access benefits like job seekers...I just don’t want the day centre to close”.

“The difficulty I have is how mental health services are being cut, people don’t understand the pressure of the situation, it doesn’t just come and go, it’s always there... I am almost pleased my son had his mental health issue earlier as provision is so much less than it used to be”.

### 3.4 Summary

As can be seen from the information gathered above there is clearly a large variety of services and support on offer to carers within Gateshead, provided predominantly by Gateshead Carers and the Carers Trust. Many carers make good use of this support. People in particular value the time they can have away from their caring role whether it be a few hours to do the shopping or longer funded holidays. The emotional support provided is also very much appreciated in the form of less formal peer support and activity groups or one-to-one support. Carers also generally had positive experiences of support to access health services, benefits and financial support. Young Carers valued the support they got from the Carers Trust and at school and the opportunities it gave them to take part in activities, help shape policy and talk to peers.

However there are barriers to accessing this support and across all interventions there were issues with carers not being aware that support existed, the scope of the support and how to access it. In particular only a minority of carers had experience of brokerage support, caring support and training, support to shape policy, emergency support and support around housing. In terms of the support more familiar to carers, a number of gaps in services were highlighted in particular in relation to support around changes and transitions and support provided by the Council and employers. In terms of particular groups, kinship carers and older carers highlighted a reduction in support whereas a BME group had simply never accessed any support.

Support for the cared for person was the focus of carers at the beginning of their caring journey and access to day centres and activities was valued the most. However barriers to accessing support included its organisation, a lack of opportunities and control over services at home. A reduction of services was also highlighted and carers were concerned about any further reductions and the impact on their loved ones.

# Section 4: Recommendations

## 4.0 Recommendations

It is suggested that NGCCG and Gateshead Council take time to analyse the findings of this project in order to understand how they can support the needs of unpaid carers and develop future services. This report should also be viewed in conjunction with the results of the Council's online survey and LEB activity. However, from the findings of this engagement some specific recommendations have been made below which should be considered in terms of practicality and implementation.

### 4.1 Key recommendation

It is suggested that greater promotion of all of the interventions available to carers in Gateshead as highlighted within the Carers' Hub tool, is needed. This should include the scope of the support or service, who is eligible to access it and how to actually go about accessing it. This information should be available to carers when they are first identified as such. It is recognised that there is not a formal process of identification therefore any professional who is in contact with the carer should have access to this information for distribution. The information should also include contact numbers for Gateshead Carers and the Carers Trust to enable carers to talk through their needs. Once a year carers should receive a review from workers where they go through a checklist of all of the support available to make sure they have the most up-to-date information available to them and are accessing all the support they require.

There was an expectation from some that they should receive information from the Council. It is suggested therefore that the roles and responsibilities of the Council and any services and support that it has commissioned, is also widely publicised.

### 4.2 Interventions

The recommendations suggested below may already be in place but have been included as they highlight again, the issue of information provision.

#### 4.2.1 Brokerage

There is a need for greater support to enable carers to manage personal budgets. As funding sits with the local authority it is suggested that there is access to dedicated support within the Council. Access to a website including all of the services could be set up but alongside this workers should be available to talk to carers through the process. This should include making clear from the outset the legalities involved such as becoming an employer and any safeguarding requirements.

#### 4.2.2 Access to health and wellbeing

GPs should have greater awareness of which of their patients are carers and provide support accordingly. There should be a protocol in place whereby patients are directly

asked whether they are a carer periodically and this should be recorded and accessible to all practice staff. Carers could be given flexibility in accessing appointments and be offered an annual health check as standard, regardless of age.

#### 4.2.3 Caring support and training

There is demand for training around first aid and moving and handling in particular. It is suggested that all carers are offered first aid training in the first instance and at the beginning of their caring role. These and any courses should be offered at a variety of times including evenings and weekends to enable accessibility for all. Carers should also be able to attend courses more than once.

