

How can people's social care needs be better assessed and supported? The perspective of those in need of care and their unpaid carers



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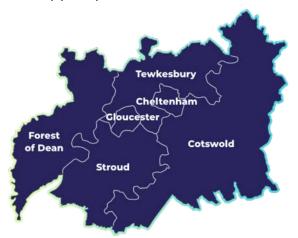
About us

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.



Background

Public concern and confusion about social care

An increasingly large number of people are contacting us to ask for help or to give feedback about getting a Care Assessment, mostly for a family member, but sometimes for themselves.

The Care Assessment service is provided by the Adult Social Care team at Gloucestershire County Council (GCC). The assessment is an evaluation of the level of care or support that a person currently needs. Anyone is entitled to request an assessment from Adult Social Care at any time, free of charge, although they may have to pay for any services offered afterwards. A financial assessment or means test will determine whether you qualify for free social care or need to contribute towards the cost of your care.

In Gloucestershire, some Adult Social Care services for carers are provided on the council's behalf by the Gloucestershire Carers Hub and Gloucestershire Young Carers. An organisation called POhWER provides various types of independent advocacy throughout Gloucestershire on behalf of the council.

In our 2022 social care project we looked at information provision by GCC. A common theme emerged in what people told us - it can be difficult to understand what care is needed, what services are provided, and how social care can be paid for. This links with wider issues around the provision of social care and unmet need.

Positive impacts of good, accessible social care

Access to social care and services under Part One of the Care Act 2014 is widely recognised as a key influencing factor on the pressures facing acute hospital services. When social care is in place people are less likely to be admitted to hospital and more likely to be able to leave hospital when they are ready to go home. Social care is therefore a priority for local health and care partners.



Social care is also an area that fits with other partners' priorities. The Care Quality Commission's (CQC) remit was extended under the Health and Care Act 2022, so that it can assess local authorities to see if they are meeting their 15 statutory duties under Part one of the Care Act. For example, three of the Council's duties are:

- 1. Prevent, reduce, delay needs from getting worse.
- 2. Provide Information about care and support.
- 3. Provide a range of services for people to access.

Social care is not meeting people's needs

In addition, unmet need in social care is one of Healthwatch England's priorities for this year. This means that a person has local authority qualifying levels of need under the Care Act 2014, but they either receive no care, the care they receive does not meet all of their need types, or the level of unpaid care is deemed intensive for at least one of their carers.

The King's Fund 2021/22 analysis of social trends highlights that compared to 2015/16, more people in England are requesting social care support but fewer people are receiving it (Social Care 360° Report - March 2023).

For those who do receive social care, the pressures on services (due to staff shortages, inflation, wage rises and rising fuel costs) can mean lack of choice.

When people's needs are not met this can lead to deterioration in health, which can lead to more admissions to hospital, and longer stays in hospital because of the difficulties getting social care in place so that people can be discharged and return home safely.

What we wanted to find out

Our aims

- To better understand how people and their unpaid carers access and experience the assessment process under the Care Act 2014.
- To investigate how GCC carry out their duties under Part One of the Care Act and how effective this is in meeting peoples' social care needs.
- To inform GCC of strengths and weaknesses identified in the Care Act assessment process and services provided, and influence improvements for people in need of support and their unpaid carers.

What we did

We worked on this project from the beginning of June until end of July 2023, actively engaging with people at groups and events, gathering people's views via an online survey, carrying out research and meetings with local partners.

Online survey

Through our online survey we gathered people's views and experiences about seeking social care, including the Care Assessment process and the support they had received.

We asked everyone about the circumstances that led to the assessment, how they had first found out how to get an assessment, and if they had been offered the opportunity to have someone accompany them for the assessment.

We then used 'skip logic' in the survey to guide people along the right pathway, to reflect whether their Care Assessment had been completed or not, and what the outcome was. There were four different pathways people could follow, depending on their situation:

- 1. Assessment complete the person has been assessed to have eligible needs that requires a care plan.
- 2. Assessment complete the person has been assessed not to have eligible needs and does not require a care plan.
- 3. Assessment is ongoing.
- 4. Assessment did not start.

Group discussions and one-to-one conversations

We visited community groups across Gloucestershire, speaking to people in group discussions and we also spoke to some people individually. The groups included:

- · Various groups run by Age UK
- Parkinson's Coffee Morning, Forest of Dean
- The Big Health Day
- CommuniTEA Event, Forest of Dean
- · Guideposts groups in Gloucestershire
- · Chat and Connect at The Churn, Cirencester
- Friendship Café, Cirencester, run by The Churn
- Information bus for Living Well, Ageing Well in Tewkesbury and Cheltenham
- FVAF information bus, Forest of Dean

Engaging with service providers and system partners

We engaged with organisations that provide and support social care services to help facilitate conversations with those in need of care and support.

