A REFLECTION ON A YOUNG LIFE WITH LYMPHOEDEMA

Caroline McGlynn

As the mother of a young person with lymphoedema, I have often reflected on the life of my child and how the condition has affected our family. This article is the first time those thoughts have been articulated to a wider audience, and my purpose is to reflect on the experience for the benefit of my family and other families who may experience a similar situation. No two families are the same and so this account is a very personal insight into our family from the day our baby girl was born.

Hannah is my second baby, born after a happy, healthy pregnancy and an easy birth. As soon as she was born no-one could deny she was beautiful, with a light dusting of golden hair, huge blue eyes and deep pink lips, she looked like a fairytale princess. There were 10 fingers and 10 toes and she was perfectly formed — apart from three of her limbs were disproportionately large compared with her size. The answer was simple according to the midwife who delivered her — she had been 'laying funny' inside me and it would sort itself out by the time I was allowed home.

The visitors came and went, but I was not the happy mother I should have been and kept asking hospital staff if they had seen this type of swelling before. My baby could not possibly be the only baby to have been lying 'funny' and if they had seen it before, it must be all right. No-one had seen it, but no-one had time to check it out either. Hannah fed and slept well and there were other babies with greater needs to take care of. Soon we were on our way home.

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Less than 24 hours later the community midwife who had more than 30 years experience had arranged for Hannah to see a neonatal doctor. It turned out that swollen limbs were not 'normal' and she wanted an explanation.

The chaos of diagnosis

The neonatal doctor turned out to be the first of many healthcare professionals we would come into contact with over the next few years. He suggested Turner's syndrome and for a while everyone agreed. Blood tests were taken but the physical symptoms were so 'obvious' that Hannah was paraded in front of 12 student paediatric doctors as an example of 'classic Turner's'. Sometimes I wonder if they have ever realised that what they saw that day was not Turner's syndrome.

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Before the results came in we saw the health visitor and she exclaimed, 'oh, this is the Turner's child'. For some reason I knew it was not right, but I was even more cross because Hannah wasn't Turner's she was mine and I did not want her referred to by the condition. I told the health visitor her name was Hannah not Turner, but she laughed and said I would get used to it. Fortunately I did not have to get used to it, but I have had to get used to different names and questions. I got used to being asked about Hannah's 'fat' hand, why she has to use a wheelchair and why she has her legs bandaged. When she was little the worst question was 'what's wrong with her?' not just because of the sheer rudeness and interfering nature of it, but because I didn't have an answer. The doctors were convinced it was Turner's syndrome but confirming it was proving difficult.

After numerous blood tests, physical examinations and a three-day stint at Great Ormond Street Hospital (GOSH) in London for every type of scan and test, including a skin biopsy, the endocrinologist eventually ruled out Turner's but couldn't offer any other label. This was a very difficult time. Until then the NHS had always been able to fix things that were not working. This not fixing and, worse, not knowing, was not supposed to happen. It was even worse when the doctors stopped taking an interest. They seemed to decide they did not know and would never know and we should just get on with things ourselves. So, for a while she was just Hannah with Hannah's syndrome, but it could not stay like that.

Hannah was growing and needed shoes and clothes that fitted properly, but we could not buy them off the shelf. For sleeves to go round her arm we had to buy clothes that were several sizes too big and trousers would not go around her legs at all. Shoes were our biggest worry. She was making moves to walk but we couldn't even find socks to fit, let alone shoes. These practical worries did not spur the healthcare providers into action at all and we felt very alone with the problem. I decided to take the bull by the horns and

research the problem for myself, starting with the test results from GOSH.

I applied for Hannah's notes and spent days poring over the results. I eventually came across something that hadn't been mentioned during the visit or afterwards, Milroy's disease.

