Title | Parents’ perspective on ‘Changing Places’

Status | For information

| History | Patient Stories are presented to the Trust Board or the Quality Committee each month.

| Board Lead(s) | Mrs Sam Foster, Chief Nurse

| Key purpose | Strategy | Assurance | Policy | Performance |
Executive Summary

1. This story relates the perspectives and experiences of two parents, Mrs SB and Mrs KE, who are mothers of children with disabilities, and the need for appropriate ‘Changing Places’ toilets when attending hospital appointments at the Oxford University Hospital NHS Foundation Trust (OUH).¹

2. Mrs SB’s six year old son has a rare chromosome disorder and Mrs KE’s fifteen year old daughter has Cerebral Palsy (CP). Both children are wheelchair users, cannot stand and have very specific needs. The needs of their children require specific changing facilities for toileting and hygiene purposes that disabled toilets are insufficient to meet.

3. The stories highlight the following:
   - the need for Changing Places/Toilets at the four OUH hospitals to meet the specific needs of people with profound and multiple physical and learning disabilities, who need extra equipment and space to allow them to use the toilets or a changing bench with a hoist, and for their carers to attend to their personal hygiene safely and comfortably;
   - the importance of an Equality Impact Assessment (EIA) and the involvement of service users early on in the planning and development of services and in particular the planning of a physical facility such as a ‘Changing Place’;
   - the strong leadership required by senior managers in listening to service users’ feedback and acting upon that feedback.

4. Recommendation
   The Trust Board is asked to reflect on these stories, optimise the learning from listening to service user’s feedback and their experiences, in order to facilitate improvements and make a difference to the quality of how patients experience Trust services, as well as enable equality of access to facilities.

¹ Changing places are places referred to by a Consortium including Mencap and Muscular Dystrophy UK, which are groups campaigning for toilet and changing facilities for people with disabilities made available in hospitals and public buildings.
1. Purpose

1.1. The purpose of this paper is to provide an example of how the Trust takes patient feedback and complaints seriously and learns from them. The leadership taken by the Deputy Chief Nurse to address the feedback was essential in facilitating the change to happen. The example outlined in this report is that of feedback from the carers of patients with specific needs who require designated and specifically-adjusted places (Changing Places) to both change and use the toilet.

1.2. The paper also demonstrates how patients and their carers are being listened to and how feedback and experiences of patients/carers can be used effectively to make a difference in service improvement and the quality of services that the Trust provides.

2. Background

2.1. People with profound and multiple learning disabilities, as well as people with other physical disabilities such as spinal injuries, cerebral palsy, muscular dystrophy and multiple sclerosis often need extra equipment and space to allow them to use the toilet/be changed safely and comfortably. The provision of appropriate spaces would support individuals, and their families and carers, to have a dignified experience and would reduce their anxiety when attending hospital appointments.

2.2. Facilities currently available to this group of patients and their families/carers, is either the use of a consulting room in the outpatient departments, which do not have the appropriate equipment, or a disabled toilet which does not have appropriate space, or a safe and suitably-sized bench, to change an older child or adult's. Neither option has a hoist readily available. Staff have offered to obtain a “mobile hoist” however, this is sometimes hard to locate and is also more difficult to use than a “ceiling hoist”.

2.3. Two perspectives, from parent carers, were related to the Patient and Public Involvement Manager by Mrs SB and Mrs KE at a pre-arranged meeting.

3. Mrs KE’s perspective

3.1. Mrs KE spoke about her 15 year old daughter, who was born at the John Radcliffe hospital. The family knew from the very beginning that their daughter had cerebral palsy (CP), and the multi-disciplinary team has provided consistent support to the family.

3.2. Mrs KE explained that as her daughter is growing older with her condition (she had spinal surgery when she was 13), she cannot stand on her own. She feels that her daughter can no longer manage toilets designed for the general population. In these situations, toilets designed for the general population can be unsafe, unhygienic, and undignified for patients with disabilities. Mrs KE’s daughter simply has to “hold on” until she gets home.

3.3. Mrs KE said: “as a parent who is dealing with the needs of your child on a day-to-day basis, there are lots of stress points that you have to think about. When attending a hospital appointment, you not only worry about issues around
parking which might cause an impact on making your appointment in time but you also worry about where and how to go to the toilet safely, with dignity and without causing injury to yourself as the carer.”

3.4. With her daughter’s condition, Mrs KE has been involved in campaigning for ‘Changing Places’; toilets for children and adults with disabilities. Currently, when attending a hospital appointment, they are offered a consulting room for use. Mrs KE expressed her difficulties now that her daughter is 15: “I cannot continue to be lifting her like I did when she was little and she needs the appropriate hoist and equipment to support her when she needs the toilet”.

3.5. In January 2017, Mrs KE emailed PALS who confirmed that there was no ‘Changing Place’ facility, but if asked, staff could provide a mobile hoist, which however would not necessarily be near a toilet.