Volunteer research

Our volunteers carried out research to help us identify what information and signposting is accessible to the public about Care Assessments and social care services in Gloucestershire.



Raising awareness

We raised awareness of the project and promoted the opportunity to be involved by:

- Sharing the survey through local networks such as Know Your Patch.
- Promoting the survey on our social media platforms.
- Including information about the project in our e-bulletin.
- Sending a poster, survey link, and detailed information to all relevant contacts involved in the running of local support groups and organisations.
- Giving presentations about the project to system partners, and asking them to promote the project and share the survey among their networks.
- Speaking to the public at events such as the Fairer Living Festival in Cheltenham and the Big Health Check in Gloucester.

Key messages

Frequently, contact is made with Adult Social Care at a time of crisis, where information and support is needed quickly.

- Many people do not know about or understand the process or approximate timescale for getting a Care Assessment which can put people off requesting one.
- The GCC website links and information about social care could be clearer and use language that is easier to understand.
- The language used to describe a Care Assessment can be confusing, and several similar descriptions are used that may mean different things to different people, such as a Care Assessment, Care Needs Assessment, Initial Assessment, and a Social Care Assessment.

Inconsistency in communication from Adult Social Care as well as the overall experience, can lead to dramatically different outcomes for people.

- It is not always made clear by the person acting on behalf of Adult Social Care whether a conversation is part of the assessment or merely a fact-finding discussion.
- Many people are not always made aware of their right to have someone to support them during all calls and meetings related to the Care Assessment.
- Having to repeat your story to numerous professionals is exhausting and frustrating and can put people off seeking social care support.
- People would like to have a named person they can contact if they have questions.

Finding out about and navigating the different services is difficult and not user-friendly.

- Those who are self-funding their care reported that they receive little or no ongoing support, signposting or information from GCC Adult Social Care team.
- There is a high risk of people in need of care and support, as well as their carers, having unmet needs.

What people told us

Survey

38 people completed the survey.

We wanted to find out what led people to start looking for an assessment and how they were advised about the assessment process at the initial point of contact.

Circumstances that led to enquiry about a Care Assessment

There were a variety of responses to this question, with many people seeking an assessment due to a deterioration in health or a stay in hospital. A few people acknowledged they were struggling to cope and needed more formal and regular help.



- The health of both my parents is deteriorating and it is taking its toll on me too as their primary carer. Both they and I now recognise we need more help, but it has taken a while to get to this place as they are so fiercely independent.
- Mental and physical health getting worse. Reaching breaking point.

Sources used to find information about the Care Assessment



The Adult Social Care helpdesk was the most popular route for finding information about the Care Assessment. One person said it was "not very successful" but another said the opposite.

Initially I spoke to
[someone] on the Adult
Helpdesk, and found she
was an absolute diamond!
Talked me through the
necessary steps/stages.

Interestingly, only two people tried to use <u>Your Circle</u> (the Council's online directory of local services) to find information about the Care Assessment, and they both came from the group of people whose assessment did not progress after making the initial inquiry.

One person was signposted by the Carers Hub and although they stated that their first contact with Adult Social Care regarding a Care Assessment for their loved one was "extremely disappointing", by the end of the experience they commented: "I feel so lucky I have been signposted, then dealt with by very professional and empathic staff."

Our data shows that several other sources were also used, outside of GCC, such as the hospital, GP, friends and family.

Accessibility of information

Out of the people who responded, most people did not need the communications to be more accessible; 11% did and it was provided; 5% had accessible needs which were not met.



GCC's website takes several 'clicks' and a certain amount of website experience as well as social care experience to find more information which is either too limited or even somewhat misleading, or, policy documents which are formally written.



Needed large print but this was never provided.

Right to advocacy

Just over half of people either did not remember or were not made aware of their right to have someone support them during the assessment process, for example, a family member or advocate. Many did not believe this ever happened.



I was asked if I would have any problem with understanding information but was not advised about having anyone with me. One of my children did happen to be with me at the time though which was a great help because I don't always remember everything, and they could speak on my behalf when I found things difficult.



I believe this is the first time I have been made aware, although I have been under pressure so may not have taken this information on board.