I clutched at this straw and searched the internet. Eventually I found some sites that mentioned Milroy's disease (also known as heredofamilial lymphoedema). The accompanying photographs were terrifying. There was no way I was going to let my otherwise perfect child have this condition. I went back to our paediatrician and offered my findings. She was quite flippant when she said if it was Milroy's then Hannah probably would never walk. Devastated, I went back to the computer and found the details of the Lymphoedema Support Network (LSN). I called their helpline and couldn't control the tears as I asked whether my baby would ever be able to walk.

The woman on the telephone was a breast cancer survivor and did not know anything about childhood lymphoedema, but she did recognise my distress and talked to me and helped me. She gave me a little hope and another name to contact — Peter Mortimer, Professor of Dermatological Medicine to the University of London at St George's and the Royal Marsden Hospitals, London and an expert in lymphoedema.

Our GP had never heard of Milroy's and would not refer us to Professor Mortimer and our paediatrician said there was no need as she had seen Milroy's before and this was not it. So, in common with many parents since, we paid privately to see him. He looked at my seven-month-old baby and told us it was congenital primary lymphoedema — a condition with similar symptoms to Milroy's. He didn't need blood tests, scans or skin biopsies. He had seen other children like Hannah and he said he would write to our GP and everything would be all right. Even though we now knew there was no cure there were things that could be done to help Hannah and the NHS really would fix everything soon.

The scramble for care

After the diagnosis I presented Hannah to our health visitor and told her we needed the NHS to provide shoes for her. She referred us to the physiotherapy department to see what they could do. The day we met the physiotherapist was a good day. Hannah's physio had never seen lymphoedema in a child before, but that did not seem to worry her. She asked what we needed. We told her about the diagnosis and the recommendations from Professor Mortimer. Hannah needed protective footwear and hydrotherapy and she was able to arrange both of these. They also organised occupational therapists to help with her fine motor development and later arranged for sibling counselling for my son Adam. The NHS really was helping at last.

Hannah also needed manual lymph drainage and compression stockings. For these she needed a lymphoedema clinic so we went back to the GP full of expectations that he would refer us now that we had a consultant who had 'prescribed' the necessary care. This is where we ran up against the 'postcode lottery' and discovered that the National Health Service is not really national. It is a local service, and if your local health authority does not provide what you need the chances of you accessing it are minimal. There was no lymphoedema clinic in our area. Hannah could not have MLD on the NHS, and worse, the doctor could not recommend anyone who would be able to do it. There was no clinic to provide stockings or advice. We had the auxiliary services but Hannah was basically no better off.

The physiotherapy team tried to provide stockings but in the absence of any expertise they did not fit properly and were not suitable. The LSN were not able to help very much either as they were not aware of any paediatric clinics. We wrote to our local health authority director. He wrote back that there was no demand for lymphoedema services in our area. We told him we were demanding it and he said it was not financially viable to provide services for one person. He also couldn't help us locate another service. Yet again we felt that the NHS had washed its hands of us.

Soon after, while still searching for answers we decided to attend an LSN monthly meeting to meet other people with the condition. Nearly everyone there had secondary lymphoedema and couldn't help us, but there was one primary patient and he had good news. His NHS therapist was treating a child. We were ecstatic. However, we were to suffer more disappointment. She couldn't see Hannah because we were outside of her area, but she told us about the lymphoedema clinic in Oxford which she thought could help us.

The Oxford lymphoedema clinic saw lots of children; they even ran a paediatric clinic once a month. Our only concern was whether our local authority would pay for it. We decided to bypass the GP and paediatrician who had been so unhelpful before, and instead went to the neonatal doctor who had referred Hannah to GOSH. Unfortunately, he only asked the clinic to provide advice for Hannah's care, but we very quickly received an appointment to attend the Oxford clinic. We were thrilled and began to feel that we would finally get some support. On the day of the appointment the neonatal doctor called to say we couldn't go as the funding had not been cleared. Enraged and disgusted we went anyway.

It is at Oxford where I can say that the traumatic period of our healthcare 'journey' ended. We have had moments of sheer panic from infections and even prolonged periods of concern with chicken pox and toenail surgery, but once we got to the calmness and tranquillity of the lymphoedema clinic at Oxford we knew things would be just fine. First Karen and now Gail, if you are reading this, you will probably never know just how grateful we are for treating us as ordinary people with ordinary children and a condition that could be treated.

