

Unpaid Carers' Perspectives on Respite and Health Services

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Summary

Healthwatch Southampton worked in partnership with Unpaid Carers in Southampton (UCSS) to develop and distribute a short survey to unpaid adult carers. The focus of the survey was to seek the views of unpaid carers on respite breaks and their experiences of being identified and listened to by health and social care services in Southampton. The survey was available to complete digitally, and paper copies were available too. A summary of our recommendations based on the feedback from unpaid carers is listed below.

Recommendations

1. Health and Social Care services should make it easier for unpaid carers to access support.
2. Explore further, the experiences of unpaid carers when supporting their cared-for-people to access health and social care services. All staff working in health and social care services need to better understand the role of unpaid carers.
3. It is important for health and social care professionals to really listen to unpaid carers and support them.
4. Unpaid Carers Support (UCSS) should continue to provide regular respite breaks for unpaid carers away from cared-for-person and occasional opportunities for activities where the cared-for-person can attend as well.
5. Health and Social Care professionals must also consider that unpaid carers may have their own additional needs for support. Professionals must ensure that carers have equal access to information and support that is available.

Introduction

Healthwatch were approached by Unpaid Carers Support Southampton (UCSS) to help them gather more information and views from unpaid adult carers that are living in Southampton (SO14-SO19 postcode areas). The UCSS had received requests from unpaid carers who are supported by their service to provide additional activities where they could bring their cared-for-person along with them. Carers had shared that they were often unable to leave their cared-for-person or find alternative care and were therefore unable to attend the existing provision of respite breaks. Both organisations agreed that it would also be useful to ask unpaid carers whether they had been identified as a carer and felt listened to by local health and social care services. It is essential to identify and support unpaid carers to reduce health inequalities locally.

Usually, a respite break means taking time away from one's caring role, whether it be just for a couple of hours or a few days or weeks. It is very important for carers to have the opportunity to have a break from their caring role. Unpaid carer's group activities give an opportunity to meet other unpaid carers, share common issues and provide peer support. This can help carers to feel less isolated and better able to manage their caring role.

Aims

1. To identify views of unpaid adult carers in Southampton (SO14-SO19 postcode areas) on whether they would like Unpaid Carers Support Southampton to offer additional activities that are suitable for both the carer and cared-for- person at the same time.
2. To identify views of unpaid adult carers in Southampton (SO14-SO19 postcode areas) on whether their caring roles are being identified and if they feel listened to as a carer by health and social care services.

National Context

A carer is anyone who provides unpaid care for a friend or family member due to illness, disability, a mental health problem or an addiction (carers.org). Being an unpaid carer can impact many areas of a person's life including health and wellbeing, education, employment, social and financial status.



In 2025 there are approximately 5.8 million adult unpaid carers in the UK with 1.7 million people providing 50 or more hours of care per week. In England and Wales, the Census data shows that there has been an increase in the proportion of people providing 20–49 hours of care (1.9% in 2021 compared with 1.5% in 2011) and a slight increase in the proportion of people providing 50 or more hours (2.8% in 2021 compared with 2.7% in 2011). The Census found that in England and Wales, women are more likely to provide care than men. 59% of unpaid carers are female. According to the Census 2021, the biggest proportion of people caring in England and Wales are from the 55–59 age group. (carersuk.org).



It can often take carers a long time to identify themselves as a carer and seek the support they might need. It is important for local health and social care services to identify carers as soon as possible. Unpaid carers often report having a worsening physical and mental health because of their caring role. Recognising carers and providing additional support is essential to help to reduce health inequalities. Three-quarters (75%) of carers said their GP knew they were a carer (carersuk.org).

Local Context

In the 2021 census, 18,136 people (7.7%) said they provide some level of unpaid care in Southampton (from 5+). 1 in 8 (12.6%) of residents aged over 50 provide some level of unpaid care, around 9,300 people. This breaks down to 31.4% (5,699) people aged 50 to 64 and 19.8% (3,582) of people aged 65+. Of these 3,582 people aged 65+, 46.8% provide more than 50 hours of care a week (1,675 residents). Older age groups provide more unpaid care and as the carers themselves they are also more likely to have poorer health.