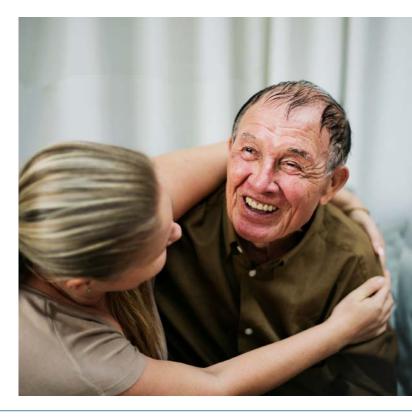


They did advise me of this, but I did not feel I needed anyone else with me.

Our findings show that many people are having a Care Assessment carried out at time of crisis. This could mean that their ability to retain, process and communicate information due to this heightened distress and anxiety will be impacted, especially if they do not feel that they have had enough information to prepare for the assessment. Therefore, if people are not aware they can have the support of a family member, friend or advocate, this could have a detrimental effect on the outcome of the assessment if needs are not identified.

Different stages of the Care Assessment process

The findings below are split according to the four different pathways that people could choose from depending on what stage of the assessment process they were in.



Care Assessment is completed

26 people who completed the survey confirmed their Care Assessment had been completed.

Timescales

58% of these assessments took place within three months, 37% within 3-6 months, and one person was waiting for between 6-12 months.

When the requirement for social care becomes urgent, for example, after a fall or a spell in hospital, people felt the process happened quickly.



I am not sure whether my first contact was classed as a full assesment or not.



Due to my accident and needing help quickly, the assessment was carried out in a matter of days.

54% of people 'strongly agreed or agreed' that the assessment was carried out in a reasonable timescale, while 35% 'disagreed or strongly disagreed'.



Patients and families are informed that a full assessment will be completed within six weeks.



If someone phones the helpdesk they are in 'crisis' and need help now, not months down the line.



Not sure whether my first contact was classed as a full assessment, so it could be less than three months, or 3-6 months.

Generally, those that had an assessment completed within three months agreed that the timescale was reasonable, whereas those who had to wait 3-6 months, or longer, did not and they felt this led to increased demands on hospitals and family carers.

Assessment completed within three months



Urgent support required but took several weeks for assessment to happen.



It was an urgent situation, so it happened quickly.

Assessment completed within 3-6 months



It took a while to sort the care plan out, so she was kept in hospital during this time.



It took a while to get sorted and I couldn't work out what the holdup was. I have agreed [that the timescale was reasonable], but only because a relative was living with him at the time and was able to help out in the interim, when not at work.

Information about what to expect from the assessment

Just over half of people felt they had received enough information prior to the assessment, although just over a quarter disagreed or strongly disagreed with this.

I believe information available via websites etc needs to consider much more [about] the situations people are likely to be in to necessitate an approach to Adult Services, the many difficulties they and their family and supporters are likely to be negotiating, including the fact that not everyone is able to use IT for various reasons. It should be a lot more obvious. A lot of the answers on the website consist of 'contact the Adult Social Care Helpline', which seems to have often failed to equip its staff with sufficient information to be of help.



This means that 20% neither agreed nor disagreed which could mean that people had no strong opinion either way. However, comments such as: "People I spoke to were very nice, but I still didn't know what to expect and didn't know what questions to ask or how they could really help", suggest there is a risk that people 'don't know what they don't know'. This is also implied by our previous findings that over 50% of people were not aware of their right to have someone accompany them during the process.

The various conversation based systems may be less formally daunting for people, but they can so easily fail to draw the necessary information from people, leading to errors in the eligibility decision.

Communication from Adult Social Care team

31% of people agreed that the level of communication received from GCC's Adult Social Care team during the process was good compared to 23% who disagreed or strongly disagreed.



- Repeatedly asked to ensure family were able to attend appointments and to contact family as person is hard of hearing this did not happen.
 - They were very good and explained everything to me.

Nearly half neither agreed nor disagreed, which again is a high proportion. Comments received such as: "The second contact I had with them was excellent, but the first contact was extremely disappointing" and "There is a long delay while requesting a service, then a wait for an assessment, then another wait for the service to begin, and it is all too slow", suggest this could be due to inconsistency in how individual people are communicated with depending on which Adult Social Care practitioner they are speaking to or what part of the process they are in.

Feeling listened to

42% of people felt their opinions about support were listened to and taken into consideration, although 19% disagreed or strongly disagreed.



I was not really informed about what was going on and actually had to stand my ground on a few occasions to ensure I was advised.



I felt well listened to and understood.

39% of people neither agreed nor disagreed that their opinions were listened to. The following comment highlights why people may have found it difficult to give a firm response to this.



