





# Support for Carers December 2019



# Introduction

Healthwatch Solihull are the voice for the public in health and social care services. We collect feedback from the public about their experiences of using health and social care services and use that feedback to work with health and care providers and commissioners to identify good practice and ways to improve the services.

One of ways that Healthwatch Solihull collect feedback is to carry out focused projects to evaluate service provision and on this occasion a project has been undertaken to consider the experiences of informal carers. With an ongoing focus on carers in Solihull and gathering feedback from local carers who told us their experiences. Healthwatch Solihull chose to explore support for carers who are caring for someone over 75 as one of our priority areas for the year.

The project was designed to follow on from an NHS Digital survey that was carried out by Solihull MBC and Carers Trust Solihull, this helped us to build the areas for enquiry around the findings of the survey by pulling out key themes for our focus groups.

# Methodology

Carers Trust Solihull sent out letters on our behalf to all registered carers caring for someone over 75 in Solihull, inviting them to attend one of our focus groups.

We arranged four focus groups, two in the north of the borough, and two in the south. Two of which were morning groups, and two in the afternoon.

There was a total of 19 participants across the four focus groups.

The focus group questions were designed by Healthwatch Solihull following on from the findings of the survey carried out by Solihull MBC and Carers Trust Solihull. The questions looked at areas that it was felt needed more investigation and gave an opportunity to explore the experiences and feelings of participants in more depth than would be possible in survey format.

Analysis has been undertaken by looking at common themes within the feedback. This project does not claim to represent the views of all carers and only reflects the experiences and feedback of those that participated in the focus groups. However, the lived experience of those participants can give an insight of the challenges experienced by and needs of carers in Solihull.



# **Findings**

#### Access to GP appointments

Participants in the focus groups were asked about their experiences of being able to access GP appointments for both the people that they cared for and themselves.

Being able to access an appointment for the person that they cared was reported to be difficult for one and they told how they 'struggle to get through on the phone, let alone get my Mum an appointment.'



However, there was more feedback that participants were able to get appointments for the person that they cared for with one saying that 'the surgery appreciate my wife's condition and always fit her in.' Another said that they 'can always get an appointment' for the person that they care for.

When discussing accessing GP appointments for themselves, participants gave mixed feedback. One participant told how it was 'two months to see a GP' and that they had 'pointed out that I am a Carer.'

It was commented that to get an appointment 'you need to physically go into the surgery to be seen, which is not easy when you are a Carer.'

Another participant said that they 'don't even bother trying to see my GP.'

However, others told that they were able to access appointments easily when they needed one with one participant saying that 'I am quite lucky with my surgery, 90% of the time I can get an appointment.'

Analysis shown that not many carers were accessing online appointments, since our focus groups Birmingham and Solihull have launched an app, which has all, but 4 Solihull surgeries registered to it.

#### **Registering as a Carer**

When speaking about accessing GP appointments, participants also discussed whether they were recognised as Carers by their GP practice. Those that commented generally said that they had registered as Carers with their practice.

Despite this, they felt that they were not recognised by their practice as a Carer. One commented that they had 'filled out the form at the GP to say I am a Carer, but they lost it' whilst another commented 'that happened to me too. They ask you to fill things out but still don't know I am a Carer.'



A participant in another group said that they had 'filled in forms to say I am a Carer but still nobody knows.' Even when they told their GP practice that they were a Carer, one participant felt that 'it makes no difference.'

#### **Being listened to**

Participants talked about their experiences of being involved in planning and decision making around the care of the person that they care for.

One participant commented that 'I am frustrated by this' saying that 'I never feel included and I feel like professionals have an attitude that they are the experts and my opinion doesn't matter.'

Another said that they had 'never been asked my opinion'. One participant told how they had been to the memory clinic with the person that they care for. 'I went to explain how things are at home, but the Consultant waved at me to not say anything. We were told everything was fine and we are discharged.'

Participants pointed out that professionals 'see a 10-minute snapshot, we are there day in and day out'. However, they were not always listened to and one said that 'professionals were not listening. In the end I had to video to prove it'.

When considering care plans one participant commented that they 'don't even know what a care plan is'. Another felt that despite their best efforts to carry out planning for what would happen if they were no longer able to carry out their caring role, nobody wanted to help them do so.

However, not being included or listened to was not the experience of all participants with one telling how they had 'mentioned' some concerns that they had about the person the care for and as a result 'professionals have tried to alter meds to help'.

Generally, participants across all groups were very positive about their interactions with West Midlands Ambulance Service paramedics when they had cause to call for an ambulance. One participant commented that 'paramedics are absolutely amazing. They listen to what you say...' and this was echoed by another participant who said that 'when paramedics have come out, they do listen and ask my opinion'.

Another told us 'they are brilliant, they really consider what's best for my mum and won't just take her into hospital, they know when hospital isn't the right place for mum and listen to what I have to say'.

