



Managing Complex Medical Cases and Education

Marie Sherlock - Assistant Head Teacher

Maria Marinho - Assistant Head Teacher

Frederic Irigaray - ICT Projects Manager

Chelsea Community Hospital School, London, UK

Chelsea Community Hospital School London, UK

- ▶ Based in 4 hospitals across West London.
- ▶ Mixture of general and specialist centres.
- ▶ Maria Marinho
- ▶ Fred Irigaray
- ▶ Marie Sherlock

Part 1 - Marie Sherlock

James - **Asthma**

- ▶ Do you have legislation in your country to protect the educational needs of children with a medical and mental health condition?
- ▶ If so, is it meaningful?
- ▶ Can you suggest other ways in which this could have been dealt with differently that might have made for a quicker and smoother resolution?
- ▶ How can we support schools in understanding that many chronic conditions can impact on individuals in very different ways?
- ▶ How might you have dealt with this?

James

- ▶ 14 year old boy in Year 9 at a local comprehensive school.
- ▶ Diagnosed at 18 months with asthma
- ▶ He is one of six children in the family. Five of the six children have a chronic condition.
- ▶ 1 with coeliac disease, 2 with asthma, 2 with eczema (one of these children receives supplementary nutrition via a gastrostomy peg).
- ▶ Increasingly his asthma was becoming more difficult to manage and both Daniel and James were under the care of a consultant at the Royal Brompton Hospital a tertiary referral centre.
- ▶ Both boys are described as being in the worst 5% of asthma sufferers.

A few facts about asthma in the UK

- ▶ 1.1 million children in the UK have asthma.
- ▶ There were 1,204 deaths from asthma in the UK in 2008.
- ▶ On average, 3 people per day or 1 person every 7 hours dies from asthma.
- ▶ 61% of people with asthma say that their asthma stops them from getting a good night's sleep.
- ▶ On average there are two children with asthma in every classroom in the UK.
- ▶ Every 17 minutes a child is admitted to hospital in the UK because of their asthma.
- ▶ One in 8 children under 15 with asthma symptoms experience attacks so severe they can't speak.



Legislation to support pupils with a chronic medical or mental health condition

- ▶ The Children Act 1989
- ▶ This Act imposes a general duty on local councils (under which education departments come) to provide a range of services to 'children in need' in their area.
- ▶ Asthma comes under the Disability and Discrimination Act 1995 and is considered an unseen disability.
- ▶ Under the Equality Act 2010, a child with a disability has the right to be treated fairly at school.
- ▶ Access to Education for children and young people with Medical needs – document Reference: 0025/2002
- ▶ Access To Education For Children With Medical Needs: A Map of Best Practice RB303
- ▶ Meeting the Educational needs of Children and Young People in Hospital 0112711359

Meeting No.1

- ▶ Following initial discussions with the SENCO (Special Education Needs Coordinator) a meeting was set for June 2009.
- ▶ We suggested that the school consider assessing James for a Statement of Special Educational Needs.
- ▶ Request that staff be updated about the severity of James's condition.
- ▶ Regular reviews of James's IEP (Individual Education Plan).
- ▶ Home Tuition.

Meeting No.1

- ▶ The outcome on that day lacked any formal commitment from the school.
- ▶ The SENCO said that she couldn't justify any funds from her budget to support James at this point as he was doing 'ok' academically.
- ▶ During this meeting both myself and James's mother argued the need to consider the future for James.

The School Agreed To

- ▶ Move the boys on School Action Plus.
- ▶ Improved communication between home and school.
- ▶ Ensure that all teachers working with James had a termly update on his condition and the impact of his treatment regime.
- ▶ The SENCO to discuss the case with the Educational Psychologist

The Reality

- ▶ No communication with home nor hospital school.
- ▶ No IEPs written for the boys.
- ▶ No follow-up from the school regarding the conversation with the Educational Psychologist.
- ▶ Responsibility for collecting and catching up with work was still with James.
- ▶ Contacted the Senior Educational Psychologist for the area.



Meeting No2!

- ▶ Happened in November 2009.
- ▶ Attended by the SENCO, mother, James, the Educational Psychologist and myself.
- ▶ A clear description of James's life with asthma was given to the Ed. Psych.
- ▶ James described his own feelings of falling further and further behind.
- ▶ Same ad hoc support for James, 'come to the Inclusion Room when you want'.