I think individual members of GCC staff did their best at the time they were involved - but there are systemic weaknesses, and everything is fragmented and communication between various agencies and departments is insufficient.

Consideration of all aspects of a person's life and social needs

31% of people agreed that the level of communication received from GCC's Adult Social Care team during the process was good compared to 23% who disagreed or strongly disagreed.



Initially the lady said, after a brief discussion with me, that she didn't think the assessment was needed as some of the questions she had to ask wouldn't fit my situation, so it wouldn't apply. But my daughter helped fill in some of the blanks and asked if she could do the assessment anyway. And it did help going through the questions as it made me remember more and realise the impact my health is having on me being able to do things I used to take for granted. I did feel a bit better afterward and we had some useful discussions.



Yes, this did happen.

Once again, a large proportion of people, 35%, neither agreed nor disagreed. The main feedback from those who chose this response was that they did not feel that social support needed to be considered as part of their assessment.



She never leaves the house, so the social aspect was not required.



Since Covid I have not really gone out, so this was not an issue to me.

The person is assessed to have eligible needs that require a care plan

22 people who completed the survey stated that they were assessed to have eligible needs that requires a care plan.

Assessment and Care Plan

52.5% of people had received a copy of the assessment decision and 63.5% had a copy of their care plan.

57% agreed that the services suggested to them in their care plan accurately reflected their needs.



I am very happy with the care plan, and it has made my life a lot easier.



The care we receive now from (the care provider) is absolutely brilliant, but it took a while to sort this out. She now has a lot of care and input which is good.



However, 19% neither agreed nor disagreed and 24% disagreed or strongly disagreed, suggesting that nearly half of people were either not sure or felt they had needs that weren't being met.



What I was told is definitely the final care plan, logically couldn't have been because the FAB Assessment hadn't been done, and wasn't done until well after the six week review.



Although they do reflect his needs, they are not always carried out, so this is an issue.

Raising concerns

We asked people if they knew where they could raise concerns if they felt their care plan did not reflect their needs. Only four people out of 22 chose to answer this and three of the four stated 'no'. The person who said they did know where to raise concerns highlighted the following:



Know only as family work in the care sector. Relative reported they felt bullied and as though their wishes were not important as it did not fit into the tightly determined parameters GCC will support.

Navigating services

Many people found it difficult to find their way around the different social care services.

- - People don't always have terms of reference to ask necessary questions and feel they have to do the provider's preference.
- Disastrous! We are educated to degree level, and we couldn't navigate the system.
- I have been 'done to' and not involved, so this is a very negative experience for me.
- Exceedingly difficult, even with knowledge of the sector.

Those who found it easier either had help from professionals, or other friends and family who had knowledge and previous experience.



Assessment review

Six people said that this was not applicable to them as they were still within the first year of their assessment being completed. Out of the remaining 16, six people whose assessment took place more than a year ago said they have had it reviewed, whereas seven people said that it had not been reviewed and three people did not know. This could mean that over 60% of people that we heard from potentially had needs not being met by their care plan.

The assessment is going to be reviewed over the next few weeks as the Social Worker has advised me of this.

It has been tweaked as we go along and what I need is taken into consideration.

This is probably due to the different care companies being involved.

Impact of the assessment experience

People's responses were mixed, with some feeling it was positive and others finding it very difficult.

Very positive and I am a lot happier.

In the end it has been positive as she now has carers coming in four times a day and actually sees more people now than she used to.

It has been very positive as we both acknowledged we needed the help.

To some extent it has given us some freedom in our own lives.

There is evidence in our findings that when people receive a good service from the Adult Social Care team, it can have a hugely beneficial impact on people's lives, both for the person in need of support as well as carers. However, the evidence also shows there is inconsistency in the experience, and for those who have negative contact, what is already a very difficult situation could be made worse.

The whole experience has been completely exhausting and thank goodness for (the care provider) otherwise I would not have a life at all.

Social Services were very intrusive, and I was not happy with the way they treated me.

It was horrible for my mother and set her back hugely.

Financial assessment

38% of people found their experience of the financial assessment was straightforward, while 33% disagreed and the remaining 29% either agreed or disagreed.



I have no money and do not own my own property, so it was easy for me.

They have taken over my mum's finances, so I don't really know what is going on.

I am still waiting to find out whether I need to pay or not. I do not own my own home, but my savings are close to the limit, so it is unclear, and no one is talking to me about it.

I am still awaiting the financial assessment.



