

*I feel it is a difficult and overwhelming situation to be in, suddenly becoming a carer to a loved one.*

Read one Sefton Residents experience with Bootle Village Surgery, Sefton Council Adult Social Care, Aintree University Hospital (LUHFT), North West Ambulance Service (NWAS), Domiciliary Care – New Directions and Sefton Carers.



# Carer 'A' lives in Sefton and told their story through 2022 and 2023

## This story involves a number of different health and social care providers...

- Bootle Village Surgery
- Sefton Council Adult Social Care
- Aintree University Hospital (LUHFT)
- North West Ambulance Service (Nwas)
- Domiciliary Care - New Directions
- Sefton Carers

## Who are we?

Healthwatch Sefton is your health and social care champion. If you use GPs and hospitals, dentists, pharmacies, care homes or other support services, we want to hear about your experiences. We have the power to make sure NHS leaders and other decision makers listen to your feedback and improve standards of care. We also help people to find reliable and trustworthy information and advice.

Healthwatch uses your feedback to better understand the challenges facing the NHS and other care providers nationally, to make sure your experiences improve health and care services for everyone. It's really important that you share your experiences – whether good or bad, happy or sad. If you've had a negative experience, it's easy to think there's no point in complaining, and that 'nothing ever changes. Or, if you've had a great experience, that you 'wish you could say thank you'. Remember, your feedback is helping to improve people's lives. So, if you need advice, or you're ready to tell your story – we're here to listen.

**"Through my journey being shared, I would hope for some positive changes for carers to help them navigate the system"**

# Carer 'A' lives in Sefton and told their story through 2022 and 2023

## Why I am telling you my story...

I feel it is a difficult and overwhelming situation to be in, suddenly becoming a carer to a family member / loved one. Through my journey being shared, I would hope for some positive changes for carers to help them navigate the system to get the help and support needed for both the person cared for and the carer.

## This is what I experienced.

- Who to turn to? Lack of direction and advice on what support is available and how to access it.
- Confusion when directed to websites with different links to follow.
- Lack of care and recognition for carers, we can help in situations and we should be recognised and supported to do this e.g. being able to support our loved one at meal times when in hospital.
- Not being kept informed of treatment and next steps.

## There needs to be.

- Clear signposting to Sefton Carers - for a range of support, guidance and knowledge on what we can access and how.
- Professionals to be educated on where to signpost carers to.
- Recognition for carers and the role we play in caring for our loved ones across NHS and Social Care services.
- Appropriate access to services that can support us in our role.



# My Story - 2022 to 2023

"My sister was unwell and had suffered four TIA's". (mini strokes).

## Sefton Council Adult Social Services

It was March 2022, I contacted Sefton Council Adult Social Services on my sister's behalf for help in her home. Initially they helped out and fitted:

- An extra banister rail
- Grab rails for the front door
- Grab rails in the bathroom
- A shower stool

"This was an excellent service and all happened within a week of me calling them.  
It was easy to get in touch with them and this was a good service at the time".

They told me about a stair lift and that we needed to request this via a physio appointment. I tried to get an appointment via the doctors, I did not know where to go for this. I found out I should have requested it via social services physio. I got this sorted in the end and found out how to get the appointment, it was down to lack of communication that caused confusion on how to arrange this.

This did not then get sorted until the end of October 2022. My sister was assessed for a stair lift and advised yes, she was eligible, and someone would come and measure up. It was measured at the end of November 22. We were advised that it could take between 6 – 18 months. So, we were very surprised to get a call from the Midlands to set up an appointment for someone to assess if a stair lift would fit.

We are now waiting for it to be fitted and have been told it will be early in the New Year 2023.

"This has been a good service other than the person saying 6, 12 or 18 months. Her response was that Covid had knocked all the services".

# My Story – 2022 to 2023

## Aintree University Hospital – (NHS Liverpool University Hospitals NHS Foundation Trust) & North West Ambulance Service (NWAS)

During Easter time, April 2022 – my sister was taken into hospital on the Thursday and presented with her third mini stroke. She was taken to Aintree A&E via an ambulance. We waited 40 mins for the ambulance and they checked her strength and speech. They did an ECG and checked her blood pressure. They looked to see if she could stand and assessed that she needed to go to A&E.

