

October Feedback Report 2022



University of Greenwich Public Health students joined us as volunteers

During October, we heard from 233 service users from the following:

- Calls and emails to Healthwatch Greenwich from Greenwich residents and service users
- Meetings between Healthwatch Greenwich and groups of Greenwich service users or advocates
- Outreach and engagement events by Healthwatch Greenwich

This month we are using a new approach, working with our system partners¹ to:

- Understand any action they've taken in response to our Monthly Feedback Report
- Share the actions taken with service users, patients and the public

¹ The organisations (NHS, Local Authorities, social & care bodies, and other stakeholders) that meet health and care needs across Greenwich

To pilot this new approach, this month we have focused on three detailed case studies from Linda, Susan and Ellen.

Linda's story: " You're left behind as soon as your child turns 18"

Linda and Michael's son, Harry - now 18, is severely autistic, epileptic, and non-verbal. When Harry was younger, he went to weekend activities and Linda and Michael occasionally got respite support from carers they found and organised themselves. *"Harry used to be able to go to all kinds of different activities in the borough on the weekends. The Toy Library was great. They had lots of sensory toys for him. He used to go to weekly swimming 'Cascades' classes. I used to meet lots of other parents and carers in the same boat as me, so these activities were not just good for him, but for us as parents too but everything we used to do has either been closed down or he's not allowed because he's not considered to be a child anymore.*

Now Harry is bigger and stronger, Linda and Michael haven't been able to find any respite themselves and they haven't been offered any. *"At every Annual Review (Royal Borough of Greenwich) I have raised the issue of respite. I've told them that we are tired and stressed and we need just a few hours here and there. But, I'm not given any respite support. This means that I've had to make huge sacrifices and put my life on hold and we can't do things that other families can do like going to important family events - funerals or weddings"*

Harry is at Charlton Park Academy - a 6th form college. Provision finishes before the end of the working day and Linda says it doesn't offer suitable add on care. As a result, Linda had to give up her job. *"I loved my work and I really didn't want to have to give it up. But, I knew that it was my*

only option to leave my job and look after Harry. If anything - he's a lot harder to manage now - he's bigger and stronger. He needs looking after full-time...and it's not easy work. He's still a child - I don't see why he's now seen as an adult"

Harry often gets home tired. Linda and Michael are unsure about how Harry has spent his day. As Harry is non-verbal, strong communication from carers is important for Linda. *"Other parents of autistic children and adults are able to communicate verbally - they'd be able to tell them if they'd had a bad day or if they hadn't eaten. I need that communication to come from the academy.*

An Occupational Therapist (OT) supports Charlton Park Academy students for one day a week. *"She is absolutely brilliant. I don't know what I'd do without her. She has been a great help for Harry and really listened to me. She was the one who got improvements to the facilities because of my suggestion, but she's only there one day a week, it's not enough"*

Linda is worried about Harry's future care and wants more support to help her think about the options. Linda's been discussing this with Harry's social worker *"She is doing the best she can... she's really trying her hardest. But she's a children's social worker. She doesn't know about the care homes for adults I'm talking about and doesn't fully understand his complex needs"* Linda feels that the OT at Charlton Park Academy understands Harry's needs well and could help her, but the OT is only available one day a week.

Looking at what's available locally, Linda doesn't think they've been designed with carers and families that understand the needs of those with complex conditions and none are suitable for Harry. Linda went to look at Kemsing Road Care Home² a Royal Borough of Greenwich home. *"Kemsing Road Care Home has stairs - this would be a disaster for Harry as he's epileptic, it's just a no-go. I have to say, it looks nice and clean but they*

² <https://www.cqc.org.uk/location/1-1382434803>

just don't have the facilities and know-how to suit his needs...He needs sensory play. For example, he enjoys being outside in a sandpit, on a swing or in water. They have none of that at Kemsing Road. I know he wouldn't be happy there and I would feel uneasy leaving him there. I would worry about him. There just aren't any options in Greenwich that meet his needs"