Improvements to the assessment experience

- A dedicated Case Worker for your assessment to meet you and help you through the process.
- Less focus on turning people away; more supportive signposting and actual assessment of needs when over threshold. Older people need support accessing care. Three tiered approach feels like an attempt to get rid of people; coaching approach might be better.
- Better first contacts and understanding that some care needs surround mental capacity.
- I believe the assessment should aim to show how the process relates to the legislation and the support plan should be explicit on how each outcome will be met. I believe it is possible to do this appropriately for the needs of each individual, without overwhelming them in 'technical language' and by retaining a contact for the person without having to wait for a staff member to be allocated for each subsequent issue/event.
- It would have been better to try to arrange care before it got to this point and for it to not take so long to implement as she was left in hospital for months while they tried to sort this out.
- For the whole system to be simplified and transparent and to deal with one person throughout. To be given a simple leaflet right at the beginning, outlining the process clearly and simply, so we know what to expect and how long it should take.
- Being included and kept informed instead of having to ask all the time and then be quite insistent about it.
- Speedier process.

Is there anything else you would like to tell us about your experience?

- My initial experience was very unhelpful, but my second contact could not be more different, and I recommend the professionalism of all those staff I dealt with. I am extremely grateful with their actions and help to provide my partner with the help and support he needs to help and ensure he (and the family) can enjoy a quality of life.
- The care workers who come in each day are all absolutely lovely and I am very lucky to have this, and I could not ask for better care, so I am happy with this. The company and all the staff are kind and caring.
- This lady is in her 90s and has done well to live in her own home all the time. She is aware of her deteriorating health and is grateful for the wonderful care she receives from the carers who come in. The organisation they work for are very kind and helpful.
- It has been very stressful and continues to be. We are not happy with the care he is receiving, but this does not seem to change, even when we do make a complaint. The whole system should be much more transparent and user-friendly, so we all understand it.
- It has been a difficult time, completely overwhelming and exhausting. I wish it were simpler and there was more of a human element to it. Sometimes it felt like a tick box exercise and not something relating to a human being and their care and welfare.
- I am just frustrated at the delay in the process, and it should be speeded up.

The person is assessed not to have eligible needs for a care plan

Four people who took part had been assessed and advised they were not eligible for care and support.

Assessment decision

Two people said they had received a copy of the assessment decision and two had not. Only one person disagreed with the decision that they did not have eligible needs but said that they knew how to raise a concern about it if they wished.

Impact of the assessment experience

- I think he was helped with identifying adjustments to be made around the house and items given to help his mobility.... He was housebound until they had done this, so being seen.
- It felt like none of her needs were of importance because the report compiled said she does not have needs.
- It did help to be able to speak to someone.

Improvements to the assessment experience

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All departments should share information, so we only have to give the details once and not multiple times.



Quicker initial contact would have helped so we would know how long the wait was.



There were two errors in the report, but I was not able to challenge the content.

Signposting

All four people had been signposted to other services, although only one felt this met their needs.

Is there anything else you would like to tell us about your experience?



It was a hit and miss experience, with well trained and caring staff, but a system with many cracks and imperfections.



I was made to feel a burden for needing support and there was no understanding shown.

Care Assessment is ongoing

Seven people who completed the survey were still in the process of being assessed for social care support, mainly due to a decline in health with one person commenting that they are 'reaching breaking point'.



Timescales

Five people had made the referral within the last three months. No-one in this group disagreed when asked if this was a reasonable timescale given their needs. However, similar to previous findings, the respondent whose assessment had been ongoing for 3-6 months disagreed with the statement, and the final respondent who has been going through the process for over two years, strongly disagreed.

- Four Social Workers have been involved in the referral; we are now on number five. Every time there is a new Social Worker, we require a new assessment. The last time we were going through this, it was not completed due to running over the one hour allocated by the professionals.
- It's been about a month so far, but we are concerned about how long it will take; I'm worried about her safety if her dementia is getting worse. We've had contact, but no-one has visited yet.

Information about what to expect from the assessment

Only one person said they had received enough information prior to the assessment for them to understand and know what to expect from the process. Five people disagreed or strongly disagreed and one person neither agreed nor disagreed.



It has been confusing because we have spoken to various professionals about her care, and we thought these might have been the assessment. But when we asked about it we were told that the needs assessment hasn't happened yet and will need to be done by the appropriate person.



I don't think I've been given any information so far. I've had a phone call, but it was to book another phone call with someone else. I don't really know what that one is for so will wait and see.

These findings highlight that people who are currently going through the assessment do not feel that they have had enough information about what to expect. This, along with the findings from those who had completed the assessment process, suggests that people 'find out more as they go along' rather than feeling fully prepared for the assessment from the start.

