Oxford University Hospitals
NHS Foundation Trust

Cover Sheet

Trust Board: Wednesday 25 May 2022

TB2022.036

Title:	**Patient Perspective: Charlie's Story**

Status:	**For Discussion**
History:	

Board Lead:	**Chief Nursing Officer**
Author:	**Caroline Heason, Head of Patient Experience and Binu George, Matron Neurosciences Directorate**
Confidential:	**No**
Key Purpose:	Assurance, Policy, Performance

Executive Summary

1. Charlie has a learning disability, and he lives at home, supported by his family with support from a community nurse with the local community team for people with learning disabilities, Oxford Health NHS Foundation Trust.
2. Charlie's first admission was stressful for both him and his family.
3. The patient's family, community team and Trust multidisciplinary team worked together to understand the problems with his first admission to improve the family's experience in subsequent admissions.
4. Everyone has learned a considerable amount from Charlie's admissions. Notably the key learning of
   - Communicate
   - Plan - a successful admission and discharge
   - Be human and be compassionate
   - Work in partnership
   - Learn from others and transfer to your own team
   - Listen to your patient and their family
5. The Directorate is implementing a two-day staff orientation programme. This will focus on communication and working with families. The Safeguarding, Learning Disability and Childrens team have been included in the programme to enable the whole directorate to learn.
6. The story is being translated into Easy Read and will be shared with the Oxfordshire Learning Disability and Autism Improvement Board, Oxfordshire Family Support Network, Carers Oxfordshire and My Life My Choice.
7. The story and learning will also be presented at the Divisional Senior Nurse and Allied Health Professional Board (AHP) and the Directorate and Divisional Clinical Governance Committee.
8. The Oxford Spinal Service has been under significant pressure as a result of the pandemic. The Clinical and Administrative teams within the Spinal Service are acknowledged for their continued efforts to ensure that we can provide the best possible patient care as the service recovers from the impact of the pandemic.
9. The Elective Recovery Fund has supported the use of the Independent Sector to treat additional patients, who would otherwise have to wait for surgery at the OUH. Work is ongoing with other providers to identify opportunities to further reduce the waiting times for surgery.

Recommendations

10. Trust Board is asked to note the contents of the paper.

Contents

Patient Perspective: Charlie’s Story

1. Purpose

1.1. A patient or staff story is presented to each Trust Board. This gives a unique lived perspective of receiving or delivering care to our patients and their families.

1.2. The purpose of this paper is to describe a family’s experience of the Neurosciences Ward inpatient services.

1.3. Charlie has a learning disability, and he lives at home, supported by his family with support from a community nurse with the local community team for people with learning disabilities, Oxford Health NHS Foundation Trust.

1.4. Charlie’s first admission was stressful for both him and his family. The patient’s family, community team and Trust multidisciplinary team worked together to understand the problems with his first admission to improve the family’s experience in subsequent admissions.

2. Background

2.1. The Electronic Patients Record (EPR) used within the OUH has a function to alert all care givers from the multidisciplinary team that a patient has unique needs such like a learning disability. Currently there are 1762 people with learning disabilities, residing in Oxfordshire, highlighted on EPR.

2.2. The Neurosciences Directorate is part of the Trust’s Neurosciences Orthopaedics Trauma, Specialist Surgery, Children and Neonates (NOTSSCaN) Division[1].

2.3. The health needs of people with learning disabilities was highlighted in the Mencap report ‘Death by indifference’[2]. This told the story of six people with learning disabilities whose health care was poor, and which contributed to their death.

2.4. Two investigations and reports followed this. Healthcare for all[3] investigated and reported on healthcare for people with learning disabilities in the UK, led by the Sir Jonathan Michael[4]. Six Lives was the

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[1] Neurosciences - Oxford University Hospitals (ouh.nhs.uk)

[2] 2006.423 report (mencap.org.uk)

[3] Front Cover (easy-read-online.co.uk)

[4] The Trust’s previous Chief Executive from 2010 to 2015

Parliamentary and Health Service Ombudsman's report into the complaints made by the six families[5].

