

Everything will be okay

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Introduction

A recent internal audit highlighted a relatively high number of cases where parents initially declined intervention following the diagnosis of a permanent hearing loss. As a result the team hope to improve the uptake of children's hearing services within our community through several agreed 'action plans'. One action was to better understand parents' experience of the newborn hearing diagnostic process at Bristol using arts based methods. This information would inform service development plans including producing information for the website and various other mediums.

TURNING HEADS

created with Jessica

It started before his third birthday -
he would turn your faces towards him.
"I can't see your mouths."

He answered "yes" to everything.
If he couldn't hear the question,
the answer was "yes". That's the kind

of boy he is - always smiling, positive.
You're so proud of him. His smile
can light up rooms by blue-tooth -

like his new hearing aids. He syncs
them up to TV, laptop. He can hear
so much better. Now he's seven,

he puts them in himself, does it so
quickly. At first, it was a struggle -
but now, he says: "I can do it

better than you" - and he's right.
Your journey can be tracked through
the pictures on his hearing aids.

He's been through all the trains.
Now he's onto Star Wars. Still,
he's drawing people to him...

like that stranger who stopped you
in the shop one day, and told you:
"I just want to say - everything

will be okay."



FINDING OUT

created with Hannah

You remember every second
in that little room.
Complete unknown -

so many questions.
Would she be able to speak?
Would she go to school?

You didn't have an image.
Meeting deaf adults and children
has given you that vision.

You have this joy in common -
you can share the celebrations.
The confidence to join a club,

sitting in bed giggling to a book.
And you can share the questions too.
Managing hearing aids can be hard --

they fall off, get lost, get chewed,
but with the right things in place,
there's nothing your child can't do.

The friend that everyone wants to play with.
Watching her play with a stethoscope
was sad at first, but over time

you've learned that there are stethoscopes
that she can use.



Method

We worked with the patient experience team within the trust and Beth Calverley, poet in residence. Parents of children were invited to work with Beth to express their experiences of having a child identified with a hearing loss as poems. Beth hosted a gentle conversation with each parent. They were free to share as much or as little as they wished. Beth wove their words into a poem, live in the moment, and invited each co-creator to shape the poem as they wished. Some sessions took place in person while others took place via phone/video call. Each person received the original typewritten poem to keep as a memento of their experience. In addition, staff members also shared their feelings and experiences of diagnosing hearing loss and supporting families through childhood.

Discussion

Four parent volunteers described their journeys as family members of a baby or child with a permanent hearing loss. The created poems (with permission) will be displayed:

- visually and with audio recording on the Children's Hearing Centre website
- UHBW social media sites (Facebook, Instagram, Twitter and LinkedIn)
- a poetry gallery within the department will be created to display all of the poems in a quieter area for private reflection
- visual snippets from the poems on the diagnostic test room walls

Taking part in the poetry session was really useful to me. It gave me the opportunity to pause and reflect on how I felt at the beginning of our journey with hearing loss (parent)

I feel a wave of privilege to have spent time with family members, listening to their experiences. They expressed many emotions: shock, worry, uncertainty, guilt, connection, pride, love, joy. Throughout the poems, there's a thread of trusting intuition, tuning into a deeper rhythm, and finding creative ways to connect with the world. These connections seem all the brighter for it (Beth, poet in residence)

I was listened to and I got a poem out of it. The fact a clinician sat in and listened as well meant she got to hear how difficult it is for parents, and that is so beneficial (parent)