Before the cared for person returns home for the first time after their health has deteriorated it is suggested that the cared for person should be asked whether they require any specific training or advice.

#### 4.2.4 Support for young carers

Most young carers feel supported within school but for some there is not or very little acknowledgement of their role as a carer. Schools should have a register of all young carers and flexibility should be given to them in terms of timekeeping and homework. Counsellors should be available to young carers at school outside of lesson time as should extra support from teachers.

It was felt that funding for activities had reduced. Consider providing additional funding in this respect.

#### 4.2.5 Changes and transitions

There were requests for more support for carers during transitions which were often very stressful. In particular it is suggested that kinship carer support be reviewed to ensure that support is available from the outset and this includes any financial support.

Timely information is also needed in advance of transition periods to inform carers of what changes to support they should expect. As carers get older they should also be informed of any changes to support and particularly financial changes associated with them reaching pension age.

Information around the process for transitions should also be made available to carers at the appropriate times, for example, in advance of a carer getting to the stage where they can no longer look after the cared for person and before the transition to independent living.

#### 4.2.6 Emergency support

It is suggested that there needs to be greater explanation around emergency plans so that carers know exactly what they mean and when to implement them.

#### 4.2.7 Breaks

In relation to the Take a Break fund there was some confusion over whether it still existed and whether it could be used more than once. If any services end or have rules about use this information should be communicated to carers as part of the process outlined in section 4.1 above.

More support to access longer breaks which should also take into consideration any accessibility requirements and the needs of working carers, is also needed.

More generally the research identified the value unpaid carers place on short term respite, even if only for one or two hours per week, allowing them to carry out their own daily tasks. This should be acknowledged.

#### 4.2.8 Peer and community support

Despite knowing of groups available at Gateshead carers a group of Muslim women carers did not access any support. It is suggested that an audit could be carried out of the support groups available, looking at the types of carers that are supported to ascertain whether there are any gaps in provision. Furthermore, further research could be carried out with this group to understand their group support needs.

#### 4.2.9 Access to benefits and financial support

As part of the annual review suggested in section 4.1 above, a review of the benefits carers and the cared for person are receiving should also take place.

#### 4.2.10 Access to work and training

There is a need for greater awareness amongst employers around the number of carers they employ and the possible impact of their caring role. It is suggested that a Carer's Passport be promoted within all workplaces.

There was no evidence of support to access training. Access to this support should be reviewed to ensure that people are being offered training where appropriate.

#### 4.2.11 Housing support

It is suggested that the Council develop a register of vulnerable households so that they can give priority to carer's homes when for example a boiler breaks down.

#### 4.2.12 Support from Gateshead Council

The Council should put in place systems to ensure that cases are passed on to other staff when social workers leave.

It is also suggested that a protocol is established which outlines the number of days carers or their loved ones should have to wait for telephone calls, referral letters, assessment reports etc. This should be accessible to all carers.

### **4.3 Support for cared for people**

Day centres and activities for the cared for person are valued most by carers. There is felt to be a lack of opportunities available in this respect and a belief amongst some that they are being reduced and are at threat of closure. It is suggested that these services are maintained where possible and the Council acts to allay carers' fears.

The scope of any paid care at home should be clearly outlined before carers set-up any support. This should include whether there is any opportunity for changing the visits.

# Appendices



## Interview questions

### Background

1. **Can you tell us how your caring role started – what tasks, activities did you start doing?**
2. **Has this changed over time? What is it like now?**  
*Did this happen gradually, was it an event – sudden illness*

### Start of your caring role

3. **At what point did you start identifying yourself as a carer? How did this happen?**
4. **At what point did you look for help or support?**
  - a. *Financial, medical- your health, their health, work, other life pressures, other dependants...what was the trigger*
5. **What help and support did you want at that time?**
  - a. *Was this support for you or the cared for person*
  - b. *Financial, medical- your health, their health, work, other life pressures, other dependants*
6. **Where did you look for this help?**
  - a. *Where did you start?*
  - b. *How easy was it to find?*
7. **Did you get what you wanted? If you didn't get any what did you do?**
  - a. **How long did it take to get this support?**