(Southampton Data Observatory – Supporting adults Last updated May 2025)

Local Provision for Unpaid Carers

The local provision for adult unpaid carers is **Unpaid Carers Support Southampton (UCSS)**. They provide support for all unpaid adult carers, from 18 years upwards, across Southampton, which includes:

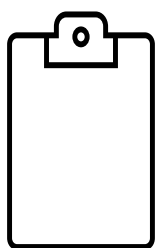
- Adult Carers Assessments
- Facilitate events and workshops
- Offer information and education in relation to caring role
- Respite breaks and activities for carers such as walks, choir, bowls etc
- Receive an adult carers identification card to share with others including professionals to recognise caring role.

In Oct 2025, UCSS were aware of and supporting 2,824 adult unpaid carers across Southampton through various means including sharing relevant information via their monthly newsletter.

There is a separate provision for young carers aged 8-18 provided by Southampton City Council ([Young carers](#)).



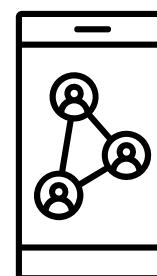
Methods



Healthwatch Southampton (HWS) developed a series of questions to ask people about their caring role, respite breaks and activities, away from, and with their cared for person. HWS also included questions about their caring role being recognised by health and social care professionals and if they felt listened to by these professionals.

HWS launched the survey during Carers Week 2025, when they attended the local Carers Week event about respite in June 2025, organised by the Unpaid Carers Service (UCSS). As well as asking people to complete the survey independently, HWS were able to chat to unpaid carers to gather their views and preferences about respite breaks and the barriers they may face when attending activities.

HWS then designed a poster which included a QR code for participants to scan and complete the survey online. Following that, staff from the UCSS service distributed the survey via email to all their service users.



Limitations

Healthwatch Southampton (HWS) are grateful to all the respondents who took the time to share their views and stories. This has allowed us to gain an insight into both positive and negative impacts on unpaid adult carers in Southampton city.

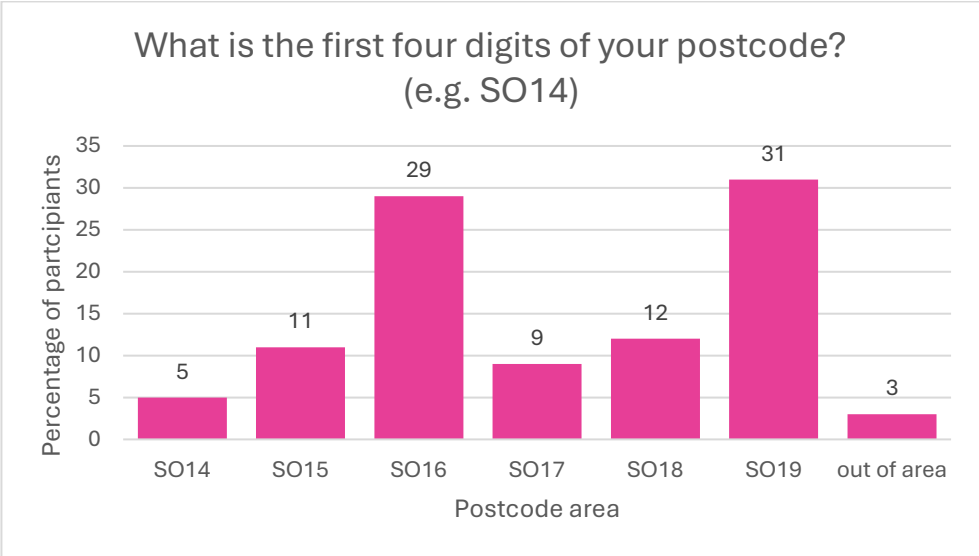
HWS Southampton acknowledges that there are some limitations to the findings in this report:

1. The survey was initially planned as a short exercise to be conducted during the Carers Week event in June 2025. We did not ask for equal opportunities monitoring in the planned questions as we wanted to make it as short and easy to engage with as possible.
2. Healthwatch Southampton and Unpaid Carers Support (UCSS) shared the survey with carers who had been supported by UCSS. We did not take additional steps to try to reach unidentified carers (e.g. website, social media, contact other voluntary sector organisations etc).
3. Adult Social Care (ASC) services were not included as a specific option for people to select when asked about identification as a carer, so there is limited data about this. People were able to share additional information by selecting the other option.

