



The story of our journey

HOW ONE PATIENT INFLUENCED A CRITICAL CARE

- Imagine one day a family is placed in your care who know much more than you do about their health and treatment needs.
- This family is also in transition from paediatric to adult services (and has been let down by both in the past)

- HOW WOULD THIS MAKE YOU FEEL ?
- THIS IS OUR JOURNEY WITH ONE SUCH FAMILY

Music
lover

Loved being
outdoors

Strong,
resilient

Sale Sharks
Fan

Billy's best
mate

Popular and
engaging

Big brother to
Dan

East Lancashire Hospitals **NHS**

NHS Trust

Let me introduce Mitchell



Safe | Personal | Effective

Medical Background

- Born with a complex neuro-disability
- Cerebral palsy, severely visually impaired, epilepsy, poor swallow, scoliosis
- Tracheostomy aged 9
- Ventilated at night age 15
- Ventilated 24/7 age 21

Transition to adult services

- Fear of a loss of control
- Who to turn to when things got tough
- Biggest fear was the 3am trip to ED and someone making a value judgement on a life they know nothing about.
- ‘Three strikes and you’re out policy’

The Challenges

- A need to build a trusting ,honest relationship immediately.
- Both parties needed to impart information.
- Jo felt let down by adult services, our approach was counter-cultural, we needed to understand Mitchell and his quality of life

The reality

- I learnt early on that Jo only brought Mitchell into hospital when she had exhausted her 'toolbox'-(so we gave her more tools)
- I had a difficult conversation with Jo and we set out Mitchells care plan. (this also included end of life)

- By opening our minds and our unit things worked really well.
- The care plan gave the family peace of mind
- We all knew our explicit roles

The care plan

- This was a tool to open a lot of conversations
- It put us all on the same page and enabled understanding
- It was a living document and helped us determine the lines in the sand..... Full resuscitation for 2 cycles but No support for organ failure

What worked well

- Open door policy during procedures
- A strong deep rooted trust between, nurses, family carers and medical staff
- Grew in confidence to manage situations at home and didn't feel alone
- Carer with Mitchell at all times who knew him well
- Our shared understanding that having had end of life conversation and plan we didn't need to talk about it again until it was time

That day came.....



End of lifeand our journey

- On the day , Mitchell was washed , shaved and changed by his family and carers
- We took a wholly person-centred approach which set the tone for everything that followed.
- Mortuary told and viewing area prepared then Mitchell was never alone.

- If I think back to that initial question, my answer looks very different these days.
- I feel energised, confident and ready to embark on a journey which is both collaborative and personalised.
- There is now a patient specific treatment plan file with over 15 names of young adults in transition. Each one ready for a journey.

- Thank you.
- Any Questions?
- In memory of Mitchell James Green
11.05.92-18.03.15