### Current caring role

8. **Has the support or help you need changed over time?**
  - a. *Has your needs changed – what do you get now, how is it different*
  - b. *Has the person you cared for needs changed*
  - c. *How easy or difficult was it to change or access different support*
9. **Is there anything that prevents you from accessing support or makes it difficult, either for yourself or the person(s) you care for?**
10. **What support or help do you currently access?**
  - a. *For the cared for person – (Financial, support)*
  - b. *For yourself – (Financial, support)*
11. **How did you find out about this support?**
  - a. *How easy was it to find?*
12. **What's good about the support you or the person(s) you care for receive?**  
*Financial (benefits), support services – social and emotional (this group), practical support – day-care, respite care, meals on wheels, equipment services, blue badges*
  - a. *How does it help you*

**13. Is there anything that could be improved?**

**Round up**

**14. Thinking about the support you and the person you care for receive, what services do you value the most?**

**15. Are there any additional services or support you would like to have access to – is there anything missing?**

*This could include more of something you're already accessing*

## Appendix 2 – Pre-questionnaire

**Q1 Do you provide unpaid care for a:**

Family member	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
If yes who.....				
Neighbour	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Friend	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
Someone else	Yes	<input type="checkbox"/>	No	<input type="checkbox"/>
If yes who.....				

**Q2 How long have you been a carer?**

.....

**Q3 How many people do you care for?**

.....

**Q4 Please fill in the table below regarding the person(s) you care for**

	Relationship e.g. Mother, Father	Do they live in Gateshead?	How old are they?
<b>Person 1</b>		Yes <input type="checkbox"/> No <input type="checkbox"/>	
<b>Person 2</b>		Yes <input type="checkbox"/> No <input type="checkbox"/>	
<b>Person 3</b>		Yes <input type="checkbox"/> No <input type="checkbox"/>	

**ABOUT THE PERSON(S) YOU CARE FOR**

**Q5 What is the condition(s) of the person(s) you care for or reason(s) why they need your care? (Please ✓ all that apply) (If you care for more than one person please use second and third rows)**

Dementia e.g. Alzheimer's	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Problems connected to ageing (other than Dementia)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A physical disability	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sight or hearing loss	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A mental health problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A learning disability or difficulty	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Long- term illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Terminal illness	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alcohol or drug dependency	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Autism spectrum disorder	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Asperger's syndrome	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Kinship (a child who cannot be cared for by their parent(s) lives with a relative or family friend)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other condition or reason (please state in the box provided)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

.....

**ABOUT YOU**

**Q6 Gender**      Male            Female     

**Q7 How old are you?**      .....

**Q8 What best describes what you are doing at present? (Please ✓ one box only)**

- |  |   |
|--|---|
| <input type="checkbox"/> Employed in full-time job (30 hours plus per week)  | <input type="checkbox"/> On a government sponsored training programme |
| <input type="checkbox"/> Employed in part-time job (under 30 hours per week) | <input type="checkbox"/> Unemployed and available for work            |
| <input type="checkbox"/> Self employed full or part time                     | <input type="checkbox"/> Permanently sick/disabled                    |
| <input type="checkbox"/> Looking after the home                              | <input type="checkbox"/> Wholly retired from work                     |
| <input type="checkbox"/> Full-time education at school,                      | <input type="checkbox"/> Doing something else (please specify)        |
- .....

