

People's experiences of paid care at home services in Gloucestershire

August 2022



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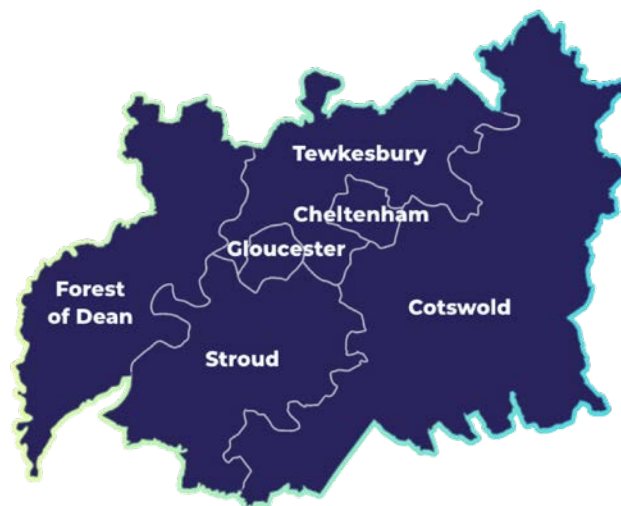
About us

Healthwatch Gloucestershire is the county's health and social care champion.

We're here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. We are entirely independent and impartial, and anything you share with us is confidential. We can also help you find reliable and trustworthy information and advice to help you to get the care and support you need.

As an independent statutory body, we have the power to make sure that NHS leaders and other decision makers listen to your feedback and use it to improve standards of care. This report is an example of how your views are shared.

Healthwatch Gloucestershire is part of a network of over 150 local Healthwatch across the country. We cover the geographical area of Gloucestershire County Council, which includes the districts and boroughs of Cheltenham, Cotswold, Forest of Dean, Gloucester, Stroud, and Tewkesbury.



Introduction

Background

Over the last few years, people have told us about their experiences of receiving care at home from paid Care Workers. Sometimes the care has been wonderful, but on occasions it has not. People have also told us how they have struggled to find good, accurate and up-to-date information on what paid care at home is available for them or their loved ones.

Often, in these situations, there is some urgency because they or their loved one are coming out of hospital or respite care and they cannot return home without care in place.

We chose to take a closer look at people's experiences of paid care at home services. We worked with the professionals who organise and provide paid Care Workers, those who commission services in Gloucestershire, and those who receive direct care as well as their loved ones/unpaid carers. By including everyone we were able to identify some key areas for exploration.

What we wanted to find out

We wanted to understand how people start to find care services (paid Care Workers), what the quality of care is like, and whether the service provider communicates well with people who are receiving care or organising care for their loved ones.

We also wanted to hear the views of those providing care services and their paid Care Workers, to understand more about the realities of providing regular care to people in their own homes.

What we did

We worked on this project during January to March 2022, actively engaging with people in February to gather their experiences and feedback.

Online surveys

We provided three separate online surveys on our website for:

- People receiving care and unpaid carers
- Paid Care Workers
- Service providers.

Focus groups

We organised online focus groups:

- Three dates for people receiving care and their unpaid carers
- Two dates for paid Care Workers
- One date for service providers.

By invitation we attended three carers groups:

- Two day care groups organised by Crossroads Care Gloucestershire. The first was attended by approximately 15-20 people, both cared-for and unpaid carers, and around 6-8 people attended the second group, which was one of their first sessions.
- We were also invited to the Ebony Carers Group in Gloucester where 26 people attended (see case study, page 11).

1-1 conversations

We gave people the opportunity to talk to us 1-1 over the telephone at a convenient time and two people took part this way. We also spoke in person to a daughter who shared her family's experience of searching for care for her mother following a fall at home and a hospital stay (see case study, page 9).

Volunteer research

To help us understand people's different experiences of researching what is available and accessing care at home, we devised six scenarios, each describing a different situation when people might need to find care at home services for themselves or a family member (see Appendix 1).

Our volunteers used these scenarios to research what information, support and signposting is available to people when they are faced with the challenge of finding paid care at home.

We also asked some of our volunteers to undertake research without using the internet because this is not always an option for some members of our community, either through choice or circumstance.

Seven volunteers took part in this research, giving over 30 hours of their time to gather some interesting information.



Raising awareness

We raised awareness of the project and promoted the opportunities to get involved by:

- Distributing posters, including to GP practices and voluntary and community groups.
- Social media activity, including posting survey questions on Facebook and Instagram during February.
- Sharing information via the press, which included promotion on Gloucester FM and Forest Radio.
- Sharing the surveys through our networks.

Challenges

Despite promoting the project widely, including sharing details with all our network contacts and through appropriate organisations and newsletters, it soon became clear we were not reaching those in direct receipt of care or their loved ones.

A total of 34 people completed our online surveys, no one contacted us to take part in the focus groups, and only a few people took part in the Facebook polls.

The pandemic has also highlighted the challenges of digital access and inclusion across many communities which has impacted the engagement we received within this project.

Only one care provider actively engaged with us. Although we appreciate that they are extremely busy and short staffed, we had hoped to give them a voice through this project.

Through our social media posts, we were contacted by two unpaid carers who were unhappy about the language we used to describe carers. They wanted us to be clearer by using the correct terminology to describe 'unpaid carers' and 'paid Care Workers', which we have taken on board.

Key messages

- Most people have no idea where to start when looking to find paid care at home services in Gloucestershire.
- There is no 'one place' for people to look for information.
- The printed information people did find was often out-of-date and not easily accessible for those who do not access online information.
- Those who are paying for care themselves receive little or no support when finding and using services.
- Being able to speak to someone to ask for help and advice would make a huge difference.
- Sometimes the costs for services were not explained well.



Volunteer research

Our volunteers looked at how easy or challenging it is for people to find information about paid care at home services, using six different scenarios. Some used the internet to find information, others did not.

Using the internet to find information

Our volunteers found there was no clear and obvious route to follow when beginning to look for information about paid care at home services, so they all followed different paths.

Google

Everyone started by using Google, so they first needed to think about what search terms to use. It became apparent that initial information and advice about paid care at home services is patchy and there is no one place for people to start looking online, or if there is, no-one is aware of it.

Through the public feedback we gathered, we found that although some families receive information about where to look, when their loved one is in hospital, many do not, so it is a bit of a lottery.

Age UK

Almost everyone came across details of paid care at home services via [Age UK](#). Many mentioned that their benefits calculator is a useful tool and they were impressed with the information provided.

GOV.UK

Everyone was directed to the [GOV.UK](#) website and moved on from there, depending on what they were looking for based on the research scenario they were investigating.

Other websites

Other useful websites mentioned by the volunteers included:

- [My Homecare Gloucester](#)
- [Gloucestershire County Council \(GCC\)](#)
- [NHS](#)
- [Gloucestershire Health and Care NHS Foundation Trust](#)

Two volunteers were directed to GCC's website, [Your Circle](#), via other websites, however most did not seem to be aware of it.

Finding information without the internet

We were keen to understand how people who do not use, or have access to, computers find information about paid care at home services. Three of our volunteers carried out research offline. They described how they went about this and what information they were able to find.

This research was both challenging and time-consuming as it is clear that the world we live in is weighted towards people looking for information and services through the internet. So, where to start?

Printed phone books

Two volunteers thought they would look in the *Telephone Book* or *Yellow Pages*, before realising these are no longer printed.

The other volunteer had an out-of-date copy of a telephone directory (last printed in Jan 2019) and within this found information under Health & Social Care, Benefit Enquiry Line, PIP Enquiries and Age UK. However, despite finding the address for the County Council under business listings, the telephone number was incorrect.

Health services

Our volunteers went to a pharmacy and GP practice, but most of the information was either out-of-date or unavailable. The GP practice did have information on Gloucestershire Carers Hub and some healthcare notices, but nothing specific on how to access information on paid care at home or social care.

Community venues and services

They also went to the library, but again found that most of the information was out-of-date or unavailable. At one library, they were directed to a Community Wellbeing Officer at a nearby community centre, who offered some assistance. They also found the GCC telephone number in the Cotswold Directory.

