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5. Support for families

5.1 Families experiences: two case studies

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Introduction

This section is two case studies from mothers talking about their experiences of being a parent of a child with a spinal cord injury.

In the first case study Janet talks about her son who was born with cancer of the spine, he has and incomplete injury which means he is able to walk short distances but also uses a wheelchair, and has gone through the education system as a wheelchair user.

In the second case study the mother talks about her son who was injured age 17 whilst playing rugby and has a C5/6 complete injury. The father is part of the HM forces and is posted abroad so there was no family home in the UK. Mother and son moved into the grandparents home who lived near his school.

Case study 1. Janet's story

Personal care

When my son, Ben, first started nursery I had to go there every day to catheterise him. Although he was statemented there wasn't someone in place who could to that, they hadn't employed someone who could do his catheter every two to three hours.

When he first got support it was quite traumatic for me because I had to entrust all his medical and physical care to somebody. He was catheterised, so it was a lot of intimate care.

When his learning support assistant started it was really important that I met her, that I spoke with her and that she understood that she could contact me at any time. Communication with the people providing care for your children is the key.

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> **There used to be lots of barriers but attitudes have changed in the past 17 year. I used to be told that he couldn't come to the swimming pool because people thought he would incontinent. However much things have changed attitude is the still the biggest disability.**

When he was older the care changed as he wanted to be more independent and didn't want anyone else to do it.

Support from his school

When my son was in year eight he had major surgery which went wrong. He was off school for weeks, and during that time he lost his confidence. He felt very isolated as he had been in intensive care in the hospital and at home.

One of his school teachers came round and brought work for him, and had a chat with Ben, a couple of his school friends came round as well, things like that meant a lot.

Ben had a very good relationship with the matron and he was able to go to her at anytime. I used to call her and she would call me. When you have so many staff working with your child, and such a large school it can make it hard. But he liked his teachers very much and they were very supportive, his form tutor especially.

One thing that was really useful for Ben was that we managed to get funding for him to have one set of books at school and one at home so that he didn't need to carry them round with him all the time. It sounds like a simple thing but was really useful for Ben and made his life a lot easier as it could be really awkward carrying heavy books.

Family support and adjusting at home

As a family we have always said to Ben ‘you can do it’. Ben’s one of four and my other children were great levellers after Ben’s operation went wrong. They were very caring for while and then just got on with it and treated him the same as before, joking and teasing each other, which was great.

Resilience is a fantastic skill, and banter with his siblings has helped him to build this up.

Ben has an exceptionally close relationship with his grandparents so they were a great support for him; it was good for him to have someone to go to outside of our family unit. They play a huge part in all aspects of his life.

Barriers and difficulties

The school could have been more understanding of the emotional impact that it had on Ben. He went off the rails a bit as he lost confidence in the system and was frustrated. It was a bit of knock for him and his anxiety could have been recognised by the school better.

Toilets were a key area where the school could have done more. There wasn’t anywhere to store or dispose of his catheters and his medication. The disabled toilet was used by other people including teachers who sometimes used it to get changed in, it could also be unlocked from the outside so he didn’t feel comfortable using it. The situation caused him lots of embarrassment.

It’s about being independent. Going to the toilet can take more time for someone with a spinal cord injury.

I would recommend schools having a disabled toilet with a shower as well in case the student has an accident they can clean themselves up without too much embarrassment.

Statementing for education has been a nightmare. I had to fight for years to get a statement in place. I’m now trying to get disabled student allowance to support Ben going to university. I have had to get input from so many people, which all takes so long. You are fighting for it every step of the way.

Getting funding is hard, and seems to be getting harder. Access to sport for disabled children is so expensive; the cost of a sport wheelchair can be thousands. But a sporting event might be the only thing that your child does with other young people that have disabilities.

He’s out playing sport at the moment. Ben gains so much form the social side of sport; the banter from the men gives him the opportunity to talk about things a 17 year old boy doesn’t want to talk about with his mum, like sex and relationships.

Feeling supported

Back Up have been really useful. Ben feels part of Back Up. He’s quite a gobby teenager so that’s no mean feat. Back Up is all about empowering people and they’ve given him the opportunity to give back through becoming a wheelchair skills trainer.

Back Up have given Ben the confidence to travel and use transport. There are quite a lot of barriers that can be overcome if you have the right training from the right people. The Back Up course Ben went on gave him the confidence to use escalators in his chair. That course had an impact on his everyday life, having the independence and confidence really does change lives.

Case study 2.

How did you feel about your child's injury?

Initially I felt disbelief. I was angry at what had happened, though not towards anybody as it was purely an accident, but at fate. I felt betrayed and questioned my religious faith. I felt defeated by life; we had always strived to do the best for ourselves and other people, and it seemed as though all we had was taken away. But usually I felt that I had to hide all this behind a public 'face'.

On a flip side I was humbled and deeply touched by the response from other people and their support and care.

> **Over the course of time I felt a whole range of emotions - hurt and cheated by life and circumstances, and felt my son too had been cheated and robbed of a 'normal' life.**

How did you feel about your child going back to school?

"My son going back to school became the only positive solution in a fairly bleak scenario."

The school community had shown huge support for us all from the very first day, and were thrilled at the thought of him going back, so we knew we were all pulling together to make a positive outcome. At the very least he would be back with his peers, albeit in the academic year that would have been below his original, as his year group would have finished secondary school.

Who helped you to deal with those emotions?

Any fears I had were allayed by the school organising me to have a teacher who would be my first point of call; she was a very empathetic teacher who was to be my son's 6th form tutor. She had lost a son suddenly a few years before and we had a 'bond' of tragedy. This liaison person was identified by the school as the key person for me and my son to contact, they weren't the SENCO, but were chosen because of their ability to empathise with the loss we were going through.