Feedback

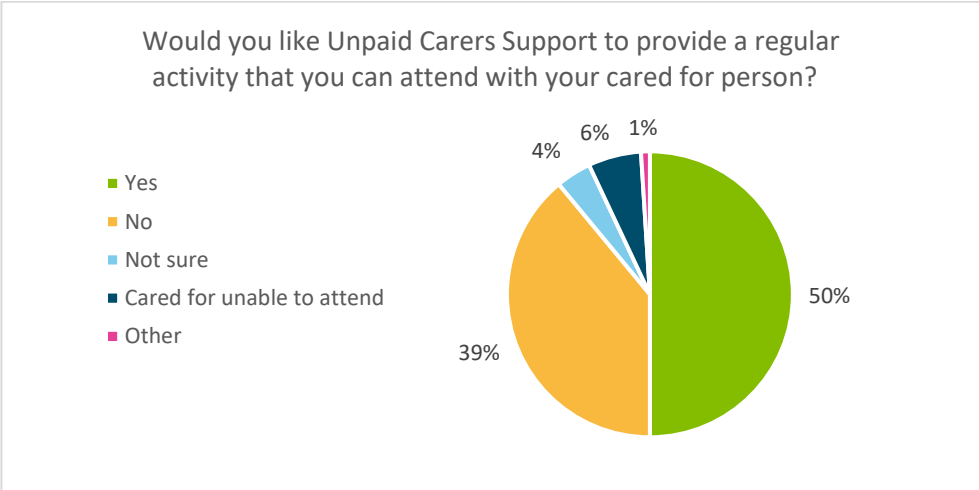
Healthwatch Southampton were pleased to have 112 responses to the survey. This helped to gain an insight into the views and experiences of adult carers in the city of Southampton. You will find more details below of the responses to each question on the survey.

1. What is the first four digits of your postcode? (e.g. SO14)



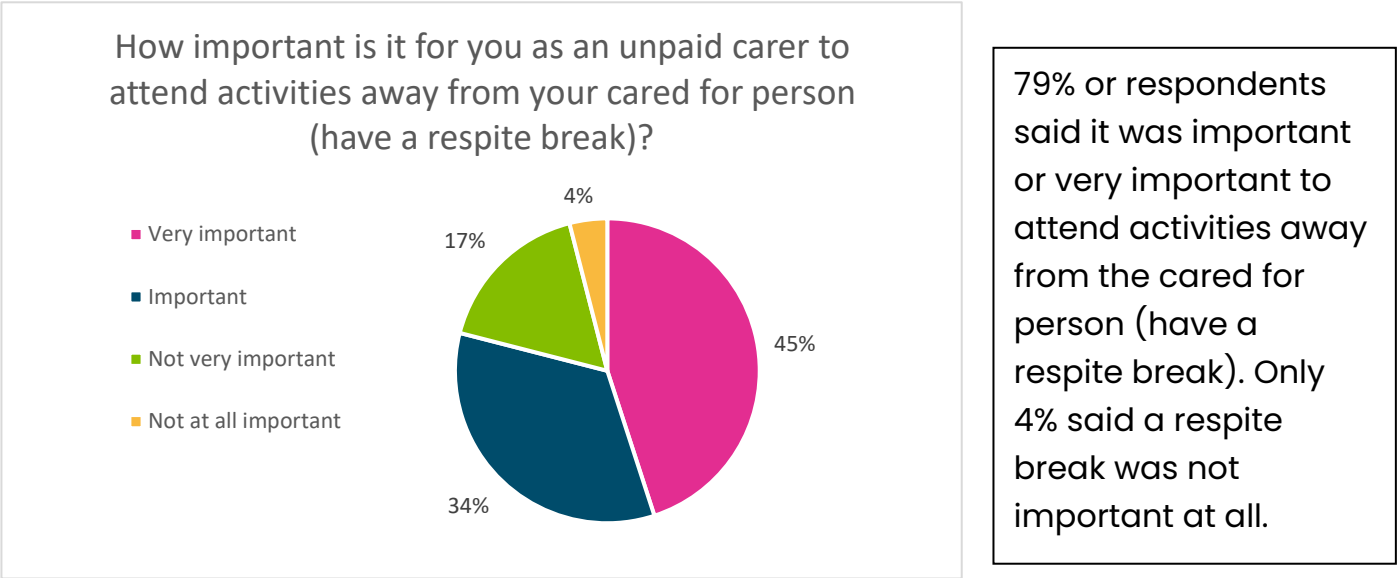
There were significantly more responses from unpaid carers living in SO16 and SO19. This reflects the data collected by UCSS about postcodes of unpaid carers supported by their service in the city: 27.3% SO19