At another library, our volunteer was offered a 2020 copy of the Gloucestershire Care and Support Guide, which despite being out-of-date, had a lot of useful information and telephone numbers, including GCC, Social Services Helpdesk and Age UK. The guide proved to be a very useful tool, although the internet is required to access further information in some circumstances.

Conclusion

All the volunteers, whether or not they used the internet, were unclear on where to begin finding information or who to speak to initially. This made the process more difficult and time-consuming.



There almost needs to be the equivalent of 'Tell us Once' for social care, which is used when someone dies and connects all the relevant agencies and organisations.

Healthwatch Gloucestershire volunteer




What people told us


Focus groups and 1-1 conversations

We attended two day care groups where we spoke to people receiving paid care at home and their unpaid carers. We held two 1-1 discussions, one with a person who has received care from paid Care Workers and the other with an unpaid carer.

The recurring themes were all around how confusing and difficult it is to navigate the system, and the challenges in finding the right care, even if you are self-funding.

Finding the right care

Q If you are self-funding, you are on your own and left to get on with it, which made me wonder, where do I start? 

Q I am currently not living in my own home, as I am not able to find suitable paid Care Workers, which is a massive issue for me and I feel trapped. 


Lack of communication by care provider

One person explained that they have a deteriorating health condition and have had up to three or four daily visits from paid Care Workers for over two years. The last care provider pulled out of providing care at very short notice, which was a complete shock and left her helpless.

Costs of care

The costs of care were an issue to almost everyone and many people felt the actual costs did not seem to be given upfront. In addition, there were extra costs, which seemed disproportionate. Others who did understand the costs, felt they were prohibitive despite being aware of how beneficial the care is.



Q We were quoted £34 per hour, and an additional £34 per visit to cover travel costs, which seems immoral. 



One person who was looking for paid overnight care, was quoted an extra £26 per hour for any night calls above three per night, which was felt to be a huge extra charge.

Sharing feelings about paid Care Workers

People found it difficult to share feelings and feedback about some of the paid Care Workers, with one person saying:

 I find it intimidating to ring up the care company about an issue, so I end up saying nothing at all. 

Within the group settings, in addition to the comments around navigating the system, people also spoke about how it feels having paid Care Workers in your home.

 In the beginning I found it intrusive having someone in my home, but I am happy with it now. 

Case studies

Freda and her daughter Sarah

Freda is in her late 80's and has lived on her own for the past 20 years, following the death of her husband. She has been living with dementia for the past seven years, and until the pandemic, remained living independently, although recently the family had noticed a marked deterioration in her health.

Following some mobility issues in 2021, Freda was admitted to hospital, where she stayed for six weeks. This was due to the slowness of the hospital to contact Social Services regarding the care package required.

Attempting to leave hospital and go home

The family were aware that Freda would need a Care Package in place before returning home and that she could not return home without the Social Services Assessment. They were frustrated at the slow pace and concerned that due to her dementia, hospital was completely the wrong place for her to be. While in the hospital, Freda did receive regular visits from the Physiotherapists who ensured she was getting up and moving around, which helped with her mobility and movement.

Deconditioning and lack of attention

Family members noticed that Freda was not doing well being away from her own home and surroundings, and Freda herself seemed quite agitated. Each day she got up and packed her bag in the hope that a relative was coming to take her home.

While in hospital, the family felt that although Freda was being helped to get dressed and showered, there seemed to be a lack of understanding and compassion around her dementia, which they found upsetting.

Social Worker assessment

Following several weeks in hospital, a Social Worker assessed Freda's ongoing care needs. They spoke to the family who asked for Freda to receive four visits each day while she was still recuperating. The Social Worker explained a six-week care package would be provided and after that they would need to sort out the care on their own.

When Freda finally went home, the care provider advised them they had only been asked to provide care for two weeks, so they knew time was no longer on their side to find the paid care Freda needed.

Finding paid care services for a loved one

The family knew they needed to find long-term paid home care for Freda, but this was completely new to them and they had no idea where to begin. Freda's daughter, Sarah, had asked the hospital for information on finding permanent carers for her mum, but she said they were flippant, dismissive, and unhelpful.

Sarah spent hours researching care providers and described the process as a complete nightmare. She asked friends and colleagues if they had any recommendations. She explained she was "pushed from pillar to post" as there was no one in a professional capacity who was there to help and guide her through it: "There is no bridge to bring the two sides together within the system."

The family were not entirely sure what they were looking for, what was available, or how much it would cost, and they felt it would have been so much easier to have been offered some support.

They did know they needed to find a care provider and paid Care Workers who would really understand how to look after someone with dementia, as well as offering personal care.

While researching on the internet, Sarah came across the Gloucestershire Care and Support Guide and through this, started the search. She then looked at the Care Quality Commission (CQC) website to find out individual ratings for the care providers. In hindsight, she now wonders why no one ever gave her a copy of this guide.

Finding the right care provider

With some of the providers, Sarah felt as soon as they answered the phone there was no warmth or compassion, so she disregarded them quickly.


She then came across a provider who was warm and friendly and came to the house and explained what they could offer, while also listening to the family. She also spent a lot of time talking to Freda directly and reassuring her. The paid Care Workers now come three times a day during the week and at the weekends the visits are slightly different.

The family are delighted with the care being provided and think that all the paid Care Workers who attend to Freda are wonderful. When they arrive each time during the day they sign in on their tablets and also add information on how Freda is feeling etc. When they leave, they sign out and all the information about Freda connects automatically to the office, so they are always up-to-date about her health and wellbeing.

Every six months there is a review and both sides are able to make changes to the Care Plan. On average there are four paid Care Workers who cover each week. The family receive a rota every Thursday for the following week, so they know in advance who will be coming into the house.

When asked what good quality care looks like, Sarah said: "the linen basket being full." She went on to explain that to her, this means Freda is being cared for and well looked after and the paid carers are ensuring Freda is washed and wearing clean clothes each day.

Sarah feels she has struck gold with the care providers and cannot praise them highly enough.

 **We are very happy with the way things have turned out with the care provider, although this is down to the research I undertook, and a little bit of luck. I am shocked at the lack of information and help given to families who are having to navigate the system in a short space of time. I strongly believe there needs to be better processes in place which are clear and easy to follow for anyone in this situation in the future.**



Conversations at Ebony Carers Group

Ebony Carers meet in the All Nations Community Centre, which was established around 1962 and historically was called the Jamaica Club. Over the years, the surrounding area has been built on and now the community centre is within, and surrounded by, an industrial estate, although it remains pivotal to the whole community.

26 people attended this group discussion. The overwhelming sentiment was one of frustration, and their feelings and experiences of how little has changed over the years run deep. They don't believe they have been heard and continue to feel this way. Their culture is not taken into account when social care is required, which is why they often do not engage or use these services.



Communication

Many of the group discussed how they do not feel listened to, by any of the professionals, including the Council. They also believe they are not asked for their views and opinions in a timely manner, and on the rare occasions when they have been asked, it feels like a tick box exercise so the professionals can then say they have consulted with the community. There was also a strong feeling around their belief that nothing changes.

There is no communication with the Caribbean Communities about anything.

Why are we never asked for our opinions right at the start – we are always being 'done to'.

Culture

Culture is important to the community and they are frustrated at the lack of understanding around this and the need for it to be taken into account when receiving paid care at home. For the community to engage in their loved one's receiving paid care at home, this needs to be addressed.

A person being part of the Caribbean community is never taken into account when respite care is offered. It is a cultural thing, even down to the food offered. To ensure they feel loved and cared for, they should be offered food they know.

There needs to be more understanding of the different cultures as we have a different understanding of caring responsibilities.

Language


Several of the group were keen to share their frustrations at the language used within the services, including in correspondence, such as letters and leaflets received, and also in person. Much of the language is unknown to them and the use of clear, plain language would help to improve their understanding.

The older generations of our community struggle to understand the language that is being used around services, whether that be verbal or on forms and in letters.

There is a need for the language to be simplified and for someone to explain what is being said and exactly what it means for the individual.

Services

This was another area where there were strong opinions and frustrations from the group. Many felt that often they are not advised of services, or how to access them, or if they are, they are then not culturally appropriate.