3.6. In February 2017 (see complaints letter at appendix 1), Mrs KE wrote the Trust’s Chief Executive’s Office to complain about her experience and got a reply that the Specialist Matron for Children’s Services was scoping into solutions (See complaints response at appendix 2). She further explained that she wrote to the Specialist Matron for Children’s Services again in May 2017, but received no reply. The complaints team was copied into the letter.

3.7. Mrs KE stressed that by June 2017, she felt lucky that she happens to know a senior manager from OUH who is also a governor at the school of her younger daughter. Mrs KE mentioned about her experiences when taking her daughter to attend a hospital appointment and the lack of facilities at the hospital to this manager. This and the concurrent uptake of multiple complaints facilitated the Deputy Chief Nurse to instigate actions to address the problem. Mrs KE felt that discussing the issues with the governor and the Deputy Chief Nurse helped to escalate the issue, as well as the problem being addressed with practical action by the Trust.

4. Mrs SB’s Perspective

4.1. Mrs SB’s six year old son has a rare chromosomal disorder. He has complex care needs and cannot communicate these sufficiently. However, the family has developed a way of understanding and addressing his needs. For example, Mrs SB can work out the time when he was last changed and relies on close observation of any changes in her son’s behaviour in order to understand when he needs to be changed. Mrs SB explained that, due to his complex care needs, her son regularly attends the hospital, including the Emergency Department.

4.2. In October 2017, Mrs SB’s son attended a hospital appointment at the JR and Mrs SB had a particularly bad experience because of the lack of facilities at the hospital, as her son is unable to use a toilet and requires the use of an adult sized bench to be hoisted onto, to enable her to change her son’s pads/clothing safely and with dignity. Instead they had to use a pull down baby changing bench which was not sufficient for her son’s size. Mrs SB described her experience as unsafe, unhygienic and undignified as “there are no appropriate hoists to lift my son and I would lay him on the floor to change him which is unhygienic as there are no height adjustable benches to lay him onto for changing”. Mrs SB explained that his feeding tube accidentally disconnected whilst transferring him to his wheelchair (by lifting him herself) and the feeding
tube leaked onto his clothing. It was eventually re-connected and her son was changed again but the whole experience of this particular hospital appointment was so stressful that she felt that there must be something that could be done to support parents and carers of children with disabilities.

4.3. On 10th of October, Mrs SB wrote an email to the Patient Advice and Liaison Service (PALS) to complain about her experience and sent photos of the space she and her son had to use to attend to his needs.

4.4. By 18th October, she received a response from the Complaints Team with apologies for the bad experience and she was invited to a meeting. At this stage, Mrs SB felt that she was listened to and not ignored; that her complaint was acknowledged quickly. Her case was passed on to the Deputy Chief Nurse who arranged to meet with specialists in disability as well as the Estates team to scope out the potential areas for 'Changing Places' across the Trust's sites. The Deputy Chief Nurse also sourced information and support from other Trusts where such facilities have been installed, to learn from their experiences.

4.5. Mrs SB is involved with the Oxfordshire Family Support Network; a not-for-profit organisation run by, and for family carers of people with learning disabilities. Aware that Mrs KE has been campaigning and is more knowledgeable about ‘Changing Places’, Mrs SB asked whether Mrs KE could also be involved as well.

4.6. In November at the Trust's Annual General Meeting, Mrs KE was able to speak with the Chief Nurse about the need for Changing Places within Oxfordshire hospitals.

4.7. In February 2018, the Deputy Chief Nurse invited Mrs KE and Mrs SB to meeting to discuss progress and plans.

4.8. On 6th March 2018, Mrs KE and Mrs SB attended a follow up meeting organised by the Deputy Chief Nurse to meet with the Head of Architectural Practice and Capital Programme and members of the Estates team to discuss the options, view the plans and see the suggested site for the first ‘Changing Place’ at the JR. Funding was also discussed and a presentation bid was made in late April to the Trust’s Charitable Trustees. At this March meeting, Mrs KE and Mrs SB spoke about layout and specifications for the ‘Changing Place’ including the positioning of the toilet, a ceiling mounted hoist, movable changing table, hand dryer, shower, height adjustable sink with appropriate taps and aspects that would enable room for a carer to manage the change. Other elements were considered, such as noise, lighting and colour schemes that may overstimulate patients with a disability and others that would be more soothing and practical. The other important aspect is to ensure the facility is secure and accessible via a ‘Radar Key’ so that it can only be used by those with additional needs.

5. Next steps

5.1. At the meeting in March 2018, the group identified a location for a ‘Changing Place’ toilet at the John Radcliffe Hospital that is accessible and easy to locate. Mrs SB and Mrs KE explained that it would important for OUH to model examples of good changing places as is the case with the Changing Places at

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2 [https://www.oxfsn.org.uk/](https://www.oxfsn.org.uk/)
the Orchard shopping centre in Didcot, and at the new Westgate shopping centre in Oxford City Centre.

5.2. The aspiration from Mrs SB and Mrs KE is to have Changing Places in all four hospital sites (see Appendix 3). It will be important to publicise the creation of Changing Places toilets widely among staff and patients in order to raise awareness and to ensure that those with additional needs can be quickly directed to appropriate facilities to reduce stress and guarantee safety.