Linda went to the Annual Autism Show at the Excel centre and picked up a brochure for a care home in Lincolnshire³. *"I really wish there was something remotely like this here - it's a special 18+ care home designed by people who understand autism, and you can tell. In Greenwich, there is this 'one-size-fits-all' approach. It doesn't work and it won't work for my son."*

Linda is worried and anxious about Harry's future. *"I have lots of paperwork to do - now he's 18, he is now seen as an adult, so we must prove he lacks capacity to get access to funds. I'm in the middle of sorting out all this paperwork and looking at how funding works. It's really hard work and is now my full-time job"*

Linda says she's not alone, that other parents in Greenwich have had to give up their jobs to provide care and who worry about future care for their adult children with special educational needs (SEND), because provision isn't available locally. *"I know I'm not the only one - I could give you a list of people to speak to who are in the same boat... you are left behind as soon as your child turns 18"*

Young people and their families face multiple challenges preparing for adult life. For those families with young people with complex health and care needs, there are many additional hurdles. Linda and Harry's experience shows the transition process (from child to adult services) is variable and

³ <https://www.homefromhomecare.com/>

that families are confused and at times distressed by the lack of information, support, and services available.

Response from Royal Borough of Greenwich:

We understand that the current transition experience for young people with an EHCP transitioning from children's to adult social care could be improved. We are investing in developing new ways of working to improve the transition experience for young people and their families. This includes new assessment processes and decision making that includes the views of the young person, family and key professionals, which in this case could include the school based Occupational Therapist.

We intend to ensure that Care Act assessments of needs are carried out promptly, and details of outcomes and needs are known and addressed before the young person turns 18. This will allow for earlier planning and more coproduction with families with professionals who know the young person best. The Greenwich Parent Carer Participation Forum have been involved throughout this process to ensure parent carer views are included.

We are also working to improve the market and range of community based support available to young people, understanding that the current offer for young adults could be improved both for activities and respite provision, this includes:

- looking at the development of a flexible respite offer within our Share Lives Service in the future*
- Our recently re commissioned home care service is being embedded and will be able to respond to various needs, including personal care, community-based activities and respite*
- We have recently consulted on a Hub and Spoke day opportunity model. Both elements of the offer are tailored to individual needs and outcomes. Further work is underway to expand the options. We are working with various local providers to build a sustainable market*
- We are taking a strength-based approach to how we work, building on the skills and capacity of service users to have more choice and control over what and how they receive their services. We use coproduction approaches to help us in shaping services*

- *We are designing a supported employment model to enable those with Autism and Learning Disabilities who wish to work to be supported to secure employment.*
- *We have recently launched our carers strategy. We recognise the valuable work carers do and want to ensure we have arrangements to support them in their caring role and meet their individual needs.*

More information on this service development can be found on the Local Offer

<https://www.greenwichcommunitydirectory.org.uk/kb5/greenwich/directory/advice.page?id=v6SLTdgVYTg>

To better understand the experience of the family and look to explore any other action that is needed for Harry, we would like to offer via Healthwatch for Linda, Michael and Harry to meet with the service.

Healthwatch Greenwich have put Linda in touch with Royal Borough of Greenwich to explore any other action needed.

Susan's story: "I came into hospital for a test and came out with a broken hip"

Susan, in her 60s, was referred by her GP to Queen Elizabeth Hospital (QEH) for a heart test (electrocardiogram, ECG). On her way to the department, she slipped on a wet surface in the corridor. There wasn't a wet floor sign to warn her of the spillage. *"I was in complete shock and in a lot of pain. I remember that staff came to help me really quickly. They took me down to A&E and then I had an X-ray shortly after".* On her way to the X-ray unit, the porter pointed at another spillage on the corridor floor and said, *"that's been there for a while too"*

Susan was diagnosed with a fractured hip and told she needed a total hip replacement. *“I went into hospital for a simple test. I did a Zumba class in the morning - the last thing I expected was to be lying in a hospital bed with a broken hip in the afternoon”*

Falls in hospitals are the most commonly reported patient safety incident. Nationally, more than 240,000 falls are reported from hospitals each year⁴. estimated to cost the NHS more than £2.3 billion.