“North West Ambulance Service (NWAS) were fantastic”.

NWAS was a male and female crew. They communicated really well with us. The only issue was the male attending was scared of the dog and we had no where to put him as the home is open plan. This delayed things a bit.

She was taken to Aintree hospital A&E and she ended up on the Acute Medical Unit (AMU). I was not here for this so I have no idea about waiting times etc.

My sister told us that she was transferred about 4 am in the morning to the AMU WARD and she had arrived at A&E the evening before at approx. 5 pm. We were phoning her and she kept saying she didn't have a bed and we phoned many times and she kept saying she had no bed.

The next day we couldn't get through to her. I then had to phone the ward. Each time I phoned the ward they said “Yes, she's fine and that there was nothing wrong with her”. We knew my sister was confused and saying she had not been fed. But now the staff were saying that she was fine and there was nothing wrong. Something did not ring right.

# My Story – 2022 to 2023

## Aintree University Hospital – (NHS Liverpool University Hospitals NHS Foundation Trust) & North West Ambulance Service (Nwas) continued...

On the bank holiday Monday, the ward phoned me to say “Come and get her now as we are discharging her”. I said I am in work for another 2 hours. They said “well we are discharging her now and you can come back later for her meds”.

I had to phone a family friend and he went and collected her. When I finished work at 2 pm I went to the ward to get her medication. When I arrived, there was no medication as the pharmacy was closed on the bank holiday. I told her that they had told me to come back for it. The nurse said she didn't know. I asked her to go and ask the Sister and find out when I can pick it up. I waited 20 minutes for her. I was told I could not get her medication today and I had to call back tomorrow. I asked for a time as it costs a lot in petrol. I then had to wait another 20 minutes. I went back the next day and still never got the medication. I never went back again.

## The discharge experience from the hospital

“Discharge was poor in every way. She should not have been discharged without a care package”

My sister was discharged and she was very disoriented and confused. I do not think she should have been discharged. She was not capable of looking after herself and they knew that she was going home to live alone.

I then had to start calling Sefton Adult Social Services to see if I could get a care package. It is only because I had rung them for the equipment I thought I would start here.

Please note: visiting times at Aintree Hospital have now changed since this residents experience – <https://www.liverpoolft.nhs.uk/patients-and-visitors/visiting-someone>

# My Story - 2022 to 2023

## Sefton Carers Centre

My brother told me about Sefton Carers. I called in and saw a lady who was very helpful and she got in touch with a Social Worker for me instead of me having to try and do it. She also got a care package put in place for me as I told her everything that had gone on and what we needed. She put all the details across and then the Social Worker rang me.

"Sefton Carers was a massive help for me and my sister".

Sefton Carers advised me of benefits that my sister could claim. I knew none of this. They were fabulous. One of the other members of staff rang me and filled in the form with me to get an assistance allowance. He spent about an hour and half with me filling in a very large form.

## We asked - Do you think you could have completed the assistance allowance form by yourself on behalf of your sister?

No, as some of the questions would have been hard to answer because you felt your answers could be vague as depends on the day but he helped me understand how to answer the questions. Some questions are repeated and asked in a different way, I am not sure why they do this!

Carers had started to come in once a day at this point but we soon realised that we needed more help as she needed help at bedtime as well.





# My Story - 2022 to 2023

## My sister suffered another mini-stroke

It was at the end of April 2022 - The day the bedtime package was due to start, my sister had another mini-stroke. This was the fourth one. She had been very poorly and not eating. Over Easter she was virtually not eating and I think this is why her mini strokes were happening. I am not sure anyone could have done anything to help her eat. I was taking her back and forth to the doctors and she was prescribed Ensure.

Her GP is Bootle Village surgery. We are extremely lucky with Dr Stephenson as she would say come back and see me and put it in her diary and tell me we could go back. This way, I was able to see the doctor with no fuss. We see Dr Stephenson on a regular basis. She was and is very good with my sister. All the GP's are brilliant here.

"Bootle Village Surgery  
- All the GP's are  
brilliant here".

