

Transition to the School Nursing Service

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Section B - Working in the community

Chapter 5: Integrated care of children with additional or complex health needs

This chapter will explore the needs of children, young people and families who are coping with additional or complex health needs. It will help to develop your understanding of the need for good, co-ordinated and integrated care. It will use a real life story to illustrate the thoughts and feelings from children, young people and their family about their specific circumstances: all names have been changed for confidentiality reasons. The role of the school health team (SHT) will be explored and the areas in which they can make a contribution to the health and wellbeing of the whole family.

The aim of this Chapter is to:

- Consider how coping with complex health needs can impact on the family
- Develop a general understanding of long term conditions
- Consider the role of the school nurse team in working with others to support children with additional needs in the community and the school setting
- Develop an understanding of the resources and networks available.

Introduction

Ideally, children with additional or complex health needs should be managed in the community using a partnership model to provide seamless, integrated care. Individualised plans need to be in place to address the specialised requirements for children with long term conditions or life limiting conditions. The whole family needs to be considered when providing care plans and their wishes respected. There are also other additional needs that may not be life-limiting or necessarily long term – there may be temporary acute illnesses that will impact on children or young people's education which SHT's will need to be aware of. Other additional needs may include children with learning or behavioural difficulties such Attention Deficit Hyperactivity Disorder (ADHD) or Autistic Spectrum Disorders (ASD).

There is an expectation that children with specific needs should, wherever possible attend a mainstream school. This is seen to be beneficial to children and young people's social and emotional as well as their cognitive development. However, there are cases where the individual needs of children and young people means that they may go to a special school. Some of these schools will have school nurses attached to them who may require particular nursing skills. Other schools are available for children or young people who have particular behavioural difficulties. Talk to your mentor about what is available in your area for children and young people with additional needs and think about referral routes to these schools.

Planning care for children with identified needs: developing pathways

The Healthy Child Programme (DH 2009) recommends a review of children and young people's health at key points in their lives. This is seen as the universal programme and targeted approaches will then focus on children and young people with particular needs. School nurses may be required to be the lead professional in coordinating care as per the Team Around the Child recommendations (TAC, 2012).

'There is an expectation that children with specific needs should wherever possible attend a mainstream school.'

http://webarchive.nationalarchives.gov.uk/20130401151715/http://www.education.gov.uk/publications/eOrderingDownload/LeadPro_Managers-Guide.pdf

If they are not the named lead professional, it is important that any care planning is done with school health involvement to ensure that there is a co-ordinated pathway of care for the child or young person both in school and elsewhere. All children need a level of education and it is important to work together to provide the appropriate resources to enable this to happen.

Some examples of situations where the school nurse may be involved are:

- Asthma
- Epilepsy
- Anaphylaxis
- Diabetes Type 1 and Type 2
- Eczema
- Sickle Cell Disease and Thalassaemia

As well as these conditions, school nurses may consider other pathways for young people in their care, for example:

- Young people with alcohol problems
- Young people who are self-harming
- Young people not in school
- Looked after children
- Weight management

More complex needs include:

- Children who are ventilated
- Children with tracheostomies
- Children on enteral feeding
- Children with life limiting conditions such as cancer or degenerative disorders.

The following case study explores the life of a family coping with a child with a complex health need:

Case scenario - Holly's story.

'My name is Holly and I was born in Yorkshire on the 14th February 1994 my mum is called Heather and my dad's called Jon. I have an older brother, Sammy, a younger brother Joe and a little sister Sarah. I don't remember much about my start in life but mum and dad say that I was a healthy 8lbs 2oz. Over the first 4 weeks, I developed what looked like a birth mark apparently but this became worse and began to cover the whole of the right side of my face. Apparently, I was rushed to hospital when my breathing became difficult and it turned out that the birth mark was not just on my face but was going into my brain, my

throat and my chest. I ended up with a tube to help my breathing and another one to help me eat. I don't remember any of this.

My first real memory is when Joe was born when I was nearly two. He was amazing and I loved him on sight. Although my mum and dad sometimes seemed worried about me, I was mostly having a great time! I could not eat myself because of my tubes but I was very good at helping Joe to eat when he got on to solid food. He really liked yoghurt. Then Sarah was born and my life got even better! I do remember lots of people coming to the house to see me and help with all my tubes. I also remember going to the hospital as well quite a lot and everyone was very kind but I got very bored and just wanted to play. I had to have some operations which were not nice. A play lady used to come to the house sometimes and we used to get very messy playing with water and sand – mum sometimes looked a bit fed up about this! Mum and dad looked tired and got cross sometimes – they had to change me at night quite a lot – but mostly I remember laughing and having fun.