Communication from Adult Social Care team

Four people agreed and two people strongly disagreed that they received good communication from the Adult Social Care team.



They were very nice on the phone.



I have had almost no help.

One person neither agreed nor disagreed with this, acknowledging that: 'There hasn't been much to update on so far."

Feeling listened to

Three people felt that their opinions about their care needs were being listened to and only one person disagreed. Three people neither agreed nor disagreed, with one pointing out: "We are currently in the process, so it is hard to answer that definitively at the moment."

Consideration of all aspects of a person's life and social needs

More than half the respondents were unable to say whether they have been encouraged to consider all aspects of their life and social needs as the assessment is ongoing and it was too early to comment. One person disagreed with this.

Signposting

Four people said they had not been signposted to other services that may be able to help while the assessment is ongoing. Two people had been signposted and one person neither agreed nor disagreed, indicating that they were unsure.



I have been to some meetings; some have been more useful than others.



We have been told to increase her support at home, but we are having to fund this at the moment.



Impact of the assessment experience

- My parents have at last recognised they need help and as they wish to stay in their own home for as long as possible, they've had to accept they cannot do this without it.
- I worry about leaving her on her own, but I also have my own family that need me.
- For both of us, our health, both physical and mental, has deteriorated over the past year.
- It's reassuring.

Is there anything else you would like to tell us about your experience?

- They should be eligible for the full amount of financial help, as they have under £20K in savings. Up to this point they have had no financial help and I now hope they will get this, given they have managed for years on their own.
- The GP and Social Prescriber have been very good, but it all came to a head when my dad kept insisting he could do the cooking and then everyday it was taking him four hours to make a meal, and it was becoming dangerous, as he was leaving the gas on with pans on the stove etc.
- It is hard asking for help, especially when you don't want to be a burden and others might need the help more than me.
- The whole assessment is too tied to procedure and process. Repeating your story time after time is exhausting, so please read the file first.

Care Assessment did not start

Five people who took part in the survey advised that they made an enquiry about a Care Assessment however the assessment did not start.

What were the reasons for this not progressing?

The main theme we found was that people felt put off by being advised there were long waiting lists to receive a Care Assessment.

I was discouraged from having one, and they said I would have to go on a waiting list to be allocated a Social Worker, suggesting that the wait was long and indeterminate. Surprisingly, when I explained my wife's needs they said basically that I knew her needs sufficiently anyway.



Received a letter saying there is a waiting list.



The waiting time for assessment and care plan has been impacted by previous situations, for example Covid.

Impact of the assessment experience



I just want some help with her as her needs are more complex.



Demoralised, cross and then furious as I felt that they were not really interested in helping me.



It did not impact on her care at home.

Signposting

Two people said that they had been signposted to other services in the community that might be able to support them, whereas the remaining three people said they were not. Of the two people who were using community services, one strongly agreed that their needs were being met by the services and one strongly disagreed.



With the Brain Injury Team, GRH and (Adult Social Care) helpdesk operators help, I contacted Headway, The Carers Hub and Gloucester/Cheltenham Stroke Cafe. All very useful.

Is there anything else you would like to tell us about your experience?



[Community services] have been absolutely pivotal in enhancing/driving care for my partner - without them, I'd be stuck! So, thank you to all of them.



When they ascertained that I had more than the £23K threshold, they lost even more interest in me. I also asked for advice about future funding for residential care when our own assets become exhausted. They gave only very vague advice but did reveal that their funding for dementia nursing was £677 per week (less pension contributions) which is less than half of normal fees. They said that they only had contracts with certain care homes.



Waste of time; very angry.

Carer's Assessment

People are considered carers if they are looking after someone regularly because they are ill, they are an older person or they are disabled, including family members. Carers can help with washing, dressing, taking medication, shopping, cleaning, paying bills, getting out and travelling to doctors appointments. They can also give emotional support by keeping them company or staying with someone if they can't be left alone.

A Carer's Assessment is free and anyone over 18 can ask for one. It might recommend things like having someone to take over so the carer can have a break, exercise classes to relieve stress, putting carers in touch with local support groups so they have people to talk to and advice about benefits.

We wanted to find out if people had been advised about their right to receive a Carer's Assessment when enquiring about a Care Assessment for themselves or their loved one.

Eight people felt that this was not applicable to them. One person said they had already completed a Carer's Assessment, and two others said they did not have an informal carer who supported them outside of their package of care.