It seems that lymphoedema is a silent condition. If no-one mentions it, then it is as though it does not exist. I can't

help wondering that if my community midwife hadn't been so experienced and sent me back to the hospital after Hannah's birth, whether I would have eventually just accepted Hannah's legs and hands the way they were, the doctors would have written her off and she wouldn't be in the good shape she is in now. I hope and pray that the NHS is now more aware of the condition and if a child presents with symptoms like Hannah now the condition would be recognised, or at least investigated. However, I know from being on an internet support group that children the world over are misdiagnosed or have to wait months and months for a correct diagnosis. They have to fight for the right to attend clinics and receive care and are still following a disturbingly similar path to our own.

You may have recognised a recurrent theme running through the early part of this article. Whenever Hannah needed anything, from diagnosis to a clinic, we had to shout and cry and write letters. Usually a lay person came to our rescue and helped us find a solution. In a way this proved to be a good grounding, as worse was to follow when Hannah started school.

Educating Hannah

Adam was attending a wonderful local primary school. It was all on one level and had a caring ethos which seemed ideal for Hannah, who we now recognised would need a little extra care and attention. The headmaster was a good man and said he would take Hannah and she would be nurtured and helped to reach her full potential. However, we must first obtain a statement of special educational needs so that the local education authority (LEA) would pay for a learning support assistant (LSA).

This process is traumatising. It involves being so negative about your child and dealing with the incredible bureaucracy of the local council. We filled in form after form, had meeting after meeting and wrote letter after letter. Eventually, Hannah was allocated the right number of hours of LSA assistance that would allow her to attend

Figure 1. Hannah in her school uniform.

school. All was well until the wonderful head teacher that had accepted Hannah left the school and the inclusive ethos of the school appeared to change overnight.

What followed could only be described as years of abuse. Instead of caring for Hannah she was excluded from school and school trips; was bullied by other pupils, parents and staff; was refused alternative activities when she was unable to take part in PE or recreational activities. Hannah was not allowed to use her wheelchair in school as it was considered a health and safety risk and rooms that did not have wheelchair access or that were not on ground level were allocated to Hannah's class which meant that she was forced to be dependent on others for help. Rather than nurturing my child and developing her independence, the school was eroding her self-esteem and confidence.

Yet again I had to write letters and make calls to find out what could be done. After calling the LEA nearly every day for two years they finally allocated a parental adviser who now attends all meetings with me. If there is a problem I tell her and she mediates on my behalf. So far, since she has been working with me, the school have responded to all the issues I have raised with a far more positive attitude. It appears that my requests for Hannah to be included in everyday school activities are not 'unreasonable' as I had been told many times, and that there are alternative options for children who are a little different.

I try not to dwell on the negative aspects of Hannah's education, but I am still so very angry about it. It made me realise how vulnerable children are, and how much we have to depend on others for Hannah's inclusion and security. I am not denying that there are many wonderful people in Hannah's school, but without a clear ethos of compassion and care, the needs of children who require extra care are not met.

The good news is that Hannah is now doing very well and the constant watchful eye of the LEA has helped.

A new special education needs coordinator took a post with the school and helped change various negative practices, and empowered the LSAs so they were able to take a more pro-active role in Hannah's care. Finally she has an excellent, experienced teacher who recognises Hannah's many talents and gifts and actively encourages her to join in. She is no longer the easy target for bullies, instead she has lots of friends and is looking forward to the move to her new secondary school in September.

Lymphoedema: an extra member of the family

Our life hasn't followed the ordered and idyllic plan that we thought it would, but this is more because of the 'not knowing' that fuelled our early experiences of life with lymphoedema. We decided not to have any more children simply because we didn't know the ramifications of the condition. In hindsight, there are worse things that can happen and we probably would have coped with several children with lymphoedema.