I did start at a local nursery but they said they couldn't take me for some reason and I was really sad about that – but then I went to a really nice one where Joe went too. When I started school I found lots of friends there and most of them did not say anything about my face which still looked a bit funny. A nurse sometimes came to school to help with the tubes and another nurse also helped me settle into school - I didn't really need that because I loved it although I found the maths and reading hard! When I went to secondary school, I had my good friends but there were some people who used to stare at me and I did get teased by some of the older children who did not know me. I went to talk to the nurse at the school sometimes – she was really nice and it was good to talk to someone about how I was feeling.

About this time I got to go riding and fell in love with horses, they helped me feel happy and improved my balance when I rode. I also struggled to talk when the tube in my throat was taken out and that is when we got Daz the dog. He was brilliant and I managed to talk to him all the time when no one else would listen or could understand me. I did get better at speaking though and a nice lady helped me talk better.

Sammy became my hero – as I got older, he used to look after me because I found school work really hard - mum said that my brain might have been hurt by the funny birthmark, she said that was why I had



some balance problems too. As I grew up, at 18, I even went to clubs with Sammy in London sometimes – I was the sensible one and just had two WKD's: my turn to look after him. When I was 16 I went to college – a special one that had horses and I got a diploma in horse care which I was very pleased about, I also got my own horse, Dobbs, a 15 hand coloured horse. I am now 21 and me, mum and Sarah took part in a triathlon to raise money for charity last year and I got a special award for my efforts. Life is great. '



Reflection point: Think about Holly's particular needs. What are the key issues for her as she has grown up? What are the positives in her life and what do you think has made her resilient?

Sammy's story

My name is Sammy. When Holly was born, I was three and I remember going to the Hospital to see her - she was beautiful and smelled nice. A few weeks after she came home though, there was a horrible night when an ambulance came and mum, dad and Holly went to the Hospital. Granny Jo came to look after me and we had hot chocolate and toast but I was worried about Holly. I did go and see her in the Hospital and that was a bit scary. When she came home, she had a tube in her neck and another one in her tummy. There was also a big red mark on her face that looked strange but underneath it she was still my little sister. I learned later that the mark on her face was like a tumour and that normally it is just on the skin but with Holly, it had gone into her throat and she had been struggling to breath. She also could not eat because it had blocked the eating tube. Later, it seemed to affect her growth because she was quite small.

It was really difficult at first because mum and dad seemed really stressed about Holly's tubes but we still all had fun and Holly was really cheerful most of the time. We couldn't go out much at first because sometimes Holly wasn't very well but she began to feel better and we had days out to the local farm. I didn't like it when people stared at her it made me feel really sad. Lots of people came to the house and Holly often had to go to the Hospital. Granny Jo used to come and look after me and we did lots of good things together – she used to give me Jelly Babies and make me fried bread for breakfast. When Joe was born and then Sarah it got really busy and noisy in our house, then Daz the dog came and he was great fun. Although he was really Holly's, I used to take him out for walks when I got older. That was a nice, quiet time for me and I talked to Daz a lot. We did not go on holiday for a long time - until I was nearly 8. Then we went to Brighton in a caravan and Granny Jo came too.

I sometimes felt left out with so much to do with Holly, Joe and Sarah but there was a nice nurse at the school who used to come and talk to me about how I was feeling. It was good to have someone just for me to talk to sometimes; I also got to spend some time at a special group for people with brothers or sisters like Holly. Most of the time though, I was really happy and liked to help out with Holly and we got to be really close. When she came to my school I used to watch out for her at playtime but she was usually with her friends. Holly struggled with learning at school and I liked to help her with the reading and maths - I was always good at school. Mum said that her brain might have been affected by the haemangioma.

As we both grew up, we used to go out together sometimes, my

'At one point, there were 17 people outside the family involved in her care.'

friends were used to her being around but she could also be a pain just like little sisters can be. We did go to a club in London a couple of times which was good fun, Holly never seemed to worry about people looking at her but I did.'



Reflection point: How has Sammy been affected by Holly's condition. What has helped him cope?

Heather and Jon's story

Holly was born on Feb 14th 1994, she weighed 8lbs 2oz, it was a normal delivery and she appeared to be a really health baby. Over the next 4 weeks however, a growth appeared on the right side of her face. It was bright red and swollen, closing up her right eye. Initially, the health visitor said that it was a birth mark and that it would go down. We got more and more worried about her and eventually, her breathing became more difficult and one night we had to call the ambulance and we rushed to the hospital. She went to the paediatric intensive care unit and had to be ventilated for a short while. We were so scared; we had what felt like a tight band around our chests and mouths so dry that we could not drink anything, we both said afterwards that it was like having an out of body experience, but we knew that we had to keep calm to answer all the questions about Holly.