Meeting No2!

- ▶ 'Disability Living Allowance'.
- ▶ The Ed Psych said he would investigate a computer based learning option for the school.
- ▶ James to undergo a psychometric assessment with the clinical psychology department at Brompton.

The Reality Again

- ▶ Surprise! Surprise! No feedback from the school nor the Educational Psychologist.
- ▶ Psychometric Assessment results.
- ▶ James prescribed Prozac.
- ▶ An overwhelming lack of support from all the educational services again.

Where Next ?

- ▶ A letter to the Head Teacher and the Chair of Governors for the school
- ▶ The letter was also sent to;
- ▶ the SENCO,
- ▶ the Educational Psychologist for the school
- ▶ the senior Educational Psychologist for the Local Authority
- ▶ Head Teacher of the hospital school
- ▶ James and his parents
- ▶ the Chief Executive for the school's Local Authority.

The Outcome

- ▶ A third meeting called by the school in June 2010.
- ▶ SENCO, mother, James, the educational Psychologist, myself and the head teacher for the school.
- ▶ Updates given on James's wellbeing.
- ▶ Academic results indicate that James is not achieving in line with his ability.
- ▶ School agree to progress with assessing James for a statement.

Aftermath

- ▶ All necessary assessment and documentation collated for a special needs panel review within 2 weeks.
- ▶ James was granted a statement which means;
- ▶ his educational needs are protected until he is 19 yrs old
- ▶ they are reviewed yearly.
- ▶ He now has a tutor assigned to him all the time who works with him between school, home, and hospital.
- ▶ The SENCO has retired and her replacement has forged a real relationship with James.



James

- ▶ Does legislation in your country protect the needs of children with a medical and mental health condition?
- ▶ Can you suggest other ways in which this could have been dealt with differently that might have made for a quicker and smoother resolution?
- ▶ How can we support schools in understanding that many chronic conditions can impact on individuals in very different ways?
- ▶ How might you have dealt with this?

Part 2 - Maria Marinho

Managing complex medical cases and education: Transition

Background

- ▶ 14 year old girl
- ▶ Living with father & brother
- ▶ Referred to the hospital school for home tuition having moved into the local area
- ▶ Had not attended school for 10 months prior to referral
- ▶ Psychiatric team heavily involved.

Previous History

- ▶ Previous psychotic episode at age 12 possibly linked to anti-malarial medication
- ▶ Hospitalised for 6 months
- ▶ Successfully transferred to small tuition unit for rehabilitation and successfully returned to mainstream school
- ▶ Lenisha and her brother lived with their mother but visited their father who lived separately.

Referral Information

- ▶ February 2009 mother died
- ▶ Lenisha and her brother moved to live with their father in a different part of the city.
- ▶ Lenisha presented with a range of psychiatric symptoms requiring intensive intervention however she was not admitted to hospital.
- ▶ She refused to engage with some members of the psychiatric team

First Meeting Between Hospital School and Lenisha

- ▶ She had not left the house for several months
- ▶ She remained all day in her night clothes
- ▶ She did not make eye contact
- ▶ She spoke in a very quiet voice only to answer direct questions
- ▶ The room was dim and chaotic
- ▶ She said she was interested in learning and liked English and ICT



Planning Input

- ▶ Needed an experienced staff member who could develop a trusting relationship
- ▶ Needed to build a trusting relationship with her father
- ▶ Needed to work very closely with the psychiatric team

Plan

- ▶ Request made to education authority for 10 hours teaching input per week.
- ▶ Refused and only 5 hours input was authorised
- ▶ Initially one female staff member to visit 3 times per week.
- ▶ Focus on subjects of interest and core skills, English, maths science and ICT
- ▶ Laptop with internet access provided with facility to message teacher outside of allocated slots

Issues to consider

- ▶ Lenisha did not know what caused her mothers death
- ▶ Father was very concerned about her vulnerability and her ability to return to her previous sociable self.
- ▶ Very little progress with psychiatric input
- ▶ Lenisha was concerned that her tuition was linked to a hospital school as she was highly anxious that she would be admitted to hospital again as she had been when she was 12