**Q9 Do you have any of the following? (Please ✓ all that apply)**

- |                                     |                          |
|-------------------------------------|--------------------------|
| A physical impairment or disability | <input type="checkbox"/> |
| Sight or hearing loss               | <input type="checkbox"/> |
| A mental health problem or illness  | <input type="checkbox"/> |
| A learning disability or difficulty | <input type="checkbox"/> |
| A long-standing illness             | <input type="checkbox"/> |
| Other (please state)                | <input type="checkbox"/> |
- .....
- None of the above

**Q10 To which of these groups do you consider you belong to? (Please ✓ one box only)**

<b>White</b>		<b>Black or Black British:</b>		<b>Other</b>	
British	<input type="checkbox"/>	African	<input type="checkbox"/>	Arab	<input type="checkbox"/>
Irish	<input type="checkbox"/>	Caribbean	<input type="checkbox"/>	Any other background	<input type="checkbox"/>
Gypsy or Irish Traveller	<input type="checkbox"/>	Other	<input type="checkbox"/>		
Other	<input type="checkbox"/>				
		<b>Asian or Asian British:</b>			
<b>Mixed</b>		Indian	<input type="checkbox"/>		
White and Black Caribbean	<input type="checkbox"/>	Pakistani	<input type="checkbox"/>		
White and Black African	<input type="checkbox"/>	Bangladeshi	<input type="checkbox"/>		
White and Asian	<input type="checkbox"/>	Chinese	<input type="checkbox"/>		
Other	<input type="checkbox"/>	Other	<input type="checkbox"/>		

**Q11 What is your postcode? (Your postcode does not identify your individual address)**

.....

**Q12 How did you find out about this consultation?**

.....

## Further engagement

If you would be happy to discuss your experiences as part of a case study and/or be consulted regarding further developments please tick the box below and leave your contact details.

- I am happy to be contacted to discuss my experience in more detail
- I am happy to be contacted regarding further developments related to the services and support available for carers.

Name .....

Telephone.....

Postal address.....

Email.....



## Appendix 3 – Participant profile

### Carer profile

#### Gender

	No. of participants	% of participants
Male	20	22.2
Female	70	77.8
Total	90	100.0

#### Age

	No. of participants	% of participants
Under 8	9	10.0
8-17	16	17.8
18-24	3	3.3
25-34	2	2.2
35-44	2	2.2
45-54	16	17.8
55-64	23	25.6
65-74	10	11.1
75-84	5	5.6
No response	4	4.4
Total	90	100.0

#### Employment status

	No. of participants	% of participants
Employed in full-time job (30 hours plus per week)	12	13.3
Employed in part-time job (under 30 hours per week)	13	14.4
Self-employed full or part-time	4	4.4
Looking after the home	4	4.4
Full-time education at school	9	10.0
On a government sponsored training programme	0	0.0
Unemployed and available for work	1	1.1
Permanently sick/disabled	2	2.2
Wholly retired from work	13	14.4
Doing something else*	10	11.1
Asylum seeker	4	4.4
No response	18	20.0
Total	90	100.0

\*Seven of those who were doing something else were full-time carers and one was a foster carer

## Do you consider yourself to have a disability?

	No. of participants	% of participants
A physical impairment or disability	1	1.1
Sight or hearing loss	2	2.2
A mental health problem or illness	7	7.8
A learning disability or difficulty	0	0.0
A long-standing illness	6	6.7
Other	15	16.7
None or the above	29	32.2
No response	30	33.3
Total	90	100.0

## Ethnic background

	No. of participants	% of participants
White British	74	82.2
White Irish	1	1.1
Gypsy or Irish Traveller	0	0.0
Any other White background	1	1.1
Mixed White and Black Caribbean	0	0.0
Mixed White and Black African	0	0.0
Mixed White and Asian	0	0.0
Any other Mixed background	0	0.0
Asian or Asian British - Indian	2	2.2
Asian or Asian British - Pakistani	5	5.6
Asian or Asian British - Bangladeshi	1	1.1
Any other Asian background	3	3.3
Black or Black British - African	0	0.0
Black or Black British – Caribbean	0	0.0
Any other Black background	0	0.0
Chinese	2	2.2
Arab	1	1.1
Any other ethnic group	0	0.0
Total	90	100.0