 **Most of us are not aware of services available to us, how much they cost and how we go about accessing them. These things need to be talked about and explained to us properly.**

Care Plans take a long time to sort out and no account is ever taken about the cultural requirements of the community the individual is a part of. Often the person has died before any help is put in place.



Information

The group would like there to be much more information available for them to access, and for it to be clear, concise, and easy to understand and follow.

 **There needs to be information for those who do not go online.**

Benefits are difficult to understand and there is a requirement for more transparency.

Even with the reports they have worked on with us, they never come back and share the findings with us.




Surveys

What unpaid carers and those who are cared for told us

When looking for paid care, where did you first start?

There were a variety of answers, but we found that many people relied on recommendations from friends and family, and some spoke to their GP or used the Gloucestershire Care and Support Guide (see Appendix 2).

 **I really had no idea where to start, so I initially asked some friends and then spoke to the GP.**



Did you have any idea what paid care you were looking for?

Most people had some idea of the paid care they were looking for which varied from multiple daily visits, right through to occasional respite care.

How easy was the care system to navigate?

This question hit a nerve with many people who completed the survey. Only one person gave a positive response and the reason being a family member works in the system.

It's really hard
Horrid Not easy
Challenging
Frustrating
Difficult
Confusing
Awful It's tough
An absolute nightmare

I am still wading through it.

It's tough and I am tired.

You have to keep harping on and hope someone listens.

There seems to be no central repository of clear user-friendly information.

Carer capacity is a major issue.

I didn't even try as it is a mine field.

Were you offered the amount of paid care required?

There were mixed messages in the answers to this question. Although some people felt the care offered was adequate, it is clear as time goes on, that there is a need for more care.

Three hours of funded sitting service per week for carer respite is nowhere near enough when I am providing 24-hour care.

I could not, and still cannot find appropriate care.

Did you feel listened to when explaining the paid care required?

Responses were varied to this question with positive and negative answers. Some people continue to experience challenges with this, while others feel listened to by the care providers, but not the Council.

No matter how much I said, I felt like no one was listening.

The care provider listened, but the Local Authority did not.

I explained what care was needed and even wrote detailed notes, but it appears they were not read.



Was the cost of care explained to you?

Some people were aware they would not have to pay towards the care, although others felt they had to fight to get help with the costs of care, and they also spoke about 'hidden costs' such as travel and waking night hours.

Q Not completely, but it is fine for now. A

Q Mum has savings so we get no financial help. A

Q We are limited on how much we can afford because it is expensive having carers. A

Do you think the paid care received is safe?

Those who have regular paid Care Workers attending them at home, were very positive about the safety of the care provided and there was clearly a lot of trust. For those who have ad hoc paid Care Workers, or who have had only one carer attend instead of two, there were occasional issues and mishaps.

One person spoke about the number of different professionals involved in the care of their loved one, the lack of communication between them, and how this can cause challenges.

Q I yearn for an app based on a central NHS database which all professionals could use and all medical teams keep the information right up-to-date. A

Does the paid care meet your needs?

There were mixed responses to this question, with some people feeling that the paid Care Workers are flexible to the requirements, whereas others had a different experience and even struggled to establish exactly what they want, despite paying independently for care.

Q The care currently meets our needs, but I need more carer respite hours. A

The paid Care Workers are poorly paid, so put minimum effort in, so get minimum effort out.

They could do more.

Nothing is too much trouble.

No, I need more help as my husband keeps falling.

Do you feel cared for?

The overall sentiment was that when there are regular paid Care Workers involved, they look out for the unpaid carers as well as those they are caring for. However, this is not necessarily the case when ad hoc paid Care Workers are used as there is no relationship. The same sentiment was shared by those who experience occasional respite.

As an unpaid carer, if you ask for support it should be there.

The paid Care Workers are lovely and look out for me, but I am aware they are there for my husband.

It is jolly hard work keeping all the plates spinning as an unpaid carer who is still working.

I am the unpaid carer and it seems the NHS in particular take it for granted that I will spend hours each week turning up to appointments at a time to suit them, despite having another life with kids, work and other responsibilities.

What, if anything, would improve the paid care received?

Easier system to navigate
To be listened to
More capacity
More training
Increased time
Carers breaks
More affordable care

What does good quality paid care look like?

It was important for the person being cared for to be treated with kindness and dignity. Their loved ones would also like a more person-centred approach, so that the paid care provided addresses all of the person's needs, for example, emotional as well as medical.

Having paid Care Workers who listen and communicate, who are well trained, have the right equipment, and are flexible and adaptable, were characteristics of good care that were frequently highlighted.

Do you feel you have been involved in the planning of the paid care?

There were mixed responses to this question, with some people feeling they had been involved, while others did not feel that way in the beginning, but they are now happy with the paid care.

I felt things have either been 'done to me' or 'done for me', but never 'with me'.

I have been involved, but when I am having a down day, it makes me sad I have ended up this way.

I do not feel I have been listened to.

I was fully involved and it was all explained well.

Is there anything else you would like to tell us?

Consequences of complaining

There was a strong sense of concern at the consequences of making a complaint to the care provider.

I do not know how to get the advice I need and I know if I complain to the care provider they will pass our contract back to the Council and we will be back at square one.

It has been a very bumpy ride and I hope by completing this survey it will help other unpaid carers who seem to have no voice.

Caring for people with dementia

Others spoke about health care professionals, including GPs, needing to have more awareness of dementia and early onset dementia, and how to communicate with people about this.

When someone has dementia, the medical profession needs to think about how to communicate with that person, as texting them is not appropriate.

It is a fluid situation caring for someone with advanced dementia, so I need paid Care Workers who are confident and competent at working in this area.

Paid Care Worker salaries

Others spoke about the salaries received by the paid Care Workers and what a difference it would make if they were paid a decent salary.

There need to be more staff who are paid a decent salary so they don't keep moving elsewhere for an extra 10p.

Flexibility around paid care provided

Flexibility for extra paid care was highlighted by a few participants, with one saying:

Having flexibility, for example for night or day blocks when I need to rest, is difficult and expensive to access.

Appreciation of paid Care Workers

Others were keen to thank those undertaking the paid caring and to share their appreciation of how their loved ones are looked after.

I cannot thank the care provider and their paid Care Workers enough for all they do.
The paid Care Co-ordinator who looks after my husband is excellent and I would like to pass on my gratitude and thanks.

Thanks for the survey. I wasn't sure I had the time to do this, but it was very therapeutic and I got a lot of things off my chest that had been worrying me, so I hope it does some real good.

What paid Care Workers told us

Eleven paid Care Workers completed the survey (see Appendix 3). Most have been working in this role for years and only a few were relatively new to paid care work.

Roles and work patterns

Their roles and working patterns varied. While some had regular shifts each week, others worked part-time, and a few experienced unpredictable work patterns due to last minute changes by clients and filling in for staff sickness.

Commitment and passion for the role

When asked what was good about their jobs, everyone gave positive comments and their commitment and passion for caring for others shone through.



I have been lucky to support some of my clients for a long time.

I meet lots of lovely people.

It is my life.

Challenges of paid care work

When asked what the challenges were, there were many different responses, although a number of people mentioned, pay, long hours, lack of time, COVID and travelling between clients.

Providing safe paid care

Everyone felt the paid care they give is always safe.



I really don't care how long I spend with a client or how late I am running, I will always deliver care safely and effectively.

There is up-to-date training in place and good communication with clients and family.



Meeting the clients' needs



Although most of the paid Care Workers felt the care they give meets the needs of the clients, a couple felt there could be improvements.

 **Due to hold ups with Social Services and referrals from OTs, I have to make do with the equipment that is available.** 

 **Sometimes we do not have enough time.** 



When asked if the clients felt cared for, the comments were very positive.

 **I care for them in the way I would like to be cared for.** 

 **They are so appreciative of what we do for them.** 

When asked if they felt paid care was responsive to the needs of the clients, there were some mixed responses, due to circumstances beyond their control.

 **Some things are out of my control and I can only deliver the best care with what is available to assist.** 

 **It takes a while before care needs are sometimes changed due to the costs of Social Services funding.** 



Areas of concern and improvement

We asked if the paid Care Workers had any issues that concerned them. A few people mentioned the lack of staff entering the profession, as well as those leaving it following the pandemic, leading to illness and exhaustion. Others spoke about the needs of the clients increasing and lack of time was also raised.

