**Engagement with carers Spring 2018 – what adult carers and parent carers told us**

**The engagement approach**

Extensive engagement was carried out to get the views of adult carers and parent carers on current and future support provision. Two main methods were used:

1. A questionnaire analysed and reported by the Carers Project Team (a copy of the questionnaire can be sent on request).
2. A series of carer workshops and discussion in small groups (a copy of the agenda used can be sent on request)

The questionnaire was widely publicised through channels including:

* Gloucestershire County Council
* Gloucestershire Clinical Commissioning Group
* Current providers of carer services
* Healthwatch Gloucestershire
* Gloucestershire VCS Alliance.

**75 carers attended workshops**

**15**

**workshops held countywide**

**346 respnses to questionnaire**

***NB This report focuses on the responses from adult carers of adults and parent carers. There is a separate report for young carers and young adult carers. There is also a separate report on what professionals told us.***

A list of the workshops held, the agenda and a copy of the survey are attached as appendices to this report. Please note that not all respondents answered every question.

**Responses to the survey: Demographics**

| **2. How many hours do you provide care per week?** | | | | |
| --- | --- | --- | --- | --- |
|  | | | **Response Percent** | **Response Total** |
| 1 | 1 - 19 hours | |  | | --- | |  | | 22.67% | 78 |
| 2 | 20 - 49 hours | |  | | --- | |  | | 16.86% | 58 |
| 3 | 50+ hours | |  | | --- | |  | | 60.47% | 208 |

**What support have you received (tick all that apply)**

The graph above shows the responses to this question. It is encouraging that over 50% of respondents are aware of universal services available to carers, including 65% accessing information and advice and over 50% of respondents have had a health check by their GP. Though, it is worth noting that those who responded to this had to check ‘yes’ to the questions above, about having received services and this was only 45% of the response rate. Approximately 35% of respondents answered the question above stating they were not aware of support available.

**Key Themes from free text questions and answers**

**Short Breaks and Respite (including day centres and companion/sitting services)**

**“short breaks to recharge batteries”**

Access to short breaks and respite was a consistent, universal theme. “Overnight respite essential for us to be able to carry on caring”.

When asked ‘Thinking about your caring role, what would make the most difference to you’ (Q7) 47 people responded with short break or respite and 5 people said time. This equates to 20% of respondents. It was by far the highest response, more than 3 times higher than money.

What is important to carers is that it is accessible and timely, as well as regular and flexible. There are some issues with how short breaks are currently accessed, with processes that take a long time to return a response, and that are not accessible to all carers, with some respondents citing this as something that could be improved: “How short breaks are assessed and how long they take to agree to”.

Day Centres were also highlighted as a good way to get a short break, whilst the cared for is offered stimulating activities. Some respondents citing this as something that could be improved: “more day care facilities not just for ' sitting ' but practical motivated support.” And “More time to rest or to get away from the situation without feelings of guilt or neglect”.

There was also a lot of consternation regarding the term ‘sitting service’, with some suggestions that the term is renamed ‘companion service’.

**“The break I get from caring duties is what I value very much”**

**Emotional support (Peer support/counselling)**

**“Often it's the emotional support that is the difference between thriving and breaking down”**

Peer support was rated as the third highest response to Q7, with responses such as “I could not manage without the support of my fellow carers”. It also featured in the question ‘What could be improved’ (Q6), with 9% of respondents citing it. Roughly 50% of these carers stated that peer support groups required co-ordination. “Have a support worker for our carers group (was taken away from us so now pressure is on me)”.

These support groups need to be locally available, as one person put it: “Support group with other Carers in my locality” and can make a big difference in problem solving, as well as offering emotional support:

**“Having people to talk to in the same situation, and comparing problems and ways to overcome them.”**

**“Relating to other people who have experience and can give me ideas or inspire me”**

They can also help with overcoming social isolation and loneliness: “Not feeling totally isolated and alone”.