### Location – first part of postcode

	No. of participants	% of participants
DH3	3	3.3
NE6	1	1.1
NE8	18	20.0
NE9	15	16.7
NE10	14	15.6
NE11	3	3.3
NE16	4	4.4
NE21	4	4.4
NE31	1	1.1
NE38	2	2.2
NE39	2	2.2
NE40	3	3.3
SR2	1	1.1
No response	19	21.1
Total	90	100.0

### Caring role

#### Who do you care for?

	No. of participants	% of participants
Family member	88	97.8
Neighbour	1	1.1
Friend	0	0.0
Someone else	0	0.0
No response	1	1.1
Total	90	100.0

## Family member

	No. of participants*	% of participants
Father	8	7.8
Mother	20	19.4
Father-in-law	1	1.0
Mother-in law	1	1.0
Husband	12	11.7
Wife	1	1.0
Son	27	26.2
Daughter	5	4.9
Brother	8	7.8
Sister	7	6.8
Granddad	1	1.0
Grandson	4	3.9
Granddaughter	2	1.9
Grandchild	3	2.9
Uncle	1	1.0
Aunt	1	1.0
Cousin	1	1.0
Total	103	100.0

\*Participants could care for more than one family member

## How long have you been a carer?

	No. of participants	% of participants
Less than one year	0	0.0
1-2 years	11	12.2
3-4 years	22	24.4
5-6 years	7	7.8
7-8 years	8	8.9
9-10 years	6	6.7
Over 10 years	24	26.7
Not sure	2	2.2
No response	10	11.1
Total	90	100.0

## How many people do you care for?

	No. of participants	% of participants
One	64	71.1
Two	14	15.6
Three	3	3.3
No response	9	10.0
Total	90	100.0

### Do they live in Gateshead?

	No. of participants	% of participants
Yes	104	94.5
No	6	5.5
Total	110	100.0

### How old are they?

	No. of participants	% of participants
Under 8	4	4.0
8-17	14	13.9
18-24	7	6.9
25-34	12	11.9
35-44	17	16.8
45-54	10	9.9
55-64	5	5.0
65-74	9	8.9
75-84	7	6.9
85 and over	4	4.0
Deceased	2	2.0
No response	10	9.9
Total	101	100.0

### Condition or reason why they need care

	No. of participants	% of participants
Dementia e.g. Alzheimer's	11	7.4
Problems connected to ageing	7	4.7
A physical disability	21	14.1
Sight or hearing loss	6	4.0
A mental health problem	19	12.8
A learning disability or difficulty	13	8.7
Long- term illness	10	6.7
Terminal illness	0	0.0
Alcohol or drug dependency	8	5.4
Autism spectrum disorder	7	4.7
Asperger's syndrome	2	1.3
Kinship	10	6.7
Other condition or reason	21	14.1
No response	14	9.4
Total	149	100.0

**Other condition or reason:**

	<b>No. of participants</b>
Arthritis	5
ADHD	4
Diabetes	2
Epilepsy	2
Liver disease	2
Seizures	2
Stroke	2
Fetal Anti Convulsant Syndrome	1
Fibromyalgia	1
Fibrosis	1
Heart condition	1
High blood pressure	1
Kidney problems	1
Multiple Sclerosis	1
Polycystic Ovaries	1
Postural Tachycardia Syndrome	1
Smoker	1
Supraventricular Tachycardia	1
Thyroid problems	1

## HAVE YOUR SAY...

# Do you provide unpaid care to a family member or friend?

Gateshead Council and NHS Newcastle Gateshead Clinical Commissioning Group are carrying out a review of services for unpaid carers.

A local charity, Involve North East is speaking to unpaid carers to gather their views.

We would like to hear about the services you use:

- What works?
- What doesn't work?
- What's missing?
- What you would like in the future?

If you would like to share your experiences please contact Dan or Julie at Involve North East

0191 226 3450

[dan@involve.org.uk](mailto:dan@involve.org.uk)

by **Friday 24 Feb**