Actions taken by tuition team

- ▶ Focus of input was to develop a positive and trusting relationship that would support Lenisha to move out of the house for short periods of time
- ▶ Activities organised that gave Lenisha some control
- ▶ Focus on bringing the outside world to her through the laptop, giving access to her teacher and a view of the hospital school classroom
- ▶ Frequent reference made to next steps outside the house

Difficulties

- ▶ Level of grief and anxiety extremely high
- ▶ Too much for one staff member
- ▶ Father feeling powerless
- ▶ Lisa's refusal to engage with the psychiatric team
- ▶ Additional pressure placed on teacher to focus on aspects of the psychiatric teams work because the teacher had developed a positive relationship with Lenisha

Positive Aspects

- ▶ Lenisha appeared to value input from the hospital school
- ▶ She liked her teacher
- ▶ Good communication between the range of professionals involved in the case
- ▶ Father supportive of input



Turning Point

- ▶ Father re-established links with maternal aunt following advice from psychiatric team
- ▶ Lenesha began using messenger frequently with her teacher and was curious to see the classroom in the hospital via video link
- ▶ Aunt persuaded Lenesha to go shopping one weekend
- ▶ Aunt agreed to accompany Lenesha to the Hospital School for a short visit

New Start

- ▶ Lenesha agreed to attend hospital school for afternoon sessions
- ▶ This quickly became full days
- ▶ Lenesha worked 1-1 with a teacher in the classroom
- ▶ She needed a lot of support to access learning tasks
- ▶ Initially she did not engage with any other students

What next?

- ▶ It was clear Lenesha had some underlying learning difficulties as well as her current psychiatric illness
- ▶ Before considering a return to mainstream school in the future she would need a full educational assessment to establish her special needs
- ▶ The hospital school arranged this and this was carried out within the legal timeframe.

Lisa's re-engagement with the world.

- ▶ Lenesha has become increasingly confident at the hospital school and with her Aunt and cousins
- ▶ She has started to engage positively with the psychiatric nurse and work has begun on re-learning social skills and skills for life.
- ▶ She is enjoying the interaction with other young people and the staff at the hospital school

Current Issues

- ▶ Lenesha has an educational statement: a legal document stating what support must be provided for her to manage at school
- ▶ She is in her final year of compulsory schooling.
- ▶ Lenesha and her father have differing views on what would be a good school placement for her
- ▶ Lenesha remains very vulnerable but desperately wants to be with other young people in a 'normal school setting'

Where we are now

- ▶ Lenesha is slowly developing her confidence in learning and in life skills
- ▶ The education authority is looking for a suitable school
- ▶ Lisa's father is ill, though Lenesha is not aware of how ill he is.

Key Questions

- ▶ What approach would you have taken with this case?
- ▶ Where would Lenesha be placed after the hospital school in your country ?
- ▶ How would you work with the other professionals on this case?



Part 3 - Frederic Irigaray

Managing complex medical cases and education: Godi

Case history

- ▶ Godi is a 15 years old boy
- ▶ Admitted to hospital after a major stroke
- ▶ Godi was a normal boy very friendly and sociable
- ▶ Unable to communicate or move any parts of his body
- ▶ Communicate by eye pointing for yes/no.

Use an alphabet chart to spell out key words

A	B	C	D	E	F
G	H	I	J	K	
L	M	N	O	P	
Q	R	S	T	U	
V	W	X	Y	Z	

School introduction

- ▶ Godi physically came to school after 2 weeks spent in PICU where he received lessons by his bed
- ▶ He likes football and enjoys making films and animations.
- ▶ He has been introduced to the idea of making an animation about his favourite football team.

Planning the animation

- ▶ Definition : A simulation of movement created by displaying a series of pictures
- ▶ Creating story board using alphabet chart
- ▶ Setting up the laptop by his bed
- ▶ Setting up the camera
- ▶ Setting up backgrounds and characters
- ▶ Introducing Godi to the switch technology (using head switch to command the laptop)

Discussion

- ▶ **Why was this case successful?**
 - Being part of a multi disciplinary team
 - Have everyone on board helped a lot.
 - It was a special case
- ▶ **What was it that made Godi's story different?**
 - Godi's self consideration
 - Parents' determination
 - Medical team was very involved
 - Flexibility of the school (as a school member of staff can be called for special case)
 - Relationship between Godi and the staff
 - Physio's timetable gets Godi ready for school...