## We called for an ambulance and my sister was taken to Aintree University Hospital

NWAS were called and they arrived within 30 minutes. It was a male and female crew and they were absolutely fabulous. My sister was very confused this time. They did all their checks and she was still very confused so this time they let me go with her in the ambulance to Aintree University hospital A&E.

On arrival at A&E further checks were done on my sister in the corridor. We were in the corridor for 1.5 hours until 5pm. It was 5 am before she arrived on the Acute Medical Unit (AMU). I stayed with her the whole time. They hardly did any checks through the night. I was able to get to the café in A&E for myself. My sister was mostly asleep.



# My Story - 2022 to 2023

## Aintree University Hospital continued...

After being in the corridor we went into majors 2 and this was cubicles separated by curtains. Staff were just too busy to speak to me. They came and did observations approx. every 2-hours or so. I was very worried as nobody told me anything.

It would have helped if someone told me something as she had an x-ray and scans and the doctor came over so they had the results. All I was told was we can't see anything. We don't know.

"The experience for me was poor. I wasn't being told anything or getting any information".

## My sister was transferred to the Acute Medical Unit (AMU)

I walked to AMU and this was a frightening experience when we arrived at 5am. My sister was taken onto the ward and they said, while we settle her you can go into the family room. There was a man kicking the door on the ward shouting and swearing let me out over an over. A nurse said don't be worried your mum will be fine she is nowhere near him. I said it's not my mum and she just repeated don't worry your mum will be fine. She never listened to me. It is my sister.

I was in the family room and worried and didn't have much faith. I felt awful and so worried, considering how the man had been behaving and my sister was confused.

Thankfully my sister phoned me and said she had been moved to ward 23. This was at 10am.

# My Story - 2022 to 2023

## Aintree University Hospital continued...

"I had to leave without seeing my sister. The nurse told me she was settled and would not let me see her to say goodnight"

### Ward 23

This was a big worry lifted that she had been in touch and moved but I was still worried as you don't know what the next ward is going to be like. Most of the staff were nice but we were only allowed two, 1-hour visits. You had to book your time but if my sister's daughter came in with me they would class that as the two - 1-hour visits so she would not be allowed a visit again for that day.

Aintree Hospital visiting -  
"I don't feel this is a good policy / process for the patient or the family visiting".

My sister's GP advised me to visit at meal times to encourage her to eat. It was difficult as she did not want to eat so when they asked her what she wanted for meals she would said she didn't fancy it so the staff did not know what to give her if we were not there. We knew what she would eat. We needed to be there when the menu came around. I would have been able to sort this.

We were encouraged to take in things she liked to eat so we did but the staff kept forgetting to give them to her. It is so difficult when someone has an eating disorder.

She was in the hospital for 2 weeks. This time it was better because staff were trying to encourage her to eat and was also getting visits from an Occupational Therapist and was being assessed.

# My Story - 2022 to 2023

## **Aintree University Hospital Ward 23 continued...**

I felt stressed having to take time off work. We had to ask constantly how she was doing. If we asked we got the information but they never come to us. If the doctor came around when we were there he would talk to us. One doctor was really good. Overall this stay was good once she got onto this ward.

## **My sister's discharge was to a nursing home.**

My sister was then discharged to a nursing home as she was then waiting for a care package. The Occupational Therapist advised us that she needed a 4-calls per day care package.

It took forever for this care package, in fact it didn't get put into place. She had recovered sufficiently in the nursing home to require just a 1-call package. She was in the nursing home for nearly 3 weeks.

When she arrived home, it was a 1-call a day. It was ok for her because she made sure she got up herself.

## **Domiciliary Care was put into place following her discharge from the Nursing Home.**

My sister finally got a rehabilitation package set up after her discharge from the nursing home. It was for once a day. They assessed her needs and said it would be for a set time but could be shorter depending on how she was. Her calls would be at a certain time for 7-days a week. We were told they would never arrive before the set time e.g. 9 am so she would have consistency and the same people covering.

# My Story - 2022 to 2023

## Domiciliary Care continued...

This never happened. Of a weekend they would call at 7 am to get her up. I got mad over this as we were told it would not be before the time. I informed them that on a Saturday and Sunday she is not getting up at 7 am as she will just go back to bed. It was far too early for her.