There were also suggestions for out of hours support, in the form of a helpline “Someone to call on out of hours maybe when I need to speak to a "friend" - similar to Samaritans”

Counselling was cited a few times as being very effective, “Counselling gives me a chance to talk to someone openly about the problems I face”, but timely access is important for support such as this “Counselling works well but the wait when you most need it is a real issue”.

**Carer health and wellbeing**

**“To be able to keep fit. If I don't feel fit it's difficult to manage as a carer”**

Carers stated the importance of being able to maintain their own health and wellbeing. A few carers mentioned the importance of basic health and wellbeing, such as “a few good nights solid sleep”. Others suggested ways in which maintaining their own health and wellbeing would be improved, including, “Carers need to be in good health- so we need a discount when visiting places like a health club, swimming pool” and also the support of GP’s: “GP's could do more to help Carers. As a Carer there are times that I need to be able to plan my personal medical appointments to fit in with my Caring role. GP appointment systems are too inflexible. GPs also need to inform carers of what specific services are available to Carers. There needs to be consistency throughout the County.”

There have been examples of GP Practices offering carers support, such same day appointments for carers, double appointment times for carers as standard and carer coffee mornings at the GP Practice. There was also a lot of anecdotal evidence regarding the number of carers on anti-depressants and anti-anxiety medication, as well as other unhealthy ways to cope, such as alcohol:

**“I have looked after my spouse for the last 10 years. My physical and mental needs have dramatically decreased, to becoming a borderline alcoholic, anything to cope with my depression and misery”.**

**Timely, personalised services (Including carer assessments)**

**“If I could have had help earlier”**

The timing and accessibility of many support services were highlighted throughout the survey, examples including:

* Carers assessments: “I have requested a carers assessment but informed it not be for 3 months”
* Support groups: “Being able to talk to people in the same situation. Any groups that are available to attend are between 9-5 when people are working”
* Positive Caring Programme: “I'd like to attend the Positive Caring programme (ideally in Cheltenham or Gloucester as I'm reliant on public transport) which I think would cover this kind of thing, but at present it only seems to run in the daytime, which would mean taking quite a lot of time off work.”

There was a feeling from some carers that the carers assessments were of little benefit:

**“Even when the assessments have been done my needs for respite or help with my Caring role has been met on two occasions only.”**

**Employer support**

**‘I lost my job. I had to make a decision between my son and my job’.**

When employers are flexible and supportive it can make a big difference, as one respondent said: “As I work full time my compressed hours 9-day fortnight greatly help with appointments for my son and being able to work flexibly makes a huge difference. Continuing with such flexibility for me is a must otherwise I would have to consider a change in job role”

Employer support came up in the survey a lot more than in the workshops. This is probably because the workshops were all held in the daytime, and we need to consider this for future engagement.

Most employer support that is required is understanding and flexibility “More support at work in the form of time to go to the hospital appointments with specialists - as you can never easily arrange these to fit outside of work hours and it eats up so much leave. To be able to have more flex in a month to help with hospital visits etc. To be able to talk to your employer and gain such support - with no guilt!”

**Feeling valued and respected (including attitude of the workforce)**

**What would make the most difference to you?**

**“being recognised for the value it gives”**

Many carers who have responded feel that their role is not valued or respected at all levels of society, from government to individual professionals, such as social care staff and healthcare professionals. As one respondent stated: “Treat me as a responsible adult and allow me to choose what's best for me; treat me with respect as an equal and capable partner who, together with my husband himself and medical and other professionals, can put together a package of support that helps us both and enables me to care for him for as long as possible.”

Carers would welcome a more positive attitude from statutory staff:

**“More encouragement from NHS staff to live with positive attitude and attempt what is possible within capability”**

as well as less focus on the ‘system’ and more on them as an individual:

**Not being promised help by professionals only for them not to keep their promises. Not being made to feel like once you are ticked off someone's list you are forgotten about. Being told to go online- I am not online”**

**“feels like there are more hoops to jump through to get support and it makes you feel less valued - the old grants seemed better and made a difference”**

**Joined up services and co-ordinated approaches**

**“Clear, timely information particular from GCC and my sons support provider and for the various bodies involved in his life to communicate with one another and to communicate honestly with me.”**

Clear and consistent communication is key and carers would like more joined up information and more co-ordinated approaches: “Direct contact with a knowledgeable individual who can help me coordinate services / support as and when I need it”.