#### Communication





# Support for Carers in Solihull

Linked to the experiences of carers feeling that they were not listened to or involved in decision making some spoke of how there was a lack of communication with one commenting that 'I don't always feel well informed. I do the communicating. Services don't go out of their way to communicate with me.'

Another participant commented that 'I spend all my free time doing the communicating because nobody communicates'.



#### **Carers Assessments**

There was some discussion about care assessments for the people that they care for, but very little mention of carers assessments for the carers themselves.

There was a consensus across all groups that Carers Trust offer a good service and those who hadn't had assessments were urged by group members to get in touch.

Only one person specifically mentioned a carers assessment, and this was in relation to the time that they had to wait for an assessment. They said that 'I was also put on a waiting list for assessment with Carers Trust- first they told me it was a six week wait. I called after that time and was told six weeks was incorrect. I am still waiting.'

#### **Domiciliary Care**

Several participants spoke about their experiences of having domiciliary care for the person that they care for.

There was discussion about a lack of reliability from domiciliary care providers with one commenting that 'carers have just not turned up in the past'.



Another told how 'our carers turn up whenever, never on time' and this meant that they were unable to go out and do anything else with their time 'because if I am out, Mum will not answer the door. So, they just leave and don't bother to call me, even though I have asked several times that they call my mobile if this happens.'

One participant told how 'when my Mum called about a missed visit she was told by the provider 'well your daughter is there'' giving the impression that the care provider felt it was not important to deliver the service because there was an informal carer present.

One participant also commented that although the person that they care for had been assessed as needing care funded by the local authority they 'work still and when I do nights I could do with some help, but they assessed and offered three visits a day' going on to say 'I tried to arrange [care visits] around my work hours but they said they couldn't do that, I actually didn't feel I needed all of the visits as like to do what I can myself, so I tried to arrange less visits but just for the mornings after I have been working late.'

The participant went on to ask, 'should I allow them to waste money and visit more than necessary or give up work and let them visit whenever they like?'

#### Support for self-funders

There were some comments about there being a lack of support for carers who were caring for someone who was a 'self-funder' with one commenting that 'the first question from everyone is 'are you a self-funder?''

Another explained that 'a lot of the time when we say yes, we are told 'sorry we can't help then''.



There was a consensus that self-funders felt alone with one person saying, 'I feel we are left to fend for ourselves' and another saying 'self-funders are at more risk, there is much less oversight'.

#### Impact on health of carers

The impact of caring on Carers' health was discussed and the issues of being able to maintain their own health.

One participant commented that 'I don't have time to look after my health' and the same group said 'as carers we are becoming poorly. How can we care if we are poorly?'

It was felt that 'physical care is taken seriously but mental health is not' and comments made by participants were generally in relation to mental health.

It was felt by one participant that 'mental health is not taken seriously. It is very stigmatised, especially in the caring role.'

It was commented by one participant that 'chasing everything impacts on my wellbeing' and another said that 'the caring role really impacts on your mental health.'

It was felt that mental health support could be difficult to access with one participant saying that they 'feel like medication is just thrown at me for mental health' and that 'mental health services are hard to access.'

A participant in another group said that 'I tried to access mental health services in Solihull, I had an initial telephone consultation and I was put on a six-month waiting list.'





Another told how their GP had 'told me to self-refer' but that 'I ended up being supported by a service in Birmingham, who then discharge me after two sessions because I am out of area.'

#### **Role of support agencies**

There was some discussion of the role of support agencies in supporting carers.

However, not everyone had been able to access support. One participant commented that 'we resign from jobs to care and we get no support' whilst another commented 'I gave up trying to access help'.

One participant told how they had contacted a charity for support but had 'never heard back'.

Those that had accessed the Carers Trust were positive with one participant commenting that when they had contacted Carers Trust 'everything was sorted' and another that 'I couldn't do without Carers Trust'. Another said, 'I can't recommend them highly enough, I've cried for an hour on the phone to them before now'.

Participants also commended Age UK Solihull and Admiral Nurses for their ongoing support with one person saying 'if you haven't, go to Age UK, they are amazing' with others in the group agreeing, someone also said 'I can always contact the Admiral Nurses, they are so knowledgeable and really care'.

#### Conclusions

19 people took part in the focus groups, a relatively small number, however we found common themes throughout all groups.

The focus groups were advertised through social media, membership and posters and leaflets delivered around Solihull. Carers Trust Solihull also sent out letters to all carers caring for someone over 75 in Solihull, inviting them to take part.

Many of the carers spoke of struggling to get GP appointments in some circumstances whether for the person they care for or for themselves. However, it is arguable that issues with accessing GP appointments are not necessarily unique to Carers, but not being able to get to the practice to make an appointment due to their caring responsibilities should be considered as an additional barrier to access.