During the hip replacement surgery, staff took out her 24-carat gold belly bar piercing. When she woke up, she asked where it had gone but was told that the member of staff that took her down to the operating room was now off their shift. She was told it would be followed up. *“It was 24 carat gold, so it was quite expensive. I asked about it several times to different members of staff, but everyone was so busy and there were so many people to see, I felt like a nuisance”* She wasn't asked to fill out a form or given information on what to do next. No one came back to her, and her gold piercing jewellery was never returned.

We searched the Trust's website for information on 'patient's property', 'patient's belongings' and 'lost property'. None of these search terms provided any information on what to do or who to speak to about missing valuables or belongings.

Following her full hip replacement, Susan was taken to Ward 17 where she stayed for a week. Susan had a positive experience with the physio team that visited her. *“The physio was almost always early. They were very attentive and kind. There seemed to be a lot of them and they visited us [on ward 17] almost every day”*. Susan saw a nurse nearly slip over in Ward 17. The nurse told her, *“That's not the first time - it happens to me a lot. You have to be careful and watch your step in this hospital”*

⁴ <https://www.rcplondon.ac.uk/projects/outputs/naif-audit-report-2015>

Throughout the week, Susan struggled to sleep on the ward. *“I tried to get the attention of the night staff to turn off my light, and could see them passing by, but they completely ignored me. One night I put a flannel over my eyes to block out the light. One patient shouted during the night “let me die”. I couldn’t sleep for a week and ended up discharging myself early”*

Sleep is important in promoting the recovery of patients. Impaired sleep is a known hospital stressor, and hospitalised patients can struggle to get sufficient sleep at night due to noise and light. This is something Healthwatch Greenwich have previously raised in our feedback reports. Patients discharging themselves early against medical advice - in a bid to rest and recuperate, could lead to increased risk of avoidable harm.

Once discharged, Susan received support from the physio team at home. *“The real positive takeaway from this experience is that the physio team were really good - I had a young guy come and visit me at home. He assessed me and saw that I was doing well - walking around and very slowly going up and down the stairs. He gave me some YouTube video links so that I can do recovery exercises in my own time”*

Response from Lewisham and Greenwich NHS Trust:

We’ve been in touch with Susan and have apologised for her experience. The Trust will investigate this case.

The Trust will consider wider work to encourage patients to raise concerns directly with PALS (Patient Advice and Liaison Service⁵)

Ellen’s experience: “I can hear them talking about hurting other clients”

⁵ <https://www.lewishamandgreenwich.nhs.uk/pals/>

Ellen is bedbound, in her 80s and receiving palliative care from Eleanor Care. Her care falls under 'Home Care' and is partly funded by Royal Borough of Greenwich.

Ellen is fearful of the repercussions of speaking out. *"I have kept quiet for a couple of years , honestly from fear of payback.. I'm speaking up because I know that there are so many people that can't. I know an older neighbour of mine who has dementia and I've heard the carers talking about her.. I know she's not treated well but she wouldn't know where to begin to voice her concerns"*

As Ellen is bedbound, she needs to be hoisted out of bed. Ellen has received injuries as a result. *"I have been dropped on my head on the headboard many times. They have now padded the edges. My head has also been swung into my bookshelves. I would get constant headaches from the bashing. I realise I was paying to be hurt"*

Ellen wants her hair washed and has asked her carers many times. *"I have only had my hair washed three times in the past year. They tell me that they do not know how to or that they don't have enough time. This made me feel very low and dirty - I even thought about hurting myself. I didn't feel human - it was demeaning"* Having unwashed hair is exacerbating her low mood, feelings of isolation and anxiety.