2.5. Following the Healthcare for all report, the Trust's Learning disability Liaison Team was established. This team employs 3.6 WTE nurses, 2.6 WTE are Registered Nurses, Learning Disability (RNLD) and 1 WTE is a Registered General Nurse (RGN). The Trust also employs a specialist epilepsy nurse for people with learning disability. These posts recognise the complexity of healthcare for people with learning disability and act as a 'bridge' between to support people with learning disability, their family, social carers, the Trust multi-disciplinary team and community health services before, during and after a person's admission.

2.6. The Trust also employs 10 RNLD in ward based clinical and senior clinical management positions. This extends the knowledge of supporting people with learning disabilities wider across the Trust's clinical services.

2.7. The Trust is a member of Oxfordshire's Learning Disability and Autism Health Improvement Board. This is a multi-agency partnership Board, chaired by the local authority to further improve health and social care for people with learning disability in the county.

2.8. The Learning from Learning Disability Deaths (LeDeR) [6] [7] is a national programme which coordinates the local reviews of the circumstances leading up to the death of a person with a learning disability to contribute to national learning to improve healthcare services. In the Trust, the sad death whilst in the care of the Trust of anyone with a learning disability, is reviewed by a clinician and is presented at the Trust's monthly Mortality Review Group. This contributes to the Oxfordshire LeDeR review, a multiagency subgroup of the Oxfordshire Safeguarding Adults Board[8].

2.9. The Trust also submits data, staff surveys and patient surveys for the NHS I Learning Disability Benchmarking scheme[9].

2.10. The Learning Disability Liaison Team have a good working relationship with Oxfordshire Family Support Network[10], Carers Oxfordshire[11] and My Life My Choice [12].

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[5] Six lives: the provision of public services to people with learning difficulties 2008 to 2009 - GOV.UK (www.gov.uk)

[6] LeDeR - Home

[7] NHS England » Learning from lives and deaths – People with a learning disability and autistic people (LeDeR)

[8] PowerPoint Presentation 16.9 (osab.co.uk)

[9] NHSE &NHSI-LD — NHS Benchmarking Network

[10] Oxfordshire Family Support Network | Learning Disability – OxFSN

[11] Carers Oxfordshire is a service dedicated to helping carers in Oxfordshire

[12] My Life My Choice | Home

2.11. The process of admitting a person with a learning disability can be complex. This can require close attention to communication, implementation of the mental capacity act, reasonable adjustments such as visits to the hospital to help a person emotionally prepare for their admission, and diagnostic procedures under general anaesthetic.

2.12. This story is told from the family's and matron's perspective. It shows Charlie's first admission which was stressful, disorganised and not person centred despite having his hospital passport with him throughout his admission. The story also shows the collaboration undertaken by Charlie and his family, the Neurosciences directorate, the Trust Learning Disability Liaison Team and Oxford Health Community Learning Disability Team to significantly improve his second admission and the care of people with learning disabilities across the Neurosciences Directorate.

2.13. Charlie and his parents, Hannah, and David have kindly agreed to share their story with the Trust Board to enable wider learning to improve care for people with learning disabilities and their families.

3. Oxford Spinal Surgery Service

3.1. Waiting times for spinal surgery grew significantly as a result of the COVID-19 pandemic. It has been a challenge to recover from this position given the highly specialised nature of the surgery.

3.2. The Elective Recovery Fund has supported the use of the Independent Sector to treat additional patients, who would otherwise have to wait for surgery at the OUH.

3.3. Work is ongoing with other providers, including the Children's Operational Delivery Network and the Children's Hospital Alliance, to identify opportunities to further reduce the waiting times for surgery.

4. Charlie, Hannah, and David's story, written by Hannah:

Charlie is 23 and was born 10 weeks prematurely. He had a bleed on his brain at three weeks old. This left him quadriplegic - he is not able to sit unaided or walk, and he struggles to do much for himself.

He has never really fitted into a group. Charlie can and does communicate. He can have a giggle and a laugh and wind people up – hold his own socially. I think this means he can come across as being able to understand everything. Most of his peers and friends who are as physically disabled, are not able to converse as he can. He can turn a conversation round to what he wants to talk about, and this means that he comes across as much more able than he is.

Our difficulties began in November 2021.

Charlie had rods fitted for scoliosis in the spine. This had been ongoing for two years had five preoperative assessments because of the delays caused by COVID.