All the staff at the Hospital were amazing and the consultant who cared for Holly was fantastic. He explained that Holly had a Haemangioma which is the commonest kind of birth mark but that in some extreme circumstances, it can penetrate much deeper into the tissues. He said that the growth was invading into her throat, affecting her breathing and also that she was having difficulty in swallowing. He explained that there were some treatments that would help to reduce the tumour but that this may take some time to work. In the meantime, she would need to have a tracheostomy to help her breathe and a tube into her stomach to feed her which made us even more scared. We thought it would be a temporary thing for a couple of weeks but the doctors said that the tubes might be there for up to four years.

The consultant was amazing, he asked another parent to come and talk to us who had a child with a tracheostomy and she was so reassuring that we felt more able to cope. She has remained a friend of ours ever since. We came home with Holly under the care of the community nursing team. We soon learned to care for Holly and all her tubes and dressings under the careful guidance of the community nurses, our GP and many others. At one point, there were 17

people outside the family involved in her care. We know that everyone was doing their very best but sometimes we wanted everyone to go away and let us get on with our lives and be a normal family.

We settled into family life with our older son Sammy and Holly and we had some real fun, able to keep our sense of humour most of the time. After a year, we discovered that we were pregnant again. This period of our lives was very difficult. The reaction to this news was very surprising from family and friends: what were we thinking, having another baby when we had Holly to look after? This really hurt and in addition to this, when we tried to get Holly into a nursery, they refused to take her saying they didn't take children like Holly. When Joe was born, Holly was fantastic, really pleased with her younger brother, loving him from the moment she saw him and the same happened two years later when we had Sarah. Our family was complete. There were some setbacks when Holly developed other health problems with her heart and her bowel and she has remained small for her age but she fought her way back from these with her usual resilience.

People sometimes stared at Holly when we were out and we often became very uncomfortable, we would have preferred people to come up and ask questions rather than simply staring, pointing or whispering about her. There were times in the early days when we just didn't want to go out. As time went on, the mark on Holly's face reduced in size and became less red and when she was nearly five, the swelling had reduced enough to have the tubes removed. It was such a relief but also rather scary, we had been caring for her for so long. As Holly developed we realised that she was slow to learn and it was thought that the tumour may have affected the frontal lobe of her brain making it harder for her to learn. She struggled to talk when the tubes came out but when Daz the rescue dog came, he made all the difference - Holly loved him and talked to him all the time and Sammy also fell in love with him, taking him out for walks often.

Today, Holly is 21 and she is amazing. She went to an equestrian college to work with horses that she loves. She graduated with a distinction in her course and we could not be more proud of her. She took part in a triathlon to raise money for charity and has become a spokesperson for others with haemangioma. We are so proud of all our family and grateful that we had such good support from so many different people. We would like to give some advice to professionals though, please don't assume



that parents always want to sit and talk about things, sometimes they just want to get on with their lives! Also, please try not to see children with complex needs as learning opportunities – it can get very wearing. Advice to other parents though, is to not be too proud to accept help, particular financial help through the benefit system which we found to be invaluable. Above all, laugh a lot and behave like a normal family!



Reflection point - Think about Holly's story and consider who might have been involved in her care over the years. How were the family supported and what difficulties did they overcome. What do you think has made them resilient?

A number of terms have been applied to a care pathway but fundamentally, they describe the anticipated care for a specific condition, diagnosis or issue over a period of time and they form part of quality frameworks. The key points are:

- Care pathways should be locally developed.
- They should be prepared using the best available evidence.
- They involve agreement through a multi-disciplinary team.
- Pathways should be created with user involvement.
- The outcomes are measured through an audit process and reviewed regularly. An expected result should be measured against the actual result (variance analysis).
- Care pathways help to demonstrate the effectiveness of services.
- Benchmarks can be set in pathways. This is basically setting a standard of excellence which is achievable (SMART indicators can be applied here).

S – SPECIFIC
M – MEASURABLE
A – ACHIEVABLE
R – REALISTIC
T – TIMED



Activity - Find out in your local area what care pathways are in place for children with additional needs.