**Contingency planning (when you can’t care, when carer dies, when cared for dies)**

**“Some pre-arranged plan for future if I am unable to continue as a carer”**

Carers worry a lot about what would happen to their cared for if something happened to them and they are unable to care. For emergency situations, there is the Gloucestershire Carers Emergency Scheme, which, as one respondent stated: “allows peace of mind”.

However, for longer term, more final situations, carers state they are not supported to put plans in place and one person said “Knowing my grown up son enduring mental health illness, will be cared for through a scheme such as Shared Lives Plus, once we, his parents can no longer carry out the task. There has to be a PLAN!”

There is also a need to support carers once their cared for dies and they lose their caring role, leaving some carers to feel lost:

**“Know nothing about support - my husband has died and I don't know what to do”**

**Long term, proactive support**

**“Gloucestershire provides excellent short term but long term is difficult”**

When asked what could be improved for carers support, long term support tied with peer support as the most common theme. Some carers suggested this needs to be proactive support, with someone contacting them every now and then to ‘check in’.

**Accessible and timely information, advice and guidance**

**“Knowing where to turn to for support when I need it”**

Generic, universal information needs to accessible as well as timely, with many people stating it would have helped if they had been provided information as soon as they became a carer, for example, when their cared for is diagnosed: “To have support and advice from the first moment the person I care for is diagnosed.” As well as when issues arise: “Helpline for help and advice when a problem occurs”

One service that was cited as very helpful for information, advice and guidance was the Hospital Linkworker and it was suggested that this could be expanded to GP Practices: “Workers need to be embedded in GP Practices to raise awareness, its why [the hospital linkworker] role works at the hospital.”

Carers want information about what support is available: “More information about help available.” As well as more information and guidance on financial support, such as information on benefits:

**“More information on benefits. When my mum was in hospital and my carers allowance stopped I had trouble finding out what I was entitled too”.**

Carers who self-fund care and support feel unsupported with regards to information and advice, as one carer put it: “For me personally I am quite informed about Carer's service. I do not think there is enough information available 'in the community' regarding services for carers of individuals who are self-funding and so not receiving any support from statutory services.”

**Carers Allowance**

337 people responded to the question asking if they knew about Carers Allowance and if they receive it. Almost 25% of those people were not aware if they are eligible.

| **12. Did you know that you may be able to apply for Carers Allowance or disability related benefits for yourself or the person you care for?** | | | | |
| --- | --- | --- | --- | --- |
|  | | | **Response Percent** | **Response Total** |
| 1 | Yes, I already receive this | |  | | --- | |  | | 31.75% | 107 |
| 2 | Yes, but I'm not eligible | |  | | --- | |  | | 37.98% | 128 |
| 3 | I don't know if I'm eligible | |  | | --- | |  | | 23.74% | 80 |
| 4 | No | |  | | --- | |  | | 6.53% | 22 |

Furthermore, 103 people responded to the question asking what they spent their allowance on, with responses below:

| **13. These allowances can be used for a wide range of things. What do you currently use your allowance for? (Please tick all that apply)** | | | | |
| --- | --- | --- | --- | --- |
|  | | | **Response Percent** | **Response Total** |
| 1 | Day Activities | |  | | --- | |  | | 15.53% | 16 |
| 2 | Day Care | |  | | --- | |  | | 15.53% | 16 |
| 3 | Help with gardening | |  | | --- | |  | | 21.36% | 22 |
| 4 | Help with cleaning | |  | | --- | |  | | 24.27% | 25 |
| 5 | Leisure activities to give you a break | |  | | --- | |  | | 11.65% | 12 |
| 6 | Sitting service | |  | | --- | |  | | 6.80% | 7 |
| 7 | Food | |  | | --- | |  | | 46.60% | 48 |
| 8 | Heating | |  | | --- | |  | | 43.69% | 45 |
| 9 | Domestic bills | |  | | --- | |  | | 37.86% | 39 |
| 10 | I'd rather not say | |  | | --- | |  | | 4.85% | 5 |
| 11 | Other (please specify): | |  | | --- | |  | | 26.21% | 27 |