Being recognised as a Carer with their GP was something that participants felt was important and that there was a need for a system that recognised them as a carer when they were making an appointment. However, it was largely felt that even when they had informed their GP that they were a Carer by way of a form, their respective GP practices had not then used that information or had lost it. Participants generally felt that they were not involved in the decision making around the care of the person that they care for. They felt that they were excluded by professionals rather than included and that their experiences of trying





to tell professionals about how the person that they care for is on a day to day basis was not listened to.

Although participants spoke about care assessments for the people that they care for, there was very little mention of them having had their own Carers Assessments. Only one person mentioned a Carers Assessment, and this was in relation to having had a long wait for an assessment and being given misinformation on how long they might have to wait.

Some of the participants said that the person that they care for also had domiciliary care, either funded by the local authority or self-funded. Those that spoke about domiciliary care told of late or missed calls and how this meant that they could not rely on the care provision. One spoke of how a lack of flexibility in the times of calls meant that they may have to give up their paid work outside the home.

Participants spoke about how if the person that they care for was a self-funder there was a lack of support. When they tried to access any additional support in their care, they were generally told that as self-funders there was no assistance available.

When participants spoke about their own health there was a recognition that caring can have a detrimental impact on their health. The impact on their mental health was a particular area for discussion and participants felt that there was a lack of recognition and support around their mental wellbeing concerns.

Out of the 19 carers we spoke to, all of them said that things across services are improving. Cares told us that they were frequently asked for feedback from different people and would like to see changes.

All the carers we asked told us that they felt the new Solihull Council Carers Strategy accurately reflected their views. Carers across the 4 groups all told us that if there ever is an issue that the Solihull Council and Carers Trust are usually quick to fix any problems.

# Recommendations

• A main theme we have found throughout the year and within this project is that carers feel it would be useful if GP Surgeries in Solihull had some sort of 'flag up' system to make front line staff aware when they are dealing with a carer over the phone. We recommend that GP Surgeries explore ways of using their IT systems to make front line staff more aware when dealing with a carer over the phone.



- Domiciliary Care providers ensure that when making visits, they have next of kin telephone details and in the event the door is not answered that they try to make contact before leaving.
- Authorities and local organisations ensure that self-funders know their rights and feel they can access services without immediate barriers.
- Analysis shows that not enough people are accessing online systems, services should seek to actively promote the BSOL App.
- Domiciliary Care providers review the ways in which they deal with calls from carers and service users and ensure they are professional and compassionate.
- GP Surgeries to ensure that if they are asking Carers to fill out forms to register as Carers, that this is then followed up. Also review systems to ensure documentation is not lost.
- Healthcare services and local organisations work to identify carers at the earliest point and refer/signpost to support services.

Thank you to all those who took part in this work spoke so openly and honestly. Thank you to SMBC and Carers Trust for their support this project.

#### **Provider responses**

#### SMBC:



## Birmingham and Solihull CCG:

Karen Helliwell, Director of Integration at NHS Birmingham and Solihull Clinical Commissioning Group said:



"We would like to thank Healthwatch Solihull for this very insightful piece of research.

"Local people are at the heart of everything we do. The CCG's aim to improve the health and wellbeing of local people requires us to understand, and can act on, what really matters to them; this report will really help us to work with our GP practices in Solihull and further improve services for carers. Carers undertake such an important role and it is important that we try our utmost meet their needs.

"We look forward to working with Healthwatch Solihull on the delivering the practical and helpful recommendations highlighted in the report."

### **Carers Trust Solihull:**

"When I heard that Healthwatch were going to look at the needs those caring for older members of the public we were keen to support them. We wanted to ensure they did not duplicate the findings or more comprehensive surveys and what resources they had available could add to our understanding. What Health watch have produced is very valuable front end of service feedback that can be dovetailed with the existing carers strategic and improvement work in various multiagency forums. We have undertaken innovate work with GP surgeries, working closely with practice managers to promote Think Patient Think Carers and have built up a rolling programme of sessions in select surgeries were members of the public using the facilities can discuss with a member of our team and find out about the support available to carers. Observations in this report will help us further to hear the voice of carers and we look forward to working with Healthwatch in the future." **Brandon Scott-Omenka** - Chief Executive Officer

# Age UK Solihull:

Age UK Solihull are pleased that carers are reporting positive experiences when accessing our organisation, as we recognise that there is a great need for emotional, practical and financial support in the sometimes daunting, often exhausting but ultimately rewarding task of caring for a loved one.

We are pleased to be here to help.

#### WMAS (West Midlands Ambulance Service):

It's really pleasing to note the comments made about our Paramedics! I know my colleagues always aim to deliver the highest standard of care for ever patient.

I do believe that access to GP appointments can be challenging for patients and carers. This has been highlighted to crews when attending cases.

Hopefully we can all work together to improve the patient journey.





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