The Child and Families act (2014) includes a legal duty for schools to provide the right care and support to children with medical conditions in a way that is non stigmatising and inclusive. Supporting pupils at school with medical conditions provides statutory guidance for schools, governing bodies and healthcare providers.

www.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf

Children and Families Act 2014 :
www.legislation.gov.uk/ukpga/2014/6/contents/enacted/data.htm

Developing your knowledge and skills

It is important to assess your own current knowledge and abilities regarding certain conditions either as they appear on the caseload or if you have a particular interest in an illness or condition. Some local or national organisations may be a valuable source for this type of information, as they will be current and up to date on treatments and initiatives relating to the national guidelines and strategies. The following websites will help you develop your knowledge of a few of

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the conditions that you will encounter as a school nurse:

- www.asthma.org.uk
- www.diabetes.org.uk/Children-and-diabetes
- www.epilepsyresearch.org.uk
- www.anaphylaxis.org.uk
- www.autism.org.uk
- www.disabilityrightsuk.org
- www.noo.org.uk/noo_about_obesity/child_obesity

Advocacy

Advocacy is particularly important when working with children and families who may not feel they have a voice. Many parents, carers and young people become experts in their particular condition and are perfectly capable of accessing appropriate services and care. Others however, may need help from professionals and as a school nurse, you may be in a good position to be advocate for your clients.

As a community nurse you will have to start to establish a personal authority and assertiveness in order to influence other health and social care professionals, colleagues and patients to promote care. Being assertive means respecting yourself and other people, seeing people as equal to you, not better or less important than you. The goal of this assertive behaviour in this context is to stand up for young people's rights and act as an advocate. Being assertive does not always mean you get what you want, but it can help you achieve a compromise. You will need to develop a deeper degree of self - awareness, self - belief in your ability to convey information with confidence and conviction. Remember, the child or young person's needs are paramount.



Activity - Think about some of the young people you may have on your caseload with an additional need in school. In what ways are they supported?

- Think about how you could help them learn about health related issues
- How could you direct them to more information and what would be the best source of information

for them?

- Can you think of where you could access resources to help you to inform them better?
- What information is there for the school on managing children with medical needs?

Using technology

The use of technology to support young people with complex needs is becoming more common. This is both in terms of advanced mobile machinery that allows very sick children to be nursed at home and also in App technology that allows children with asthma, diabetes and epilepsy to monitor and manage their own condition. This is particularly helpful as a child grows into an adolescent and looks for more independence.

- Asthma App: <https://itunes.apple.com/gb/app/myasthma-uk/id488576939?mt=8>
- Diabetes App: www.diabetes.org.uk/How_we_help/Diabetes-UK-apps/Tracker-app/
- Epilepsy App: www.epilepsysociety.org.uk/how-download-iphone-app#.VGt0KDSsVHw



Reflection trigger point- what would you do if?

These reflection triggers are for you to get together with your mentor and if appropriate other team members to debate possible solutions. They could be used as a basis for a discussion or even a teaching session. We are aware that the solutions to these triggers may vary from Trust to Trust according to local policy and procedure. We are also aware that there may be no 'right or wrong' answers to how certain situations might be tackled and therefore it will be for you as a qualified nurse to apply your thinking within the parameters of your own professional practice.

- You are visiting a 14 year old girl in school who has type 1 Diabetes but who, according to teachers and her parents, is becoming very reluctant to take her medication?
- A primary school asks your advice about a boy of 6 who has severe eczema. The other children in his class are reluctant to play with him and he is becoming very withdrawn and unhappy. You are unsure if he has medications/creams and so



what would you do next?

- A 5 year old boy in one of your mainstream primary schools has been recently diagnosed with Muscular Dystrophy. His mother has asked to see you about how this information may be handled by the school and whether the other pupils should be made aware of his needs. What action might you take?
- A girl of 10 is going to a mainstream secondary school. She has Cerebral Palsy and you want to ensure a smooth transition into secondary education. Who should you liaise with and what action should you take?
- A boy of 13 is in mainstream school. He has Asperger's Syndrome and until recently has been managing well but recently he has become disruptive in class. He has started to develop physically and he seems to be going into puberty. How would you help him through this developmental stage?



Chapter Summary

This Chapter has raised some awareness of the vast topic of children with complex and additional needs. It has identified some definitions of the conditions that are considered to be complex needs and highlighted some cases for further discussion with your mentor. It has outlined a case scenario for you to consider the impact on a whole family coping with a child with an additional need.

Web Resources

Managing medicines in schools 2014:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf

Supporting children with special educational needs in schools:

www.gov.uk/schools-colleges-childrens-services/special-educational-needs-disabilities