2. Would you like Unpaid Carers Support Southampton to provide a regular activity that you can attend with your cared for person?



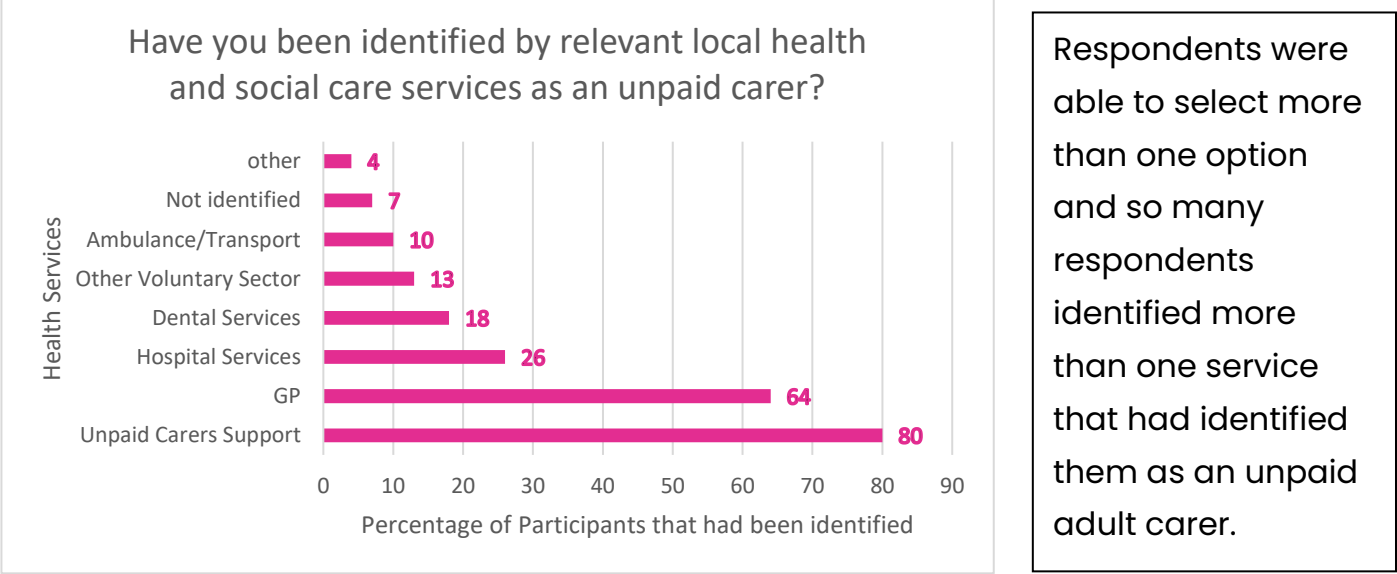
50 % of respondents said that they would like UCSS to provide a regular activity that they can attend with their cared-for person. 39% would not like UCSS to provide this.

3. How important is it for you as an unpaid carer to attend activities away from your cared for person (have a respite break)?