The highest responses were food and heating, followed by domestic bills, giving an insight into the financial situation of the carers who are eligible and receive this allowance, with some respondents mentioning it replaces their salary as they have given up paid work due to their caring responsibilities: “Having given up work to care it replaces a salary”.

**How carers currently access services**

**“Have you used any of the following to access support?”**

The majority of carers responded that they accessed services through their GP, followed by the current service provider and adult helpdesk (Gloucestershire County Council) third. This shows us that we need to be working more with GP Practices to ensure they have the correct information available for carers and can easily refer people to carer support services in the county. With 67% of people not aware of our online platform for information, Your Circle, we also need to do more work promoting this as a source of information, especially as the majority of people responded to the question ‘How would you like to access information about support available for carers in the future’ answered online (59 from response total of 235), followed by email (45), then post (41).

**You said, we did**

|  |  |
| --- | --- |
| You said… | We did… |
| *I want to feel valued and respected* | The new specification puts a lot of emphasis on Gloucestershire becoming more Carer Aware. We need to work with all aspects of society, including health and social care professionals, to ensure carers feel valued, respected and empowered. |
| *I need an opportunity to have a break from my caring role.* | The new specification will ensure timely access to carer breaks following a proportionate assessment |
| *I value peer support from people who have similar experiences.*  *I want improved access to training to help with the cared for.* | The new specification will ensure new infrastructure to support peer groups  There is a focus in the new specification for better partnership working with condition specific training available in the county and for more accessible Positive Caring Programme courses. |
| *I want to be identified as a carer as early as possible.* | * There will be a renewed focus on the hospital liaison role. * A work programme is being developed to increase the awareness of carers, and what support is available for carers, to GP Practice staff. * There will be a renewed focus on collaborative working. |
| *I feel overlooked by professionals* | * More focus will be required to raise the profile of carers in Gloucestershire and the value of involving them as “experts” in the people they care for. |
| *I am put off a carers assessment because I feel that there is very little support I can access.* | * A new diagram demonstrating the range of support which can be offered has been developed to establish what is available. * There will be more universal, early intervention/prevention support accessible to all carers. * The Provider will be able to make more timely decisions. |
| *I feel that there is no one to talk to in a crisis – this often happens during the middle of the night.* | There will be a new requirement to develop a personalised plan through the Carers Emergency Scheme (CES), e.g. identify who to call for urgent support.  Commissioners are also exploring options for access to a helpline over-night. |
| *As a working carer, I need support from my employer.* | There will be a new requirement to work with local employers to promote Carer Aware and Carers Passports. |
| *I need a bit of extra support during major life changes, e.g. diagnosis, a change in circumstances, a death in the family, transition into adulthood etc.* | The provider will be required to work collaboratively with other complimentary services in the county. |
| *I want accessible and timely information, advice and guidance, including information about benefits and financial support* | There will be more focus on collaborative working with services that can provide financial advice and guidance. |
| *My own health and wellbeing, including mental health, is important and the role of my GP is important* | There will be a requirement to work with CCG and Primary Care to share best practice and support GP Practices in supporting carers. |
| *I want long term, proactive support, with co-ordinated approaches and ‘joined up’ services* | The new service will work collaboratively with services that offer long term, proactive support, as well as by providing a carers hub and outreach in all localities. They will also be required to build relationships with health and social care professionals, that will help to join up and co-ordinate our approaches. |
| *I need plans put in place for when I cannot care* | As well as continuing the highly valued Carers Emergency Scheme, we need to ensure that when carers are getting their assessments and support plans, contingency plans are considered and put in place, to give carers peace of mind. |