5.3. Real engagement with carers and service users will continue to be ensured throughout the development of the spaces so that adjustments can be made to minimise any negative impact. “We know the needs of our children as we are helping them on a day to day basis, so we are in a position to provide input into what needs to be put in place in creating a ‘Changing Place” (Mrs KE and Mrs SB). The Deputy Chief Nurse is also in contact with two other parents of disabled children who have spoken to PALS about the need for these facilities.

6. Conclusion

6.1. This story highlights:

- the difficulties experienced by patients and their parents/carers when having to use unsuitable facilities and the need for appropriate changing places to be established at the OUH sites;
- effective leadership and examples of good practice when senior managers listen to service users’ feedback and their experiences, and act upon that feedback accordingly;
- the importance of service user engagement and undertaking equality impact assessments (EIA) early on in the process to consider the specific needs of service users when developing or planning a service;
- the importance of a quick response and subsequent action following a complaint, making the complainant feel listened to and that the Trust takes feedback seriously.

7. Recommendation

7.1. The Trust Board is asked to reflect on this story and comment as necessary on possible ways forward.

Authors:

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25 June 2018
Appendix 1 – Complaint Letter

Chief Executive’s Office
John Radcliffe Hospital
Oxford
OX3 9DU

17th February 2017

Dear [Redacted]

RE: Changing Places in Oxford Hospitals

My [Redacted] daughter and I are regular visitors to various outpatient clinics at both the Children’s Hospital and the Nuffield. Since she underwent spinal surgery this summer it is no longer safe for me to manually lift her out of her wheelchair when she needs the toilet. Being able to access a public toilet is something most of us take for granted. We assume that when we’re away from home we will be able to find somewhere to ‘go’ if we need to. This is sadly not the case for my daughter who needs access to a hoist, changing bench and plenty of space to be able to go to the toilet. Such facilities do exist but they are rare. They are called ‘changing places’ and there are just FIVE in the whole of Oxfordshire!

I recently contacted the PALS office to find out how and where I would be able to see to my daughter’s personal care needs next time she has an appointment. I received a reply saying that there is a changing bed and mobile hoist available in the children’s hospital but that they are not near a toilet – it did not go into detail about exactly where they are. I find this particularly disappointing in relation to the newly built children’s hospital wing. A Changing Places facility within each hospital complex would make such an enormous difference to the experience and dignity of a hospital visit for so many patients, not just my daughter!

The changing places campaign aims to make fully accessible toilet facilities available in public buildings in every town. To find out more about the campaign please visit the website [www.changing-places.org](http://www.changing-places.org) or contact the Changing Places campaign by calling 020 7696 6019 or emailing changingplaces@macmillan.org.uk. By installing Changing Places toilets we can change people’s lives.

Yours faithfully,

[Redacted]

21 FEB 2017
Appendix 2 – Complaint Response

Oxford University Hospitals
NHS Foundation Trust

Our Ref: 
77 March 2017

The John Radcliffe
Headley Way
Headington
Oxford
OX3 9DU
Tel: 01865 221000

Dear,

Thank you for your letter of 17 February 2017 in which you highlighted a number of deficits in the provision of amenities in the outpatient toilet facilities for people with disabilities.

Your concerns have been investigated by [name of specialist matron or similar role] Specialist Matron, Children’s Services. [Name of individual] is very appreciative of your helpful observations about the bathroom amenities in the Children’s Hospital which have been useful in identifying a number of areas for improvement.

The bathrooms in the inpatient ward areas meet the requirements for hoists, rails and space. However, it is recognised that there is a lack of appropriate sized changing tables and [Name of individual] is keen to rectify this. At the moment a bed is provided in the bathroom, which can be used to create a suitable surface, and she recognises that this should be sign-posted in the Outpatients Department and she has arranged for this to be done.

You will be pleased to know that there is a mobile “wheeled” hoist available in the Outpatients Department and again it is acknowledged that the availability of this resource could be more obviously signposted. [Name of individual] has agreed to discuss with the Adult team the toilet amenities and the provision of larger changing tables because, as you have highlighted, this is clearly needed.

There is confidence that, if necessary, the Children’s Hospital Charity would be keen to support this project. [Name of individual] would welcome any further advice that you might have or from your daughter’s perspective as a user of the Children’s Hospital and Nuffield Orthopaedic Centre’s services. She can be contacted on [phone number] or email her at [email address]. If you have any further questions, please do not hesitate to contact [Name of individual] in the Children’s Hospital Complaints Coordinator or [Name of individual] in the Adult Complaints Coordinator.

Yours sincerely,

[Name of individual]
Chief Executive

From the Chief Executive’s Office
Oxford University Hospitals NHS Foundation Trust
Appendix 3 - Example of a ‘Changing Places’ Facility

Larger than average accessible toilet that can:
- Accommodate bigger wheelchair & two assistants
- Adult-sized changing bench
- Hoist
- Toilet
- Sink