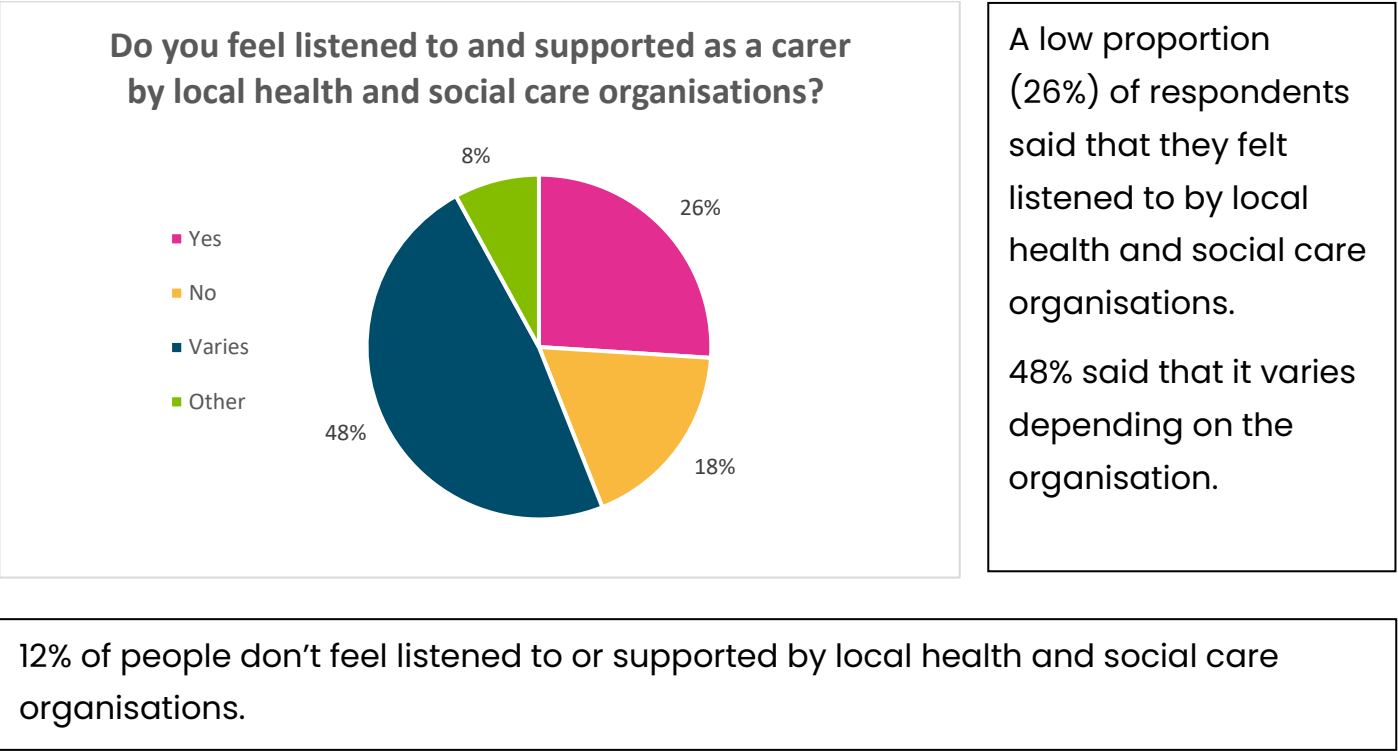


The Unpaid Carers Support Service had shared the survey with their service users, so it is not surprising that 80% said that they had been identified as an unpaid carer by UCSS. People were able to share additional information by selecting the other option. 64% of respondents said that they had been identified as an unpaid carer by their GP surgery. This figure is below the number in the national Carers UK survey of 75%. It is a concern that 36% of respondents have not been identified by their GP as a carer.

4. Have you been identified by relevant local health and social care services as an unpaid carer? (e.g. GP, hospital services) – tick all that apply



5. Do you feel listened to and supported as a carer by local health and social care organisations?



We asked for more details about whether respondents felt listened to by health and social care organisations. The themes relating to **positive** and **negative** responses covered: accessing support, recognition of the caring role, support received from organisations, financial impact, staff training issues and lack of consideration of the impact on carers.

Positive Responses

Accessing support

- Easy access
- I feel supported by UCSS, I know they are a phone call away to give advice.
- I think I have enough knowledge to contact support if I need it.
- For my son, we get family hub support, which we access.
- Everyone that I have been contacting has been so supportive.

Recognition of the caring role

- Usually accepts that I am my husband's carer and need to assist him.
- The unpaid carers card helps to activate responses, both health and social care systems. Also, being recognised as an unpaid carer means my GP takes my wellbeing more seriously. I'm lucky to be registered at an excellent GP practice.
- Respect shown for myself as a carer and my husband who finds it hard to make decisions.
- Most services will now contact me about appointments etc. I am also registered on NHS app to view health record and receive results etc.
- It took a while to get things sorted but now GP and hospital especially know I'm the carer and contact me first, ask me things, advocate for him etc.
- Recognised by health service.