Of the remaining 30 respondents, 43% were made aware of the Carer's Assessment. The comments we received in response to this were mixed and reflected different people's circumstances. For example, a quarter of people in this group stated that although they were made aware, they chose not to have it as they felt that it was not required or did not see the point of having it.

Those who did choose to have the Carer's Assessment gave positive feedback.

- I have had this and am registered with the Carers Hub and they are very good.
- This was done first, which alerted me to the Social Care Assessment.
- The Carer's Assessment was good.

However, this means that 57% told us that they had not been informed of the right to a Carer's Assessment for either themselves or their carer, suggesting that there is a large amount of unmet need among unpaid carers

- There's never seemed any point to going through this as it appears very unlikely to be of any benefit.
- She is my mum and I will continue to look after her.
 - I do not wish for this to happen.





Case Study: Alice and Richard's story

Alice has cared for her husband for over 25 years

Until recently, Alice had been looking after her husband Richard. Early in their marriage they lived abroad but moved back to the UK about 25 years ago. While abroad, Richard underwent brain surgery and had a shunt fitted. He experienced seizures which became more frequent in 2022, resulting in him not wanting to leave the house. He started to have more falls and was diagnosed with Alzheimer's and dementia.

Request for social care was rejected

Over the past two years Alice has contacted Adult Social Care to request help and each time has been advised there was no funding available. It was suggested she speak to the family and ask for their help.



We have lived here for the past 25 years and never asked for any help, yet when we do ask, we are advised it is not available.



Assessment while Richard was in hospital

Richard was in hospital during November and December 2022. The day after he was discharged, he experienced a grand mal seizure and returned to hospital where he stayed for a further six weeks.

The time in hospital was very positive and he was looked after extremely well. It was at this point they were asked by the hospital if there was a care package in place for Richard, which there was not. Alice and Richard were advised they were eligible for help on being discharged, however Alice said she was not included in any conversation or assessment of his care needs.

Discharged from hospital with Covid

Richard was discharged from hospital again, and it was realised that he had been discharged with Covid. During this time Richard had a package of care that enabled carers to visit him at home three times a day and helped him to get up and down the stairs to go to the toilet. After only a few days, they were advised this was too dangerous, so a commode was brought to the house for Richard to use. Alice reported that this turned out to be a complete 'nightmare' and did not work.

Richard deteriorated rapidly in the care home

Eventually, when Richard was Covid free, he was moved into a care home. Alice was advised not to visit for a few days to enable him to settle in, but as she had contracted Covid she did not see him for 10 days.

On her first visit to the care home Alice was shocked to see the deterioration in Richard. She described him as "slumped in a chair like a rag doll" and he was experiencing paranoia and delusions. He also had diarrhea and vomiting and looked like a 'stick insect'. Richard can no longer feed, wash or dress himself and he is incontinent.

Alice is unhappy with the care he is receiving but feels because they have some financial support, she cannot complain.



My feeling is I am watching a slow death. It is a miserable existence for him, and I feel guilty I have put him in prison.



Richard's pension now pays towards his care home, so Alice is struggling

Although Richard is receiving financial assistance from the Local Authority, his pension is also used to pay a contribution to his care. This means Alice is struggling financially, as she still has to pay all the household bills, which is difficult as she does not have a pension and is living off savings.

Alice has never been consulted about Richard's care needs

Alice said at no time has anyone ever sat down with her and discussed Richard's care and explained the Care Needs Assessment, so she has no idea whether or not this has happened. She feels very isolated and alone and would like to have been involved and asked for her input in Richard's care.



Sometimes I think about the loneliness and think, why me dear Lord.



Volunteer research

Three of our volunteers used the following questions to investigate what information the County Council provide about the Care Assessment to help people access care and support. This is what they discovered during the five and a half hours spent looking for information.

1. Where/how did you find this information and what steps did you have to take to find it?

All volunteers used the internet and searched 'Care Needs Assessment'. One was directed to Your Circle (yourcircle.org.uk) where they found the information they were looking for, while another found it through the GCC website (gloucestershire.gov.uk).

2. Were there any challenges in finding this information?

One person found it very easy to find the information, while the other two volunteers struggled.



It was far from straightforward and a bit of a lottery as there were so many links or tabs to choose from. The most helpful page was 'Contacting Adult Social Care' and the 'Additional information' section on the same page proved more useful and contained more detail.



Be careful not to click on South Gloucestershire Council's page as that came up first. It does take a bit of searching through various pages and links to find out how to request a Care Needs Assessment.

3. How confident are you that the information is up-to-date?

Everyone agreed that both the GCC and Your Circle webpages clearly gave the dates the information had been updated.