He had a lot of initial anxieties around the surgery and developed some pressure ulcers because of the delay in surgery. Charlie didn't cope well with the cancellations, and it was difficult as still on the day we didn't know if the surgery was going to happen. I have found that I need to present the full options to him, so he worries less.

This was the most significant surgery he had ever had. It was a balance involving him and not over worrying him at the same time.

I stayed in the hospital until I knew he had come out of the operation OK. When he left AICU I didn't know which neuro ward he had gone to. I sat in reception and camped out to check he was ok. It was difficult keeping in contact with him as he had no way of contacting us and from a parent's perspective, I needed to make sure everything was fine - that's a parents job.

Charlie came to Neuro Red – the high dependency unit and they allowed us to see him for half an hour each. We live an hour away and I asked if we could extend a bit but that was not possible. When I did see Charlie, he was laid pretty much horizontally on his back. The spinal doctor come in and said why is he on his back? - this should not be the case because of the risks to Charlie, thankfully though, he was fine.

His care was Ok but what annoyed me that no one seemed to have got him anything good to eat. We had struggled to increase his weight before his surgery so he would be able to recover more easily. All he seemed to have to eat was mash potato and gravy - is that all I said, and the reply was yes there are problems with the kitchen. I did not question it as I only had ½ hour. I came out and said my husband that is not right as he must have been fed more than that. Charlie had undergone major surgery – a diet of mash and gravy isn't enough. We had spent a year trying to help him put weight on so he would recover quicker.

That night I messaged texted Charlie's community nurse and put down my worry was that he would lose a lot of weight. I also spoke to the ward sister and asked why is Charlie on the soft food of mash and gravy as he has a hospital passport, and it wasn't clear where that information had came from. Charlie's food was better on Neuro Blue ward. We could spend more time as well which was helpful. Communication was a bit easier as we could spend a bit more time with Charlie.

Care wise, Charlie was uncomfortable, quite pasty and this usually means he is in pain. He struggled with contacting nurses as he either couldn’t work the buzzer or it didn’t work. He had to shout for medication. One day I was with him and he was in a lot of pain and he had half an hour before his medication was due. He shouted for the nurse. Whether they did not hear or they ignored him because knew wasn’t ready for medication, I don’t know, but there wasn’t any acknowledgment or support on how to cope.

By this time, some things were better, but I couldn’t work out whether it was the general lack of empathy or that he was just too much bother. I struggled with that, and it felt like they did not want him there. No one interacted with him they just did the bare bones. One day when Charlie said he was in pain, I rolled him, and the honeycomb dressing had become dislodged. That should have been checked and sorted out. Charlie’s hospital passport was put in his room, but it did not seem to help.

Charlie’s first discharge home was not good. It was difficult to get hold of the ward to find out what was going on. I tried for four hours – no one answered. Then I couldn’t park, and sat outside for one and a half hours and I couldn’t let the ward know because I couldn’t get hold of anybody. I knew Charlie would be worried but I had to turn around and go home. David drove me back in his lunch hour and I waited until 7pm to be picked up.

The following day I used the park and ride to see Charlie and then the ward phoned me to say he was ready for discharge. I couldn’t take him home because I had no transport so we agreed for the following evening when parking was easier. I asked that if it was any different then please can someone contact me. As there was no communication we arrived, ready to roll and take Charlie home when the nurse said that he wasn’t able to go home that evening. I was so cross as I was expecting to pick him up. Charlie of course was disappointed, and I could have come earlier to see him and spent more time with him.

I asked someone to confirm so we knew what to expect. When the ward team said can you phone the ward, I said no please phone me as I can never get through. Thank fully the team did confirm and we collected Charlie. I asked if Charlie was ready to go and asked a nurse for some pain killers for journey home as I was worried that it could be a painful experience for him. And the nurse said ‘here is the green bag and its over to you now’ and left. David looked at me and said ‘was that for real’.

I waded through 9 pages of discharge notes which was in doctor and nurse lingo. I knew what the medication section meant – but imagine if people didn't, like my parents for instance - they wouldn't have a clue about working out the medication.

