

# 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.