Support received from organisations

- As a carer, with my own physical and mental health issues, I have found Unpaid Carers Support invaluable.
- I only have experience from carers in Southampton. I feel they care and can support me.
- Most of the services I deal with as a carer are very helpful.
- We have a great Social Worker and a great team under the Adult Social Care Services.

- My wife is now in a Nursing Home, so my caring role is no longer 24/7. While she was at home we had excellent support from the NHS & Social Services. Since then UCSS has been a lifeline for me, especially the weekly choir sessions.
- GP has been great and provided lots of links to help e.g. Southampton unpaid carers.
- Regular health professionals who know our circumstances are good, A & E are dreadful, Special needs dentist and GP are exceptional.
- Some people are fantastic and obviously keen to help.
- Health has been supportive.

Negative responses

Accessing support

- Despite filling out forms to state I'm a carer, I frequently get told I can't deal with partner's care – it has to come from them.
- Difficulty accessing on phone.
- No help is offered as long as we continue with the support of our son.
- Please remember that carers are NOT all drivers and venues in many cases hard to get to. Portswood for instance would mean 2 buses and travelling is longer than event for me.
- Basically, social services just left me with my granddaughter as soon as the Special Guardianship Order (S.G.O) was awarded in 2013no support since.
- Difficult as being deaf can't use the phone can't understand what is being said.
- There is no provision for parent carers, everyone just sign posts to other organisations who also sign post. None of them actually provide anything for me.
- Sometimes it feels like banging your head against a brick wall, and repeated requests and conversations are needed to get any action or results required for the cared for individuals. Very exhausting and mentally draining.
- Adult mental health is very hard to access. Also I have to constantly find out about support for my daughter and fight for it.
- Everything took so long to go through and get any kind of help and guidance. I didn't know where to start to get help for my mum so had to rely on information from friends who had experience
- Too much passing stuff on to someone else. Not always easy to get in touch with right person immediately.
- Have not tried as don't know how.
- Still awaiting assessment.

Lack of recognition of the carer's role

- Adult mental health is supposed to allow me to advocate but they ignore me.
- I don't actually know which services formally identify me as a carer.

- It's a challenge and you have to really be relentless to achieve what you request. Once you are heard it gets easier.
- It's done via a care home but it's hard to keep up with social and care developments as ultimately we have responsibility for representing our son and ensuring his needs are met.

Lack of consideration of impact on carers

- Last time I went to my GP practice, which is based in Portswood, they insisted I took an appointment at their sister surgery in St Mary's. This meant a 20 minute car journey, with difficulties parking, as opposed to 7 minutes, no trouble parking. I haven't even attempted to get in touch with social services based on history. We manage without them.
- Do not make allowance e.g. what time I need to phone the doctor for which appt. I'm housebound carer so I am not included in activities. My difficulties are not understood e.g., I cannot escort the person I care for. Disabled carer isn't linked.
- When my husband has had time in hospital he has been sent home the last 2 times with problems i.e. impacted bowels infections. The help has not been good resulting in myself having burn out and really struggling.
- Getting Doctors' appointments are a joke.
- Feels like everything is comparable – people with more severe disability and fight to access support, too many forms.
- It's better now I have learned what to do. When it first started, I was struggling with everything. Mostly learned from google.

Not appropriate support

- Not always listened to – tend to talk about finance more than support, quite often told there's a waiting list.
- Just lots of smiles, nods but nothing worthwhile – my situation is unique.
- Dad has late-stage Alzheimer's. Not much support is given to carers of people that have such complex needs.
- No offer of a social worker as of yet, not even sure if my son is still on the list for assessing support?
- Appointments not always at the right time. Judgements made by social services based on their budget constraints which reduce care.
- When you need help it's a struggle to get the help and support at the time you need it.
- Health authorities don't seem to care.
- Could be better specially with mental health team.
- I feel my GP doesn't listen to me most of the time. Especially when I explain my daughters get very nervous around medical persons.