A nurse brought in a mobile hoist and then left, – we shouldn't have been left to figure this out. I wouldn't have been able to do it on my own. To be honest we got Charlie into his chair and legged it home. We had no after care instructions and no dressings, we didn't know what to do. It was a significant operation and it was the worst ever visit my family had ever experienced.

I wrote to Charlie's community nurse to express how we all felt. That led to a meeting with the neurosciences matron to explain my concerns and to plan for Charlie's next admission.

The second time Charlie was admitted to hospital was very different and I did not fret. Once I knew he was going to be looked after – I could let go a bit. The nurses were amazing, it was not stressful, and we had a really good relationship. They kept in contact with me and that made a big difference.

It is really important to be able to empathize, walk in someone else's shows for a bit - understand your patient and family's life from their perspective. They did that. When it was time for Charlie to go home three members of staff came out to say goodbye – he cried but good tears. That to me went beyond care, it was human being to human being. It made a huge difference and showed David and I that the team had looked after Charlie as a person for who he is.

4.1. Please read the emails from Hannah and Charlie's community nurse in Appendix 1.

5. Neuroscience Matron's story:

Hannah's email was forwarded to me by the Lead Learning Disability Nurse asking me to help move things forward for Charlie and his family.

I contacted Charlie's Learning Disability Community Nurse, as I wanted to understand more so I could help to improve Charlie's experience whilst an inpatient.

We all met up (Adult Safeguarding, Learning Disability Community Nurse, Learning Disability Lead Liaison Nurse, Hannah, and I) so we could listen and understand what happened.

As a dad, I could really understand Hannah and David's stress and worries.

Most of the issues Hannah told us about and we heard were about communication and basic care.

Following the meeting, the Learning Disability Lead Liaison Nurse and I spoke with the Childrens spinal team, to understand how they look after children in their care and how could we learn to better support young people with learning disabilities.

I shared those issues with multidisciplinary team - I wanted everyone to be aware so we could improve our care.

Following this I worked closely with the community nurse and Hannah to keep in touch. It was tricky as the hospital was very busy and we did not have many beds available. So, Hannah and David had short notice of Charlie's 2nd admission.

I made sure that the waiting list team kept in touch with Charlie, Hannah, and David.

All the senior ward team had a copy of Charlie's Hospital Passport and we made sure that Charlie went to Neuro Green and had a side room (Spinal unit).

During Charlie's previous admission, Hannah and David had been given conflicting information about how long they could stay with Charlie. I spoke with the ward team to clarify that as Charlie's carers, Hannah and David could stay.

Throughout Charlie's 2nd admission, his community nurse, Ward Sister, and I were in regular contact. After surgery, Charlie moved to the High Dependency Unit and I used to visit Charlie first thing in the morning to check all was ok.

It is important for us to advocate for people with learning disability and to do so with kindness.

It is always difficult and challenging to get complaints, but if Hannah and David had not raised their concerns with us then we would not have been able to improve the situation for others.

It is not about listening and making false promises. The root cause here was communication or the lack of it. At the fore front of my mind was – what else can we do – keep in touch, telephone, and email. I wanted there to be a plan in place always and make sure everything was about Charlie – all the time.

The Directorate is implementing a two-day staff orientation programme including safeguarding, learning disability and the Childrens team so we can learn.

I hope this was a one off event for Charlie and his family. At the same time it isn't a one off event - we need to get it right for everyone

Always remember - how would you treat your patient if they were your family?

6. Lessons learned:

6.1. The Multidisciplinary Team and the Directorate and wider team learned a significant amount from Charlie and his family.

- Communication
- Planning - a successful admission and discharge
- Be human and be compassionate
- Work in partnership
- Learn from others and transfer to your own team
- Listen to your patient and their family

7. Next Steps

7.1. The Directorate is implementing a two-day staff orientation programme. This will focus on communication and working with families. The Safeguarding, Learning Disability and Childrens teams have been included in the programme to enable the whole directorate to learn.

7.2. The story is being translated into Easy Read and will be shared with the Oxfordshire Learning Disability and Autism Improvement Board, Oxfordshire Family Support Network, Carers Oxfordshire and My Life My Choice.

7.3. It is important for the whole multi-disciplinary team to learn from Charlie's story. The story and learning will also be presented at the divisional senior nurse and AHP board, and the Directorate and Divisional Clinical Governance Committee.

