

Cambridgeshire: Pinpoint and Addenbrooke Hospital – making hospital a more disabled-friendly place

Background

Pinpoint run parent network meetings across Cambridgeshire, funded by the county council. Pinpoint frequently heard from parents about their experience of taking a disabled child to Addenbrooke hospital. Some parents had good experiences but others found it fraught with problems because of a lack of equipment and lack of understanding by staff about their child's additional support needs.

Pinpoint invited the children's service manager from Addenbrooke to meet with some of the parents. They took the manager through the fraught journey experienced by one family of a child with complex needs, from arrival in A&E by ambulance, the various problems experienced during their stay and finally being discharged against medical advice, as there was no bed in the hospital suitable for an older child with a learning disability. Even the journey home from hospital was difficult because there were no suitable wheelchair at the hospital and the child's wheelchair had been left at home.

The other parents at the meeting were also given the opportunity to mention the problems they had experienced. Many of them complained about having to repeatedly explain their child's medical condition and support needs again and again with different staff. Asking parents to repeatedly focus on all the problems their child experiences can be very distressing as well as frustrating. It also takes the parent away from being with and comforting their child.

Solution

Some of the parents agreed to form an action group and work with the hospital to design a hospital passport for parents of disabled children, which would provide hospital staff with information about their child's condition and additional support needs.

The WellChild nurse at the hospital agreed to coordinate the work and invited clinical staff from different departments; for example A&E, physiotherapy, Outpatients to work with the parents in designing this. Involving staff from different department meant the passport would be useful in all departments.

The passport includes information about how the child communicates, their support needs, what they like/dislike,

their medical history and medication, how to know if they are in pain, and any consent issues. This information is helpful to staff when caring for the child or carrying out medical procedures.

A few families tried using the passport and gave feedback to the forum about how well it worked. The WellChild nurse also followed up with clinical staff to get their feedback on whether they found the passport helpful.

The WellChild nurse has also delivered disability awareness training across the hospital – so staff are more aware of the issues – and how to avoid them.

Outcomes

Families attending Addenbrooke say the passport has helped improve their hospital visits. Happily the parent whose story had been used to illustrate the problems that were occurring has since revisited the hospital and had quite a different experience.

"...had a trip into Addenbrookes with her on Saturday. The experience was completely different to last time. There was a special bed and we were in a room on our own. Staff lovely and very helpful."

There are two passports, one for children and young people with additional needs, and another suitable for adults.

The passports can be downloaded from the internet at www.cuh.org.uk/addenbrookes/patients/patient_information/for_people_with_disabilities/for_people_with_disabilities_and_their_carers_index.html#carers along with two communication booklets developed by the hospital with pictures, to assist staff in communicating with patients who cannot speak to them.

- Communication Book 1 – provides advice to staff to assist them when communicating with people who have difficulty understanding or communicating – including some very basic Makaton
- Communication Book 2 – a set of symbols to assist staff when communicating including pictures of drinks, food, people, personal things, personal care, symptoms, pain, procedures, body parts, places, week calendar.

Pages from the hospital passport

...CONFIDENTIAL... My photo

This is my Hospital Passport

For children and young people with special or additional needs coming to Addenbrooke's Hospital

My name is: _____

If I have to go to hospital this book needs to go with me. It gives hospital staff important information about me.

This passport needs to stay with me by my bed.

This passport belongs to me. Please return it when I go home.

Nursing and medical staff please look at my passport before you do any interventions with me.

Things you must know about me

Things that are important to me

My likes and dislikes

Cambridge University Hospitals NHS Foundation Trust

Things you must know about me

Name: _____

Likes to be known as: _____

Date of Birth: _____

Address: _____

Tel No: _____

How to communicate with me: _____

Contact person: _____
Relationship (e.g. Mum, Dad, Support Worker): _____
Address: _____
Tel No: _____

My support needs and who gives me the most support: _____

Date completed by _____

Things you must know about me

Allergies: _____

Hearing/reading problems: _____

Risk of choking, Difficulty with eating, drinking & swallowing: _____

GP: _____
Address: _____
Tel No: _____

Other services/professionals involved with me: _____

Spiritual needs: _____

Religion: _____
Religious Needs: _____
Ethnicity: _____

What to do if I am anxious: _____

Date completed by _____

Things you must know about me

Current Medication: _____

How I take medication (2 capsules tablets, injections, cream, 3x Weekly, Gastrostomy (nasogastric tube))

Decisions about my treatment (Consent) (I may need support to make decisions about my care): _____

My medical history (aggravates and triggers conditions that I have had and treatment plan): _____

Medical Interventions (how to take my blood, weigh me etc): _____

Date completed by _____

Things that are important to me

How I drink (small amounts, bottled water): _____

How I use the toilet (Bed rails, support with challenging behaviour): _____

How I use the bath (Continence aids, help to get to the bath): _____

Sleeping (Sleep pattern/routine): _____

Date completed by _____

My likes and dislikes

Likes: for example - what makes me happy, things I like to do (e.g. watching TV, reading, music, routines).

Dislikes: for example - what I don't like, food I don't like, physical health.

Things I like	Things I don't like
<p>Please do this</p>	<p>Don't do this</p>

Date completed by _____