As it is, we came to think of lymphoedema as an extra member of the family — ultimately attached to Hannah but belonging to all of us, we all take responsibility for it. Whenever we left home we took the things we all needed and the things we needed for the lymphoedema. Holiday packing consists of five piles of essentials, books for mum, laptop for dad, games consoles for the children and bandages for the lymphoedema. We are used to allowing quality time for each of the children and for the lymphoedema; Scouts for Adam, Brownies for Hannah and massage for the lymphoedema. We each became expert in an area of its care, no-one can wrap as fast as mum, but dad is quicker with tights in the morning. Adam would read to Hannah while she was wrapped, and he makes her laugh when it hurts. They have a little routine that involves Hannah pulling Adam's finger while he makes faces and dances. After all these years it still makes her laugh and it is better than paracetamol for pain relief. It is funny to think of it this way, but it works for us. It meant that we each had the time we needed and the condition was always considered in decisions and planning. Even everyday things like when to eat would depend on the needs of the lymphoedema.

Some medicines have to be given on a full stomach, others on an empty stomach. For so many years Hannah has suffered with recurrent infections in her feet. She has an almost permanent case of athlete's foot and has had ingrowing toenails on several toes on both feet. This means that she is frequently on medication, indeed, not very long ago she completed a 13-month course of antibiotics, yet a few months later was back for more. Her dad now has a system of alarms that get activated whenever she is on medicine. I get so easily confused that if not reminded to medicate at the right time we end up eating at strange times of the day or night.

Having a child with an 'unusual' condition has made life a little complicated in other ways too. For many years I was known only as 'Hannah's mum', which didn't really worry me until I realised that Adam was also known by so many people as 'Hannah's brother'. People who should have known Adam as an individual referred to him in this way and I found it quite distressing. In addition, I began to realise that the decisions we were making for the treatment of lymphoedema were affecting Adam in other ways. His social life was very limited compared with other children in our social circle. He didn't have many friends over because Hannah's legs were often tired after school and she would need to rest. He didn't take part in many physical activities as it was difficult to justify to Hannah why she couldn't do it too. As a result, we made the decision to send Adam to a boarding school and he has flourished there. He has become more outgoing and adventurous, he has regained his individuality and has opportunities that we couldn't offer at home, not because of lack of will or resources but simply because of the time involved in looking after the lymphoedema and the limitations imposed upon Hannah by the condition.

This article has been written to articulate the meanderings of the condition and how it has affected our family. In conclusion, though, I would like to concentrate for just a while on Hannah, because what I haven't written about yet is the wonderfulness of my little girl.

She is now nearly 11. She is growing up and becoming more independent and taking more and more control of her condition. Although there will always be things she finds difficult because of the condition, she is starting to understand the implications of those limitations. She answers the questions people ask about her herself now, even when directed to me or her dad. Sometimes she answers honestly and sometimes with a tall tale of tiger fights and crocodile hunting — it is her choice. Sometimes, when she is not too tired she wraps her own legs, but the toes and hand are still difficult for her. She applies her own creams and takes her own vitamins. She is starting to plan her days and weeks so she doesn't have to use her wheelchair as often, and is therefore less dependent on others. She gets a lot of pain in her legs when she walks too much and until she qualifies for a power wheelchair, she is making pragmatic choices about her involvement in activities.

When asked recently if there was anything good about having lymphoedema, Hannah said 'yes', and reeled off a whole list of benefits I hadn't thought of from horse riding to hydrotherapy, from everyone knowing her name to being rescued by the fire brigade from the school lift, from staying in at playtime when she wants to working in the library during PE.

I don't ever remember her complaining of the lymphoedema. She complains about homework and going to bed early, she complains about her brother and doing chores, she complains about eating cabbage and cleaning out the rabbit, but she never complains about the lymphoedema.

She is bright and beautiful and clever and wonderful. She is caring and considerate and honest and funny. She is energetic and enthusiastic and talented and creative. She is friendly and outgoing and articulate and brave. She also has lymphoedema. JL