4. What was included in the information? Does it include details of someone you can speak to directly about the process?

Although a named contact was not provided, all volunteers felt the information clearly stated that people should speak to the Adult Social Care helpdesk; the phone number and email were provided.

5. Is any indication given about how long to expect to wait for an assessment to take place?

No one found any information to indicate approximate waiting times for a Care Assessment.

6. Is the information accessible, for example, use of language, Easy Read, alternative languages, available in paper copies, alternative formats etc?

One person found the information on the GCC website relating to alternative language options and two people found information on how to change the text size and language. One person found an accessibility link at the bottom of the web page which contained useful information.



Recommendations

We believe that health and care providers can best improve services if they listen and learn from people's experiences and feedback. Based on what people told us we recommend the following actions to help GCC improve the Care Assessment process and social care support for local people.

Information

- Provide a leaflet or booklet clearly and simply outlining the Care Assessment process, including approximate timescales, the steps involved and possible outcomes.
 Information about the Carers assessment should be included in this to raise awareness.
- Consider updating the GCC website with a direct link from the homepage to 'Request a Care Needs Assessment' that provides further information and the Adult Social Care helpdesk number.
- Clarify the language used to describe an assessment under the Care Act 2014 and keep it consistent in all information provision to ensure everyone understands.

Communication

- Adult Social Care helpdesk operators should ensure all people enquiring about a Care
 Assessment are advised they can have someone support them, and/or they should
 share details about advocacy support services. This should be reiterated at each stage
 of the process before gathering information as it is possible that someone's mental
 capacity or support needs may fluctuate over time, or in case they change their mind.
- Provide in writing or in a person's preferred format (letter, text or email):
 - The date, time, location of the assessment.
 - The communication method to be used (phone, online or in person).
 - Approximate timescales as to how long it could take.
 - Guidance on what to expect from the conversations during the assessment.
- This will create more consistency in the process and allow people to prepare, enabling them to better communicate the things they are able to do well for themselves, and the things they find more difficult.
- Update websites and other information and ensure that Adult Social Care helpdesk operators are informed, to emphasise that everyone has the right to an assessment under the Care Act 2014 regardless of their financial situation.
- Provide each person with a named contact to ensure continuity and remove the requirement to repeat their story, who can provide face-to-face/telephone support and advice if required.

Navigation of services

- Ensure those who are self-funding are given help and advice to help them make informed decisions.
- GCC should review how information and signposting of services that can help promote
 wellness or prevent deterioration is shared, to aid and increase public awareness, for
 example through reviewing the awareness and efficacy of Your Circle.

Stakeholder response

Gloucestershire County Council: Emily White, Director of Quality, Performance and Strategy, **Adult Social Care**

Adult Social Care welcome the opportunity to provide a response on the findings from Healthwatch. Overall, none of the recommendations come as a surprise and chimes with the information we hold about ourselves (including demand for services and complaints). This matches other insights we have received in the last year including a Local Government Association Peer Challenge (Sept 2023) and our preparation and engagement in writing our self-assessment for Care Quality Commission Assurance processes. This report provides us with more evidence to support our improvement plan and approach.

We are aware of the challenges faced by people who use our services particularly in relation to our capacity to meet demand. This includes the information we share with people (including providing this in a range of formats that are accessible) who are waiting for an assessment. This is a key enabler for us in our early intervention and prevention work, alongside how we work with the care provider market to assure ourselves of quality provision to meet people's needs.

Our Practice Model (Making the Difference) in use by our operational teams promotes staff to undertake Carers Assessments where it is relevant to do so. However, we realise in practice that our staff utilise our commissioned provider The Carers Hub and in doing so there can be a feeling of disconnect for the individuals being assessed and their carers. We recognise that our operational teams needs more visibility of what this provider is doing/ has done so we can join up the support offer for people. We have already updated the assessment and care support planning paperwork to ensure we understand the informal networks of care people may have. Understanding contingency planning is crucial in this process and our practice audit tool already considers these matters.

Our new Customer Experience role within our Transformation team will help to address some of the recommendations in relation to information accessibility and how we communicate with people, their families and carers in a simple way about the Social Care Process and what to expect. oucestershire

October 2023

Thank you

Thanks to everyone who took the time to complete the survey and share their experiences with us. Thanks to the staff and people attending events through Age UK, Guideposts Trust and The Churn, who welcomed us to their groups and spoke so openly. Thanks also to the staff at Gloucestershire Health and Care Trust and Retain Healthcare for working with us and arranging for us to speak to some of the people they are supporting.

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