We asked what could be done to improve their working lives and once again, more staff, more pay and more time with each client were recurring trends.

 **I love my job and although constantly tired, wouldn't change it for the world.** 

Finally, we asked if there was anything else they wanted to tell us. One person said they would like to be recognised as much as NHS Staff, and another person thanked their employer and said they are very supportive.

 **I feel my role as a paid Care Worker is very rewarding.** 

 **I just wish the pay was better.** 

What care providers told us

We felt it was important to hear from the care providers. We wanted to give them the opportunity to share their experiences of providing the paid Care Workers, and to try to understand their perspective.

The survey was only completed by one care provider, so we have been unable to compare experiences or identify common themes.

Job vacancies for paid Care Workers

The care provider that completed the survey employs 15 paid Care Workers and currently has five staff vacancies. They believe some of the reasons for these vacancies are around pay and the lack of knowledge and understanding of what home care entails.



Home care is part of the forgotten sector of care and does not get the recognition it deserves.



Self-funding clients

90% of their clients pay privately for paid home care, and most of them are word of mouth referrals, built on a good reputation over the past 20 years. They currently have 65 clients on their books and are not up to full capacity.

As they are not on the approved provider list, they are unable to source work from Social Services. They do not advertise at all and only take on clients if they know they can fulfil the contract to suit the individual.

Home care services provided

They offer personal care, home/domestic help, specific medical and health conditions, emotional support, respite and holiday care. Staff rotas are issued weekly through an app on their mobile phones.

Main challenges

Being a small team, the main challenge throughout COVID and beyond has been to ensure all clients receive the support they require. In addition, any sickness can have a knock-on effect on rotas and can cause short notice changes.

Recommendations

We believe that health and social care providers can best improve services by listening to people's experiences and feedback. We have analysed what people told us and we recommend the following actions to help improve paid care at home services in Gloucestershire.

- Make the process of finding paid care at home services easy for people to follow by having everything in one place – 'Tell us once for social care' – online and in print.
- Information provided should use clear and simple language and be designed to highlight the different types of paid care at home services, the things people should consider, and what they need to do.
- Provide face-to-face support and advice if required.
- Ensure everyone who is looking for a care provider is given a copy of the [*Gloucestershire Care and Support Guide*](#), printed or digital dependant on their needs.
- Provide information for everyone looking for social care, irrespective of their financial situation, whether their care is paid for by the local authority or they are paying for private care themselves.
- Work with different communities to understand and include, where appropriate, their cultural requirements. For example, information provided should use language that people can understand, and paid care at home services should recognise people's different needs, such as the food they eat.
- Make the costs of care completely transparent, with no 'hidden costs', and explain this clearly and fully without people needing to ask.



Stakeholder response

NHS Gloucestershire/Gloucestershire County Council

Jenny Cooper, Head of Integrated Commissioning – Older People, Integrated Adults Commissioning Hub



“Thank you for the opportunity to comment on the report. Our responses are as follows:

Recommendations

We agree with these and find that they give a useful focus on improvements that can be made to our system. Some of these are already in development and others can be enhanced as suggested.

Process

We have some concern that the report is based on a small cohort of respondents and might not therefore be representative of all people using/providing the service, but can confirm that some of the key messages have been heard from other sources such as carer feedback so we recognise them as areas to address.

Context and timing

Our biggest concern is that the report comes after a period of extreme and unprecedented strain on the care market (that of a global pandemic) and at a point when capacity is at an all-time low. Any negative publicity of care services can only have a further detrimental effect on recruitment so we feel some disquiet as to the effect of releasing this report at this time. Given the extreme issues around recruiting the emphasis on culturally appropriate services is particularly difficult to manage. Whilst as commissioners we want to ensure that the market can provide a personalised service to all individuals the reality is that this is sometimes difficult to achieve.”

Thank you

Thanks to everyone who took the time to tell us about their experience. We can only do what we do because you talk to us. Particular thanks go to Freda and Sarah for allowing us to share their story, to Ebony Carers for talking to us so openly about the challenges they face, and to Crossroads Care Gloucestershire, for working with us and allowing us access to their staff and groups.

Appendices

1. Scenario research for volunteers

The scenarios are:

1. You have noticed an elderly relative you visit regularly, and lives alone, is now struggling with day to day activities, including climbing the stairs to the bathroom. Following a gentle conversation, they confirm they could do with some occasional help and you agree to look into the services available to them. They do not have a lot of disposable income and do not want to move.
 - Retired
 - Owns own home with no mortgage
 - Receives work and state pensions
 - No other benefits currently received.
2. Farooq is a man in his 40's, and following a serious car accident, he is now a wheelchair user and needs help with all day to day tasks. He is determined to live independently, but understands adaptations will be required before that can happen. What help is he entitled to and how does his family find out how to access these services and how they are paid for.
 - Still working age and is an IT Consultant
 - Owns his own home and has a mortgage
 - Currently receives no other benefits.
3. Following a few weeks in hospital after a fall, Jack comes home to his wife, who herself has her own medical issues, including onset dementia. Jack cannot completely care for himself, and up until now he and his wife have been fairly self sufficient, and have declined any formal intervention. What social care is available to them and what are the steps they need to take to action them.
 - Jack and his wife are both retired
 - They live in a Warden Assisted Flat which they rent
 - Jack receives a work based pension
 - Both of them receive the state pension.
4. A young man (Dario) is away on holiday and falls ill and has to be flown home, which is organised by the insurance company. When back in the UK, he is diagnosed with bacterial meningitis and has suffered some brain damage, currently cannot walk and will be unlikely to work again. The hospital have done all they can for him and his family would like him to come home and live with them, but know they will need some adaptations to their home and help in looking after him.
 - Lives at home with his parents
 - The parents are both of working age
 - Father works fulltime and mother part-time
 - They own their own home and are still paying a mortgage
 - Dario is employed as an Engineer
 - At the time of the accident, Dario was paying into a work-based pension scheme and will now be pensioned off as he will be unable to return to his job
 - Dario will be entitled to some benefits.
5. Ben and his mum (Cath) currently live together and he has been a carer for her since she first became ill with MS when he was 10 years old. He is now 18 and has recently taken his A Levels. Over the past few years, his mum's mobility has deteriorated and she is now using a wheelchair almost all the time and needs help with daily tasks. Ben has been dealing with all this, but now he is ready to leave for University and they are both aware his mum will need help on a daily basis. Can you look into what is available, what they are eligible for and how it will be paid for.
 - Ben & Cath live in a social housing flat
 - Cath receives benefits including disability benefit
 - Currently they have no other paid help.

6. Elaine is an 86 year old lady who lives on her own and enjoys relatively good health. She currently manages most of her daily activities but struggles with doing her weekly shop, having a shower/bath twice a week and getting her to medical appointments. Her family live a long way away and are keen to explore what support there may be for Elaine for these activities. They are also anticipating that Elaine may need some help with a hot meal each day in the near future and so are looking into this as well so that they are ready when the time comes.
- Elaine owns her own home and has lived here all her married life
 - Elaine's husband died 5 years ago
 - Elaine has no mortgage
 - Elaine receives a private pension, a proportion of the pension from her late husband, and the state pension
 - Elaine receives no other benefits.