- Reception at doctors could be more helpful
- I know when the person I care for needs medical assistance and it is very frustrating to be told the only way to be seen is to go via A&E it is very distressing and time consuming – surely there must be another way to be seen urgently.
- My daughter's mental health condition means that it can be difficult for all conversations to take place in her presence as it can lead to her arriving at the wrong conclusions (e.g. about murder). So local health and social services insisting that they can only speak to me about her when she is present is not helpful.
- There have been times when my husband would have preferred to stay at home, but no service for this (hydration via a drip).
- Social care – little to no support from them.
- Adult social services have been awful. They took a week to contact me when I was incapacitated and had no support for my husband, stating the council had no money and it wasn't their fault!
- I get little support from Social Services in regard to helping the person I care for.

Staff training

- Paid carers refused to stay for the allotted 30 minutes 4 times a day, would not even speak to my brother apart from sit down and stand up. Management came 3 times, told them how to behave. It was dreadful for me, let alone for my brother but the Council wouldn't change us to another company.
- It depends on who you get as your social worker as we've had 4 different social workers, and the latest one seems efficient and helpful at this time. I do feel that more training and understanding is required when dealing with dementia cases as we've found that our requirements and requests have been met with incredulity which adds to our frustrations.
- Services who don't know us, are a mixed bag, some understand from day 1 some will never get it.

Financial impact

- Low pay which financially means that a lot of the time, we are unable to pay or do things. My son's specific needs means unexpected financial expenses.
- When I was ill, I was told to employ a carer for family members. They didn't get that I didn't get paid so couldn't afford it.
- I have not been very lucky at getting any additional help, I made the mistake of having some savings and I often feel that I would have been better if smoking and drinking and living in rented accommodation.
- Have been in touch with Southampton City Council , Wellbeing (Health and Adults) a number of times to ask why my son's personal budget has not increased for the past

2 years, when his activity centre's daily rate increases every year. His personal budget no longer meets his needs. I have chased them up many times & I am still waiting for an answer. I will pursue the matter with them.

- Feels like everything is comparable – people with more severe disability) and fight to access support, too many forms.
- My mother (my cared-for person) has recently received attendance allowance. I have yet to receive any respite breaks. The Princess Royal Trust people are a godsend.
- I have been a carer for my 36 year old son from birth. My wife is now a carer for me! We have had good support from NHS and Social Services, but we have had to fight for it.
- Often positive, sometimes v stressful (e.g. process of obtaining personal care).

Recommendations

1. Health and Social Care services should make it easy for unpaid carers to access support by:

- Providing clear and easy to understand information about the process and ensure unpaid carers do not have to repeat the information or requests for support.
- Simplifying forms.
- Improving accessibility for people with hearing impairment for contact via phone.
- Providing information for parent carers.
- Taking action to reduce delays in assessment and provision of support.
- Providing information about what carers are entitled to, the timescales within which they can expect to receive money and how they can raise issues.

2. Health and Social Care services should explore further experiences of unpaid carers when supporting their cared-for- people to access health and social care services. All staff working in health and social care services need to better understand the role of unpaid carers:

- Health and Social Care Services staff training to include a clear understanding of the unpaid carer's role in providing support to the person they care for.
- Consider how housebound carers can be better supported.
- Health and Social Care Services should prioritise identifying unpaid carers and including them in cared-for-person's care or care plan where appropriate.

3. It is important for health and social care professionals to really listen to unpaid carers and support them. Action is needed to respond to the following points in the feedback:

- Health and Social Care Services should prioritise identifying unpaid carers and including them in cared for person's care or care plan where appropriate.
- Health and Social Care Services staff training to include the importance of listening to unpaid carers, and being sensitive to the impact on them when making appointments, making decisions and providing support to the person they care for.
- Consider how housebound carers can be better supported.

4. Unpaid Carers Support (UCSS) to continue to provide regular respite breaks for unpaid carers away from cared-for-person and occasional opportunities for activities where the cared-for-person can attend as well.

5. Health and Social Care professionals must also consider the unpaid carer may have their own additional needs for support. Professionals must ensure that carers have equal access to information and support that is available.



**Healthwatch Southampton
Voluntary Action Centre
Kingsland Square
Southampton
SO14 1NW**

**www.healthwatchsouthampton.co.uk
t: 02380216018
e: info@healthwatchsouthampton.co.uk**

healthwatch
Southampton