It did change after this. The manager phoned me and did have an attitude with me but she sorted it. After this they started to come for the next 3 days at a normal time but then New Directions terminated the calls and said she no longer needed it.

"I am not sure as to the real reason why her care was terminated".

The care was certainly shorter than we anticipated. On a positive note, there was one nice carer, her name was Tamara. She was wonderful when she visited. The care provider was New Directions.



## We asked: What do you think worked well or could have been improved with each of the services your sister accessed?

Service	What worked well or could be improved	Healthwatch star rating 1 star poor – 5 stars excellent
North West Ambulance Service (NWS)	'I give this service 5 stars – they have been brilliant'	5 stars
Bootle Village surgery	'Brilliant treatment and care'	5 stars
Sefton Council Adult Social Care – for Domiciliary Care	'It was difficult to set up the 4 call package for my sister. I kept having to chase them up and this was hard. There was a lack of communication and I had to keep calling'.	3 stars
Sefton Council Adult Social Care – Equipment	'This was a very good service '	4 stars
Sefton Carers	'The staff were great and helpful and sorted everything for my sister'.	5 stars
Aintree University Hospital – A&E	'They need to improve communication. Waiting times for a bed needs to be improved. During my sister's time in A&E she was offered no drinks. If I was not with her, she would not have had a drink at all'.	2 stars
Aintree University Hospital – Acute Medical Unit	'They need to improve communication and listen to family and realise the impact on family. The issue with patient prescriptions being ready to be collected and patient discharge needs to be reviewed and addressed'.	1 star
Aintree University Hospital – Ward 23	'The staff were great on this ward'.	3 stars
Aintree University Hospital – Visiting	'The visiting policy needs to be reviewed and Improved. If the restrictions were because of Covid then this needed to be explained. Staff have different ways and different ideas of what the 2-hour visiting actually meant'.	1 star
Domiciliary Care – New Directions		0 stars

## Additional questions we asked...

Would your sister have been able to get the care she needed without your help?	'No, I had a difficult time'.
Do you feel it was difficult for you as her carer, to get the help needed for your sister?	'Yes'.
Is there anything you feel could be done to support carers to navigate the system?	'There should be a central organization to go to for help. I knew there were benefits to help but didn't know how to access them. The Direct Gov website is a minefield when you are trying to find out what you need. You keep having to click through the links and it is so confusing'.
What do you think would have happened to your sister without your help?	'She would have given up and wouldn't be here now as she didn't get the proper care from the hospital'.

**"Since this has happened my sister has gone through breast cancer during 2023, and she has received superb care through the Marina Dalglish Centre. She is now attending a weekly support group run by MacMillan. "**

# We asked Sefton Carers to read the Carer's story / journey and give us their comments.

“Sefton Carers Centre is a charity supporting unpaid carers in Sefton from the age of 5, all our services are free to every unpaid carer at the point of contact. With the implementation of the Health & Care Act 2022, carers have increased rights, particularly with regards to hospital discharge for the person they care for.

Sefton is currently developing an All Age Carers Strategy, we need to ensure that all unpaid carers are supported in their journey as an unpaid carer as this is role that never stands still. I cannot stress enough the importance of the right support, at the right time, from the right people, for unpaid carers is vital.

In the last Census over 30,000 people living in Sefton identified that they have a caring role, this is not a small percentage of our community and they have the right to expect support for themselves.”

**Vicky Keeley – Chief Executive Officer  
Sefton Carers Centre**





# Your voice will make a difference!

## What do you want me to do?

Your experiences can help improve care, share your experiences and stories with us.

If you would like share your story and be heard and listened to:

Contact us via

- Email us at [info@healthwatchsefton.co.uk](mailto:info@healthwatchsefton.co.uk)
- Telephone us and speak to Mandy on our Freephone number 0800 206 1304

Access our information and support via our website:

- [www.healthwatchsefton.co.uk](http://www.healthwatchsefton.co.uk)

"Recommend us to friends and family or even get involved and volunteer at your local Healthwatch."



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