Ellen says her carers *"sometimes come in unannounced and without a uniform on. They'd wear these long false nails which I think are unhygienic. They would sit on the sofa together, chatting away to each other. When I ask them to do small things, like to open the blinds, they would moan - making out that this was a chore. They would let food go off in the fridge regularly. The list goes on"*. Ellen says she sometimes overhears her carers talking about other clients, how they've been injured. *"They think I can't hear but I've overheard them talking about other clients - I became more anxious when I heard about one lady who has herself - wrapped a tea towel around her hoist to prevent injury because she'd been knocked against something so many times before. I heard*

them saying things like, “she told me not to hurt her” - they imitate other clients voices and laugh about it”

When Ellen confronted her carers directly the situation became more unpleasant. *“They used to shout and get angry at me. I felt like I couldn’t speak up. They told me - “We can do what we like in your house, we can sh*t on the floor if we want to” I’m not a nervous, timid woman and never have been - but they really broke me”.*

After two years, Ellen plucked up the courage and found contact details (online) for the management of Eleanor Care. *“I don’t know how anyone would be able to find this information if they weren’t online or didn’t have an iPad. I couldn’t find any paperwork that had ever been given to me with this contact information on it”* Eleanor Care sent two managers to her home to speak with her. *“I didn’t get any letters or paperwork documenting what I’d told them or what action they would take - they just came over and had a chat with me and the carers. It was very informal. It felt like a nice social occasion for the managers to chat with the carers, who had been pre-warned of the managers visit. I didn’t feel like it was being taken seriously until they sent in these new wonderful carers last week”*

Ellen was allocated two new carers and notes the vast improvement in the quality of her care. *“They are the opposite of my previous carers. Now I know what it’s like to have proper care. They’re kind, efficient and thoughtful. They really listen to me - they remember what I have for breakfast, how I like my tea. Whereas everything before seemed like a struggle, they now deal with things without fuss”.*

Despite being very happy with her new carers and asking them to wash her hair, it’s still left unwashed. Ellen is unsure of what she is entitled to under ‘personal care’. *“The carers tell me that they don’t know how to wash it. I have just accepted it now, maybe I’ll never have my hair washed - I’m not sure if I’m entitled to hair washing or not”*

Ellen wants more checking - like unannounced 'spot checks' of care companies providing services for Royal Borough of Greenwich. *"Chance calls to carers and clients without warning would help. Many older people are too scared to speak up. These spot checks would work more effectively than letters to care companies or emails - who would know if they are ever logged or actioned or if they're just deleted? It would be great if they [RBG] just turned up with a clip board - unannounced. These Care Companies are working for RBG and representing RBG- they need to be better monitored"*

Response from the Integrated Commissioning Unit:

The Integrated Commissioning Unit which oversees strategic Commissioning of support for those with Adult Social Care, jointly commissioned services between health and social care and some aspects of community health provision includes a Quality Assurance function that oversee the quality of the Adult Social Care provider market. This includes a framework of quality indicators including obtaining feedback from people who use the service. Any concerns or alerts about poor quality care are investigated and monitored to identify emerging themes and enable service improvements. The team work proactively to support and enable providers to offer high quality support to residents and also have a close working relationship with the Care Quality Commission to ensure join up with legislative requirements and actions being taken to support providers.

Healthwatch provide valuable insight from people who use services, our advice to those in communities and to Healthwatch colleagues is that concerns of this nature must be reported to enable a full investigation and any actions or learning to be taken.

In line with our Healthwatch Greenwich Safeguarding Vulnerable Adults Policy⁶ we reported this incident to Adult Social Care officers on receipt of receiving it. We were made aware by the Royal Borough of Greenwich that an investigation was underway.

⁶ <https://healthwatchgreenwich.co.uk/report/2022-06-29/our-policies>

Next Steps

We follow up on all concerns or issues raised.

We work with commissioners, providers, and service users to understand where services are working well and where further development may be needed.

Contact Us

For more information on our June 2022 feedback report, contact Penny:

'penny@healthwatchgreenwich.co.uk

Telephone: 02083018340

Email: Info@healthwatchgreenwich.co.uk

Website: www.healthwatchgreenwich.co.uk

Twitter: @HWGreenwich

Facebook: @healthwatchgreenwich