8. Conclusion

8.1. Supporting a person with a learning disability and their family during a hospital admission can be complex and challenging especially if the admission is not going to plan, or the person and their family do not feel listened to or ignored.

8.2. The Oxford Spinal Service has been under significant pressure as a result of the pandemic. The Clinical and Administrative teams within the Spinal Service are acknowledged for their continued efforts to ensure that we can provide the best possible care to our patients as the service recovers from the impact of the pandemic.

8.3. The Elective Recovery Fund has supported the use of the Independent Sector to treat additional patients, who would otherwise have to wait for surgery at the OUH. Work is ongoing with other providers to identify opportunities to further reduce the waiting times for surgery.

8.4. Everyone has learned a considerable amount from Charlie's admissions. Notably the key learning of

- Communicate
- Plan - a successful admission and discharge
- Be human and be compassionate
- Work in partnership
- Learn from others and transfer to your own team
- Listen to your patient and their family

8.5. The Neurosciences Directorate will be holding a two-day staff orientation programme to learn from the experience of Charlie and his family to translate into the care of other people with learning disability.

8.6. The story and learning will also be presented at the Divisional Senior Nurse and Allied Health Professional Board (AHP) and the Directorate and Divisional Clinical Governance Committee.

9. Recommendations

9.1. Trust Board is asked to note the contents of the paper.

Appendix1: Charlie, Hannah, and David's story

From: Oxford Health
Sent: 13 April 2022 12:11
To: OUH
Subject: Charlie - Feedback

Hello All

Forwarding you Hannah's email to me from a few moments ago, see below. She has consented for me to share with you.

It's the most heart warming and really positive letter of thanks. What a different experience this has been to last time and what a difference you have made making this experience a better one and a richer one for both patient/family and staff.

Can I just say a huge thank you to all for making Charlie's hospital experience a much more positive one, I know this is rightly and mostly about the matron and the ward staff providing such brilliant care, but I also want to credit the 'behind the scenes' work which has taken place with the matron, LD Hospital Liaison working together to enable change and enable complex LD needs to be better supported.

I know everyone has put in huge amounts of work to make this experience what it was, and so good to hear Hannah and Charlie's feedback. It's great learning experience for staff and us all, and probably a great model to be rolled out for all LD patients coming in with complex needs.

Thank you everyone for supporting Charlie and his amazing family so brilliantly.

Best wishes,

From: Hannah
Date: 12 April 2022 at 22:00:15 BST
To: OUH
Subject: Charlie

I'm hoping you managed to have a relaxing break. I wanted to write an email to thank you for popping your head in to check that we were okay. This wasn't necessary but it was appreciated so thank you for that.

Charlie had a much more relaxing stay. He was less anxious although he had a couple of blips due to X-ray being delayed but I did explain to him that it might not happen when they said but would get done at some point.

By Monday he decided it got too much as he wanted to go home and had his iffy (blip) moment but seemed fine when we got up to the hospital and told him just one of those

things etc etc we joked about it and said he was a Wally.
The nursing staff kept popping they're heads in and when I wasn't about fed and watered him which he quite liked. They also kept us updated and spoke to us when we were on the ward they also phoned when Charlie asked if he needed supplies or thought we needed to be aware of anything. From our point of view this was greatly received however I could imagine probably annoying to the staff as I know he whittles about things.

When he was ready to go home he was already sitting in his chair ready to roll which was surprising, he was joking with the staff member stripping his bed down all smiles. The handover was great fully explained about meds and dressing of wound etc if the nurse didn't know the answer she found out for us.

Most of the staff said goodbye to him when he left as we got to the door 3 male members of staff came up to him had a joke and quiet words with him that left him emotional so he left in tears (but good tears). From a parents point of view this was lovely and went beyond any training and expectations so again THANKYOU to those 3 men.

When we got in the van and on the way home Charlie said "he liked the ward and the staff were a lot nicer".

I felt this warranted a letter of appreciation and thanks to all staff members and yourself for the turn around in care and empathy for Charlie's needs both physically and emotionally. THANKYOU for taking our concerns into consideration and acting on them. Credit to you all. I hope you will pass our thanks to the ward that made a difference to Charlie stay.

Many thanks

Hannah and David