2. Survey data: people receiving paid care at home services

1. Are you completing the survey as the cared for, or as their carer?
Cared for - 4
Their carer - 18
2. How long have you/your loved one been receiving care?
Less than 3 months - 1
3 to 6 months - 1
6 months to 1 year - 2
1 to 2 years - 1
2 years + - 17
3. How many carers that know you/your loved one, do you have?
6 people have one carer
4 people have two carers
5 people have three carers
3 people have four carers
2 people have four to five carers
1 person has five carers
1 person has eight carers
4. Do you/your loved one, have the same carers regularly visiting you?
Always - 7
Mostly - 12
Sometimes - 3
Never - 0
5. Overall, how satisfied are you with the care you/your loved one receives?
Very satisfied - 10
Satisfied - 10
Unsatisfied - 2
Very unsatisfied - 0
6. Do the carers arrive on time?
Always - 8
Mostly - 12
Sometimes - 2
Never - 0
7. Do the carers stay for the full allocated time?
Always - 9
Mostly - 11
Sometimes - 2
Never - 0

8. Are the carers able to complete all the tasks required in the allocated time?
 Always – 12
 Mostly – 6
 Sometimes – 4
 Never – 0
9. How do you know what they should be doing? (tick as many as apply)
 There is an information sheet – 1
 It is written on the Care Plan – 12
 I was advised by my Social Worker – 0
 There was a recent review – 2
 The Care Staff told me – 0
 I do not know – 2
 Other – 7
10. When looking for Care for yourself/loved one, where did you first start?
 – Glos hospital allocated a care home temporarily, then home care on coming home.
 – Adult help desk
 – Hospital discharge
 – CQC and suggestions from other people I know
 – Advice from Carers Gloucestershire and Gloucestershire County Council, but in the end online
 – Gloucestershire Care and Support Guide
 – I really had no idea where to start so I initially asked some friends and then spoke to the GP about it
 – Care company and Carers Gloucestershire
 – I spoke to my GP and they helped me as I had been caring on my own for a long time
 – I was signposted from Dementia Health Professionals
 – With the Alzheimer's support
 – Word of mouth
 – My family sorted it
 – My son was aware I needed help, so he looked into it and arranged it for me
 – It was a struggle as I was not sure where to look, so I initially spoke to the GP and explained what I was looking for and they provided me with some information and websites to look at
 – I asked friends and other family members as I had no idea where to start
 – My wife sorted it out and she knows where to look and who to speak to, so I left it to her
11. Did you receive any help when looking for care?
 Yes – 15
 No – 6

Tell us more:

- The care service provider was advised to us, we had very little knowledge how this came about
- I had to speak up and ask for extra care twice and a continuing care assessment several times
- We were introduced to a care provider by a housing organisation
- Advice from Carers Gloucestershire and Gloucestershire County Council
- Many lists and brochures. Carers Hub Well Being service was very helpful when I was having problems finding a paid carer
- District Nurses arranged via Hospital and GP
- Council initially contacted care agencies. When they weren't successful after several months I then tried
- I had some idea of what was involved so I didn't ask for help and haven't really asked for any help since
- GP and friend recommendations
- A little verbal help from various people
- I met our Carer at a Memory Café and the day care was arranged through the Carers Hub
- I had no idea where to go for help
- Family members
- Initially yes, from the GP, but then it was left for me to deal with
- Friends and family and also asked the GP

- Yes, my wife spoke to the right people and got it all sorted. I am lucky she knew where to look

12. Did you have an idea of what care you were looking for?

Yes – 18

No – 4

Tell us more:

- I need carers to help me with everything, including to get up in the morning, with meals and to put me to bed in the evening as I am a wheelchair user
 - I am the main carer for my sister and I knew I needed some help to give me a bit of a break and for someone else to also help take on some of the personal care as I was struggling with it
 - My family decided what was required
 - The need for care increased, so I was aware of what I was looking for
 - I knew and the GP recognised I needed a break from caring, so I had a Carers Assessment to begin with
 - An interview with a care provider manager helped clarify what help I needed
 - Yes, although I had no idea that the carers wouldn't always do what they should have done for Mum when they came. I have since gone with a different agency, more expensive, but I have more confidence that Mum is being looked after properly
 - Yes, one individual who could do the hours that work best for the cared for person, including waking night, be friendly, understanding of complex medical needs and be flexible with their hours if needed
 - Yes, however care plan was never reviewed
 - No one tells you how things will become steadily worse
 - Constant care throughout the day whilst I went to work. I then did the evenings and nights.
13. How easy was the care system to navigate?
- We were in the hands of the hospital / care home
 - Awful. Because I had to move in with my Mum to provide care, particularly at night (I had my own house), there was a constant threat to take the direct payment away from me. I was being paid by the direct payment scheme but in reality I was using that money to provide support in other directions. There were no payments for night care.
 - Horrid. You aren't really involved in the assessments and as pensioner with health problems myself, they never seemed to be recognised or are recognised even now. You have to keep harping on and hope someone listens.
 - It's really hard.
 - Not very. There seems to be no central repository of clear user-friendly information and it seems very difficult to work out when and if paid for care with have to give way to free care when a person's savings run low and how to plan for that.
 - Not easy. Many agencies but not many cover the area. Ringing around is difficult when in caring role at the same time. Carer capacity is a major issue. Agencies advertise care they can't provide. Costings vary hugely when privately funded.
 - Confusing!!! Frustrating. Nurses referred to adult social care. Adult social care said it was not their responsibility.
 - Very hard. You are left on your own to find your way, once the patient is released from hospital
 - Challenging. Getting an assessment involved 3 phone calls. Getting a plan involved multiple visits and long email conversations. Getting any carer took months. We've been charged for care we never received, was told the invoices were stopped and credit notes would be issued, but am now being threatened with debt collectors.
 - Not easy, I am still wading through it. It's tough and I'm tired.
 - Not very easy, and without the help of others I don't know what I would have done.
 - It was straightforward 6 years ago but it is now more complicated
 - I think I was lucky with the help I received as I know I would not have known what to do had I been left to sort it out on my own
 - An absolute nightmare! Still there is no funding available!
 - I didn't even try as it is a minefield
 - I don't know as it was arranged for me
 - It has been difficult. I have struggled to find the right sort of care

- Very difficult. There is no one place that everyone knows about and really, it depends on who you speak to as to what sort of advice you will receive
- Because my wife works in the 'system', she knew what to do

14. Were you offered the amount of care required?

Yes – 14

No – 7

Tell us more:

- We knew we would have to pay for it, but it was a case of necessity
- Not completely, but it is fine for now
- We are limited on how much we can afford because it is expensive having carers. If money were no object we would definitely have some more
- I could not, and still cannot find appropriate care
- I did not feel I needed lots of support, but to have a break one day a week was what I was looking for. Thankfully, my husband now goes to a Day Centre Club one day a week and it gives me a break from caring.
- I wanted some respite and then some help a few times a week with personal care, but I now think I will need to increase this in the near future.
- We are paying for Mum's care. We get no financial help as Mum has savings.
- The carers (the family) needed training in how to care for someone with his disability. How to deal with them physically and mentally. There was nothing to support us.
- 3 hours of funded sitting service for carer respite is nowhere near enough when providing 24 hour care
- He has reasonable savings for now. So although an assessment was done, we sourced it ourselves at his expense.
- Not with what they knew my husband was going to experience.
- Absolutely not. During the last 2 weeks of my Mum's life I had to fight for additional money from the direct payments to pay for extra care to give me a break.
- A full report on needs was made and the care required and frequency was determined for us

15. Did you feel listened to when explaining the care required?

Yes – 16

No – 5

Tell us more:

- The care provider really listened to what both me and my mother wanted
- The carer who comes in to help my sister is fantastic and my sister thinks it is a friend who has come to see her and not a paid carer
- I explained to my son about what I wanted and did listen to me (son arranging care)
- The family spoke to me and we agreed what sort of care would be best for me
- I did from the Care providers, but not by the Local Authority
- The first thing I was asked was what sort of support I was looking for
- The person I spoke to was very caring and understood what I wanted
- Yes, although that does not always translate into the tasks being done properly
- You felt listened to, but the reality of the care was different
- I explained what my cared-for needed, I even wrote detailed notes and suggestions on how we could work together and handed them in. It appears these notes were not read.
- Sitting service, yes. Live in respite, no – lots of errors in care assessment meaning I had to contribute to care plan for the information to be accurate.
- It took some chivvying to get a meeting but when these meetings happened they were very helpful and there was attention to the family's views and insights
- Most recently yes, but know his legal rights and very experienced at fighting for what he needs
- No one talked me through it
- No matter how much I said, I felt like no one was listening. I got the impression that they thought I was just making a fuss and that they were not able to offer anything else.. I am angry that I spent the last 2 weeks of my Mum's life fighting for care rather than spending precious time with her
- A senior officer from the Council interviewed and, with information from the doctor/hospital, compiled the programme now in force

16. Was the cost of care explained to you?

Yes – 18

No – 3

Tell us more:

- Domiciliary care was provided at no cost, given the condition, capabilities and financial situation
- I knew my husband should have continuing health care, but we had to fight for it and stick to our reasons. It was very upsetting when we knew how ill my husband had become. Many tears were shed.
- We sourced care ourselves so obviously the cost was part of the conversation from the outset
- Extras are variable
- It was a health care issue. However, as it became more difficult for the nurses, it was suggested that I might look into employing a private nurse or carer
- I had to do my own investigations
- We talked about it together (as a family) and came up with a plan
- My family member sorted it all out, but I knew we could afford it
- It is expensive
- We knew it would cost a lot, but there was no other option

17. Did you find the costs easy to understand?

Yes – 16

No – 5

Tell us more:

- Nothing more to say, other than it costs a lot, which I understand, but the benefits received do not allow us to have any more care
- It was quite easy as I just wanted the one visit a day
- It was explained to us and I am grateful we do not have to pay the full amount every week, as that would be a struggle financially
- I find it quite worrying that I am in charge of Mum's finances
- If we had to pay as pensioners, the house would have to be sold

18. Do you think the care you/your loved one receives is safe?

Always – 13

Mostly – 5

Sometimes – 3

Never – 0

Tell us more:

- The regular carers I have are good, but some of the occasional ones are awful and I dislike it when they are in the house
- The carers are lovely with her and really take good care of her
- The carer is brilliant
- I now feel happy and confident with the carers
- I have complete confidence in the carers and I know they are well trained and know what they are doing
- The agency is good, they have safeguards in place and I can read the care workers notes
- If there are spills with drinks, they may not be mopped up then this becomes a slip hazard
- Carer always checks with office/me if unsure
- There is a real issue with information on medication. Our cousin receives meds in the form of tablets and eye drops for a neurological condition and two serious eye conditions and had a recent serious hospital admission which also required medication. Between the hospital teams who struggle to understand multi-carer relationships, the GP surgery who receive information from the hospital but are very hard to talk to, the paid for carers who visit him twice a day, us (who normally accompany him to medical appointments), the staff at the day centre he attends twice a week and the staff at his residential setting, there is ample opportunity for missed information and miscommunication and sometimes it seems almost impossible to co-ordinate. When he was admitted to hospital, routine meds for his eye conditions were initially missed. When he was discharged there was total chaos as the hospital discharge

team literally communicated with no-one more than a day before discharge and made no plan for who would administer meds. The team who visited him post-discharge (from a company called Retain) no absolutely idea who they were supposed to be visiting or what his needs were and had no contact information for his carers. The dust has settled on all that now and an official apology and promise to feed into service review received from GHNHSFT but even now in the community it is still a struggle to co-ordinate information on meds as this goes from the various hospital teams to the GPs who never seem to communicate pro-actively with carers. And there is no central point of reference we can all consult to make sure the right meds are being administered. In practice, the carers and residential staff try to co-ordinate ad hoc and do a pretty good job but I don't think it's entirely safe. I yearn for an app based on a central NHS database where everyone could just look this stuff up and medical teams could keep information right up to date.

- We have a hospice at home service right now and cannot express how good they are with a couple of exemptions
- Not at end of life
- Providing both carers attend as required the care given is mostly OK. However there have been occasions when mishaps have occurred. In particular it has caused stress and hardship when one does not attend. This has been frequent over the past year.

19. Do you think the care you receive meets your needs/the needs of your loved one?

Always – 8

Mostly – 7

Sometimes – 5

Never – 0

Tell us more:

- Providing both carers attend as required as hoisting is involved
- It seemed to be a constant battle
- I struggle to establish exactly the care that is needed even with the private care firm we employ to visit him twice a day. So for instance I have repeatedly asked for them to accompany him on paid shopping trips for new clothes and to cook him hearty breakfast as he has had some nutrition issues. But this never seems to happen. The carers are conscientious and perform important work keeping our cousin clean and hygienic but I cannot seem to get through to them these wider needs despite being prepared to pay for them. I notice other local care firms offering these services but am worried at disturbing the current arrangement which otherwise works really well.
- Meets loved ones needs but need more carer respite hours
- The carers are poorly paid, so put minimum effort in, so get minimum effort out
- They could do more
- It does at the moment, but I think more care will be required soon
- I need more help as my husband keeps falling. He also has Alzheimer's which is becoming more difficult
- We moved to the area fairly recently and professionals have kept in regular contact with us, even through the pandemic. Not long after we first moved, my husband had two falls at home and we were very grateful that grab rails were quickly fitted around the house to help him, which has made a big difference.
- At the moment it is sufficient
- It is fine for now and I know when the time comes I will be able to ask for more
- Nothing is too much trouble
- Sometimes carers come too early in the evening and I end up in bed for far too long, but I cannot change that

20. Do you feel cared for?

Always – 6

Mostly – 5

Sometimes – 9

Never – 2

Tell us more:

- As an unpaid carer, if you ask for support it should be there. I work in the elderly sector and I am seeing the refusal of help more and more
- My husband has no speech now so it would be hard to get respite care to give me a break. It has never been offered, though.
- The care staff are really fond of our son and want the best for him and follow his lead every day
- I'm the carer not the principal person cared for and the NHS in particular does seem to take it for granted that carers can spend hours a week at the time of their choosing turning up to appointments with the person we care for despite have another life with kids, work and other responsibilities. But I guess that is rather inevitable and no-one is ever deliberately thoughtless.
- There are many aspects to care. For a blind person there is also the executive aspect of managing money and private papers. Having never been trained as PA. It is hard to know if you are doing right by the blind person. No one thinks about financial well-being side of care.
- The carer is very good
- I know Mum values my input, but it's jolly hard work keeping all the plates spinning as an unpaid carer who is still working
- The carers are lovely to me and look out for me, but I am aware they are there for my husband mostly
- The care co-ordinator who looks after my husband, also cares about me and encourages me to have some breaks myself and to take help offered from other family members
- The carers are amazing
- The carers are kind and caring
- I know the carer looks after my sister well and that gives me a break. Also, my work are very good and I am able to continue working from home which helps. However, I have a husband and family and it is hard as I know they would like me to do more with them, but I have to put my sister first and it is a struggle to keep juggling all the plates at the same time.
- I do need some time away from my mum sometimes, as I visit her every day and sometimes it is good to know someone else is there to look after her
- With the regular carers I do, but with some of the occasional ones I don't feel they take enough care in washing and drying me

21. What, if anything, would improve the care you or your loved one receives?

- Dependability and the knowledge that when only one comes, the reduction in charges made to the Council are properly adjusted. There have been at least 50 occasions in the last year when I have had to provide the backup to a sole carer.
- Please have a nursing assessor who is inexperienced. Please have it as a specialist role by someone who has been around for a while and can use their discretion. Everyone is different. My mum ate (which seems to be the criteria for end of life nursing by the hospice) right up until 2 hours before she died as did my dad. THIS NEEDS LOOKING AT AS A CRITERIA. I appreciate that there must be rules at end of life care but please listen to the opinions of the people who are nearest and when they say their loved one is fading please listen.
- All the services seem to speak from the same page. GP, district nurses, palliative care at hospital nurse, oncology nurses. All of whom I can contact at anytime. The only sticking point is the Gloucestershire incontinence service. No leaflets given, no helpline given, they will only speak to district nurses or carers if I feel we need more incontinence pads. My husband is bed bound with hardly any movements in his body. The carers have a hoist to move him and he is far too heavy for me to move (weight gain from steroids). We need to keep his skin intact, prevent sores and pressure sores. His continence padding is crucial to this end. He can be faecal incontinent 3 times & more a day, but we are only allowed 3 day pads & 1 night time. If we pad him so I can remove it easily between visits we have to buy them. Better service needed.
- For adaptations to be done on his house as 6 months on and he still hasn't been able to fully move in
- 1) A central database of up to date meds information that multiple carers can access, ideally on an app. 2) A directory of local activities and their providers and cost. 3) Support or perhaps even standard checklists or audits for family carers dealing with paid for services that don't seem to be getting it quite right.

- More capacity for increased calls
 - Better communication and team work. As a carer I was not consulted, and asked, how I see that things could work smoothly. Also the cared for was not involved in any way to let him know, what is happening. I feel a conversation with me, as the carer and the expert of the cared for, to discuss the best way forward and how to go about it, would have made a smooth process. Instead things were arranged for me and my cared for without any discussions and this caused a lot of problems, which could have been avoided. Essentially a lot of time and resources were wasted due to the fact, that that I, as a carer was not considered and valued as member of the care team, who has expert knowledge of the cared for.
 - For the carers to be trained in the disability they are caring for e.g. blindness. For there to be support outside of office hours, management contacts.
 - To be listened to
 - Much easier system to navigate, more information, consistent and fair application of DRE, recognition that family carers shouldn't have to do all the care - plan should show need for 24/7 care to be provided (and funded) with acknowledgement of care provided by family, not for this to be assumed and disregarded
 - I could move in with Mum - she would then have me 24/7 and the carers on top but I would have no life
 - Perhaps more affordable care. I know it is expensive and I know he needs more, but I don't know whether we could afford everything we need
 - More Care Workers choice that's supports my need and not a prescriptive list by an organisation
 - It would be helpful for me if were given an extra amount of money, maybe once a year, to pay towards a Carers Break for about a week, so I could have some proper respite. Where we used to live, the council did exactly this and it helped me a lot.
 - Respite care to allow me a week away
 - More time on each visit
 - I cannot think of anything for now
 - This may seem like a simple thing, but we have been turned down twice for a Blue Badge because they say my sister is able to walk. However, it is sometimes really difficult to take her to some places because she cannot walk too far and it would make life so much easier for me to be able to use that when I take her out.
 - Maybe more of it, but we currently cannot afford any more. Also, a week's break for me would make a huge difference.
 - I would like them to spend more time with me and sometimes just to sit and chat to me. Some of them come in, do what they need to do and leave, despite the fact they should still stay with me for a bit longer and they could come and spend some time talking to me.
22. What does good quality care look like to you?
- Caring, compassionate people who take time with me
 - Kind, compassionate and caring people who put the person first and listen to their needs as well as the needs of the family
 - Giving time and space to the person who requires care. Someone who genuinely cares and wants to help
 - Caring staff, who listen and spend time with me
 - Caring, helpful, kind
 - Carers who are kind and patient and are aware of my husband's needs
 - Safe and caring, where you feel confident your loved is being well looked after
 - Compassion. Regular carers that understand the needs without me standing over them to needing to advise
 - Me being understood about how I feel as a carer and being listened to. My husband being cared for in a safe environment by people who genuinely care and I do feel we have this.
 - Trustworthy, honest, thoughtful and flexible and sympathetic support, friendship
 - Kind, helpful, efficient staff who are well trained and know what they are doing
 - Safe, trusted, good communication, kindness, compassion, reliability, trained carers, empathy, safeguards, alerts when things aren't right
 - A carer who takes the time to understand, and appreciate, the cared for person as well as

their physical, emotional and medical needs. A suitable payment for the carer's skills and the complexity of the carer. Building a supportive and responsive relationship considering the carer's and cared for's needs.

- Respected, treated as an individual, time, patience, understanding, and treated with dignity
- For Acute Trusts to work with social services from day one of the accident or illness. For the family carers to have training. For the provided carers to have training in the specific illness or injury. For the carers to be paid more and the agencies to be not for profit.
- The carer and the cared for need to be listened to and there need to be ongoing communication and reviews on how things are working out.
- Carers/nurses need to have the required training and expertise and inter-personal qualities to deal with the required health situation, in my case dementia.
- Also carers/nurses need to be given sufficient time to be able to connect with the cared for, so the cared for/patient actually feels cared for. There should be allowance for delays, due to any unforeseen care requirements.
- Continuity of care so carer really knows us. Reliable so I can be confident carer will turn up. Expertise and confidence in fulfilling tasks required. Caring and empathetic.
- Person happy, safe and independent, and not bored or taken for granted.
- Staff matched to the individual. Flexible and adaptable. Listening. Caring.
- Not rushed. Patient entered. Enough equipment. Good explanations of how things are going and steps needed to achieve certain aims. Good coordination between services, so everyone is on the same page. Well trained carers, who are paid properly and given good flexible hours. People in care companies offices to also have good training and understanding of care times needed for patients. For them all to shadow care staff for this understanding. The continence service to be there for patients and not a distant body adrift from all the services.
- Looking at the person as a whole and their personality traits. My mum would never moan about anything and when she was uncomfortable she really was in a great deal of pain. She could often be heard to say to a social worker. Yes I'm fine but the reality is very different. I felt that when we expressed different views about this I was seen as just wanting more money from the direct payment. The professionals need to listen to the families and believe them.
- A dependable, well trained carer who listens to our needs and understands what its like to be paralysed, doubly incontinent, with a heart condition and suffering from a hernia caused during a kidney removal.

23. Are you told by the care provider if there are going to be changes, such as a different carer, or a change to the time they are arriving?

Always – 8

Mostly – 7

Sometimes – 5

Never – 1

24. Do you receive a weekly rota?

Always – 7

Mostly – 3

Sometimes – 0

Never – 6

Tell us more:

- We receive this every week
- This is not required because we have help once a week and it is generally one of two carers
- I always know who is coming to see me and at what time
- It rarely changes, so I don't think I need a new one every week – maybe only when one of the regular carers is on holiday
- We agree shifts in advance and invoices are issued to be paid for before the carer comes
- Have requested many times
- Only one visit a week with same carer. Am told of changes.
- This sounds bad but it is almost always the same carer and it's a small team in any case.
- Monthly
- The rota is generally followed but when a carer turns up alone, it is sometimes very difficult

to step in at no notice to assist (I am 80 years old) and it does have a big impact on my well being.

25. Do you feel you have been involved in the planning of your care/the care your loved one receives?

Yes – 18

No – 3

Tell us more:

- I have been involved in it, but if I am having a down day, it makes me very sad I have ended up this way
- They did listen to me and what I thought and also gave some suggestions which were useful
- I always have to put my sister first, so it was really important to me to know it would be right for her
- My son knew I needed care, although it took a while for me to agree to it, but now I feel happy about it and look forward to their visits every day
- I was fully involved and it was all explained well
- To a degree
- I feel things have either 'done to me' or 'done for me', but they have not been done 'with me'. I felt that I had not been listened to and when things did not work out, I felt totally powerless to do anything about this. Communication from my side, either verbally or even my written communication, seem to be ignored.
- Co-produced
- Mostly now, but not in the beginning
- Set up by the person in charge and reviewed each year

26. How involved are you in the delivery of the care?

- Too much when the care programme falters. I have to stand in if diarrhoea occurs during the night, there is no help, so it's a struggle and of course lack of sleep impacts on the next day
- Shared at the moment
- Not much in the actual delivery (I tend to do the visits to the pub!) but I have a good dialogue with the various care providers and medics
- Very, to prepare for carer visits and to explain what is needed
- I am not really involved as I just let them get on with it
- We work as a team. I am very much involved
- Very

27. Is there anything else you would like to tell us?

- I don't know how to get the advice I need. I know if I complain to the care company they will pass the contract back to the Council (this has already been intimated once and we can't risk losing our carer support).
- Sorry about the rant. I just feel that it is important that you get a true picture.
- At every stage it has been emotionally draining and I don't think this is taken on board by the people involved in securing my husband's needs. I don't know how this can be changed but thought needs to be given to this. It has been a very bumpy ride. I hope this survey will help other unpaid carers who seem to have no voice. From what I pick up from nurses and carers, people are using kitchen roll and towels as incontinence products and carers have taken my husband's incontinence products for other people, so I have to hide them away. What a sorry state to be in. I understand why people leave their families in hospital wards as they have no money for extra food, incontinence pads and heating, and probably are aware of poor standards of care. Not on my watch. I have good voice, not everyone has.
- We need to recruit more staff for when he can move into his house but it is hard – wages need to go up so that staff don't keep moving for an extra 10p somewhere else and care competes with supermarkets
- Thanks for the survey. I wasn't sure I had time to do this but it was very therapeutic and I got a lot of things off my chest that had been worrying me so I hope it does some real good.
- Fluid situation caring for someone with advanced dementia so I need carers who are confident and competent at working in this area. Also flexible at providing extra care if required for example night care or day blocks when I need to sleep/go out. This is difficult and expensive to access.

- I feel, that in a care situation, all voices have equal value and need to be listened to. Only if the cared for, the unpaid carer, the paid carer and the health professionals work together, can we find a workable satisfactory solution.
- I have concerns for the future and what that looks like as I get older
- If it weren't for the input I give to Mum, she would have struggled massively. I am her only support.
- I wish the system to find the care in the first place was easier. I think I am lucky with the carers we have, although I do worry about the cost.
- Carers are unpaid. Care workers are paid. They are not Carers. This survey is very confusing in that by the time I got to the end I wanted to put down the cared for health problems as well as mine.
- The Care Co-Ordinator who looks after my husband is excellent and I would like to pass on my gratitude and thanks. It would be so good for me if I was able to have regular check-up appointments with my GP and to be asked how I am feeling and for them to try to help me sometimes.
- I cannot thank my care provider enough for all they do and they are always so accommodating to any changes required. The staff are amazing.
- Sometimes when carers come in they have to wake me up as I am still asleep, but I am happy with that.
- I think GP's need to have more awareness and a better understanding of early onset dementia, leading to a more timely diagnosis. Despite another relative having the same diagnosis at an early age, my sister's issues were put down to depression, anxiety and the menopause. The family were initially not listened to and it was only when we moved my sister to Gloucestershire to live with us, that the medical profession began to take notice of what we were saying. Also, when the diagnosis is confirmed, the medical profession need to think about how they communicate with the person, as texting someone with dementia is not appropriate.
- Currently the amount of care works for us, but I can see in the not too distant future this will need to be increased.

3. Survey data: paid Care Workers

Care workers survey responses from people who are employed in the care sector

1. How long have you been a Care Worker?
4 months / 3 years (x 2) / 6 years / 12 years / 14 years / 17 years / 18 years / 20 years / 21 years / 22 years
2. How long have you worked with your current employer?
4 months (x2) / 6 months / 2 years / 4 years / 5 years / 6 years / 9 years / 12 years / 16 years / self-employed
3. Do you have a standard working pattern or does this change?
A standard working pattern – 4
It changes – 7

Tell us more:

- I am team leader so I work in different areas of the county and will often work extra days to ensure shifts are covered
- I currently do one 10 hour shift a fortnight providing respite care for a young person with complex needs. The arrangement is directly with the family via direct payments rather than through an agency
- Have to work flexibly, due to changing needs of clients
- Mostly due to staff sickness
- I work part-time
- Given availability when started
- It changes from week to week and also depends upon holidays, sickness etc...
- I have regular visits, but these can change due to clients cancelling or changes in staff cover
- Due to staff sickness usually

4. How often do you receive your working rota?
 1 person said ad hoc in agreement with the families
 1 person said monthly
 1 person said daily
 7 people said weekly, with a comment: due to covid sickness and short of staff they can change daily
5. What are the good things about your job?
- The clients, being able to enable and assist them with day to day routines. And my colleagues
 - The young people I support are fantastic. I have been lucky to support some of them for a long time (almost 5 years) so a real bond of trust has been built up. It's a privilege to know them
 - Being able to be flexible and seeing the difference I make to my clients quality of life
 - I love looking after people
 - It is my life
 - The flexibility it gives me
 - I meet lots of lovely people
 - I have some lovely clients
 - Meeting the people and looking after them
 - Regular visits, lovely staff and support from everyone
 - I meet lovely people
6. What are the challenges in your job?
- Travelling, work out of area a lot which means I often am up at 5am and then return home at 6pm having travelled 70 to 80 miles and delivering care in between. Also covering shifts due to lack of staff
 - Long hours
 - The pay is not great for some of the roles I do, considering the level of experience and knowledge that is required to support someone with complex care needs
 - Can get attached
 - Care needs
 - Covid has been a challenge
 - Finding the homes
 - The expectations are higher
 - Not having enough time to spend with them
 - Traffic, weather conditions, time etc...
 - The time it takes to get to the clients
 - In my role in foster care in Gloucestershire, I am currently not allowed to give the young people that I support their meals via g-tube (enterally), even though I have other clients that I support in other counties where I do this regularly! It is really disruptive for the young person and their family because they can only have very short respite breaks and I have to take them home to have their meals. Very frustrating and I am fully trained and capable to support people with an enteral blended diet, but for some reason foster carers in Gloucestershire aren't allowed to do it?? Which is not at all in the young person's best interest
7. Do you think the care you give is safe?
- Always – 10
 Mostly – 1
 Sometimes – 0
 Never – 0

Tell us more:

- I really don't care how long I spend with a client or how late I am running. I will always deliver care safely and effectively
- Up to date training in place. Good communication with client and family.
- I will always follow policies and procedures
- Everything is risk assessed before we enter
- People's needs and health issues are expanding

8. Do you think the care you give meets the needs of the client?

Always – 5

Mostly – 4

Sometimes – 1

Never – 0

Tell us more:

- See previous comment about enteral meals
- Due to hold ups with social services and referrals for OT's, I have to make do with the equipment etc that is available
- Care given is always person centred. By talking to client and asking what it is they need each visit. And discussing any other options when needed.
- Time restraints
- I follow the care plan
- We always follow the care plan
- Sometimes we do not have enough time

9. Do you think your clients feel cared for?

Always – 9

Mostly – 2

Sometimes – 0

Never – 0

Tell us more:

- They would like us to stay longer
- When I visit the clients they always appear happy with the support we provide to them
- They are so appreciative of what we do for them
- I care for them in the way I would like to be cared for
- I have been doing this for many years
- I give 100%
- I have a very good relationship with my clients and always talk about their needs. Always letting client make decisions
- Some of my clients are able to tell me explicitly that they feel comfortable and cared for. Others are non-verbal so I can only judge by their non-verbal communication, but I do hope so!
- They always seem happy to see me and thank me when I leave

10. Do you think the care that you give is responsive to the needs of your clients?

Always – 5

Mostly – 6

Sometimes – 0

Never – 0

Tell us more:

- Some things are out of my control and I can only deliver the best care with what is available
- Daily routines can vary, but always checking with the client that they are happy with tasks to be done. Always respecting the privacy and dignity.
- It takes a while before care needs are sometimes changed, due to the costs of social services funding

11. Are there issues that concern you?

- Not enough Care Staff who want to do the job
- No
- Time and charges
- No
- The needs of people living at home have changed so much
- Time
- No, I deal with issues when they arise
- The lack of staff coming into the home care sector and that, due to the current covid issue, the staff that we have are starting to become ill and are exhausted

- Accessibility is my main concern for the people I support. Progress seems to have ground to a halt. There should be a changing places toilet in every town by now! It really limits the things that they are able to do and places they are able to go.
12. Do you feel comfortable raising any concerns you have?
- Yes – 11
No – 0
- Tell us more:
- My manager is very supportive and she appreciates that the staff are going above and beyond at the cost of their own health and family life
 - Good communication with clients and their families. Also district nurses and health professionals.
 - We have regular meetings
 - The management are very supportive
 - The managers are understanding
 - I always like to be honest
13. If there is an unpaid carer, do you alert your office and ask them to provide information on the Carers Hub?
- Yes – 7
No – 4
- Tell us more:
- I have access to this information and pass it on as well
 - I feel happy to give feedback
 - Or I would let them know about the Carers Hub myself
 - I wasn't aware of this
14. What could be done to improve your working life?
- More staff
 - Nothing really
 - To feel more valued by the Government
 - I am more than happy
 - I am happy at present
 - More pay
 - Having more time with each client and more pay
 - A 4 day week!
15. How satisfied are you with your job?
- Very satisfied – 8
Satisfied – 3
Dissatisfied – 0
Very dissatisfied – 0
- Tell us more:
- I just wish the pay was better
 - I am enjoying my role
 - I feel my role as a carer is very rewarding
 - I love my job and, although constantly feel tired, wouldn't change it for the world
16. Is there anything else you would like to tell us?
- I would like to be recognised as much as NHS Staff are
 - I enjoy my job although it can be hard when staff are off sick as it means there is more to do
 - I will probably still be working here until I retire
 - I have very supportive employers
 - I enjoy my job
 - I enjoy what I do but sometimes the unpaid carer is struggling and I need to spend time with them as well as the client

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