Who was it helpful to talk to?

> **I had the teacher's home and school email, and was able to contact her with any worries or notifications of illness.**

The school linked me to a specialist in adaptive IT who talked over some of the IT packages that were available (though not through the LEA). The school in consultation with the OT made physical adaptations and decided on a classroom that would be accessible to my son that was also near to the 6th form common room with good access to the library (the school is built on a very steep hill and is a rabbit warren of building and classrooms on all levels stretching up the hill, so potentially was not the easiest of places).

What advice would you give to a parent

whose child has recently been injured and going back to school?

Find out how positive the school is about your child going back. The school will be obliged to take your child back, but if there is a reluctance you may need more help form outside agencies, such as Back Up to educate the school and encourage positivity.

Find out how transport will work, and what's available. I have heard that once a pupil is at 6th form, the local LEA may be reticent to provide any sort of special transport, regardless that the school is state school or a college.

Find out the physical constraints of the school and realistic approaches, i.e. total accessibility may not be possible or necessary as long as the key rooms are accessible. What is satisfactory to you and your child?

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> **Find out how positive your child is about going back. What are their fears and anxieties,a nd how can they remedied? For out son physical worries such as catheter blockages and spillages were a worry and a possible embarrassment. What are they looking forward to about returning to school. Do they have a choice of school?**

Emotional inclusion

Ensure emotional inclusion is considered, your child may feel moody, tired, not fully included, and these feelings are not always easy for people to deal with. We were unsure how our son would be affected by these feelings as we were all feeling very raw when all this was happening, and everything was an experiment and an adjustment. In the event, our son was allocated a 'quiet room' with a bed, where he could go to get some peace, rest if he felt in need of a break, get changed if there were any 'accidents' etc. It did, in fact, become more of a room for the PA/Carer to have respite.

Morning routine and timetabling, and time missed

Ensure school is aware of the lengthiness of morning routines: our son has already done half a day's work in the 2 hours it takes to get ready in the mornings. We made arrangements to miss the school morning assemblies and tutorials as this meant we had more slightly more time in the mornings and did not have to get my son up at even more unearthly hours (often after a fractured sleep). The school also timetabled some of my son's class lessons to begin at a slightly later time in the mornings.

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> **We went to see the school nurses and explained in detail about my son's condition. They were also put in touch with the district nurse to be made aware of the implications.**

He was very susceptible to infections on his return to school, and in the first term only made it in on 3 of the 5 days of the week on average, due to poor health and extreme tiredness. Teachers should be made aware in advance that this may happen. Some teachers are concerned that this will affect their performance targets (SATS results/A Level results), which sounds a bit unfeeling but in reality teachers/schools are under a lot of pressure in performance league tables, in which raw statistics are recorded and human stories omitted.

My husband and I also met with the teachers who would be teaching my son and explained aspects of his needs. At this meeting I did feel as if I was supporting the teachers though, who seemed quite nervous at the prospect of how to deal with our son's condition, and we had to reassure them that some of the things we mentioned were worst case scenarios. Ascertain staff worries and help resolve with strategies. If your child has autonomic dysreflexia then explain what can cause it and what can be done. It may be that a medical professional can help with their medical concerns. Back Up can now help with explaining to staff life back in school after an injury.

Have a medical emergency strategy in place for dysreflexic attacks.

Ensure the school have thought of appropriate evacuation procedures in the case of a fire. Are mustering points wheelchair accessible, who will open fired doors for wheelchair access?

I always made myself readily available to go and collect my son if he was feeling rough at school but I know that this is not always an option for parents.

Before your child goes back to school

Look at the classroom(s) to be used. Where is it best for you child to sit – so that they can see the board, be near a plug point for their computer if needed, won't block other pupils way, won't block access doors, electrical leads for their computers will not be trip hazards, and that they won't be in a draughts.

> **Before the return to school, and after adaptions have been made it is useful to go on a 'dry run' before other pupils are about. Will the wheelchair fit through doors, get up slopes, are all the places that need to be accessible actually accessible? What further adaptations need to be made?**

What kind of things helped you when your child went back to school after their injury?

The things that really helped were seeing the school's joy at having him back. My son's pleasure of being back with his peers and having good, open communication channels between us and the school.

What did your child' school/ teachers do that was useful and good

The teachers welcomed my son back and him back and fundamentally treated him the same as they always did. It is important to remember that post injury the person is the same person sitting down.

The teachers gave him their notes and lesson plans to file, this helped to reduce the amount of note taking he had to do. They also made allowances for when homework was not handed in on the exact day required.

They had a laugh with him and the class, as had always happened. It has always been a school where my son has laughed a lot.

> **I think people are sometime sacred of appearing too light hearted when a tragey strikes, but sometimes one needs to escape into comedy.**

What did your friends/family do that was useful and good?

My friends and family sent positive e mails and phone calls of support. I really needed to hear that the whole situation was unfair and that we were a 'good family' and 'good people' and did not deserve what had happened. I had a few friends who would just get in touch and make me laugh, or send comedy videos and funny emails.

What could your friends/family have done better?

Some tried to 'problem solve' if issues arose, but there are many problems that have no real solutions and one just wants to have a sympathetic ear to let go of emotional worries, or tales of battles lost, rather than proposed solutions given from a position of ignorance. People want to help by over-simplifying sometimes, but they do not really understand the full gamut of emotions one is dealing with and the power of those emotions, or the frustrating issues with which one has to cope. For example, on the issue of me driving every day to the school, people were saying appeal here and appeal there, but there are only so many appeals one can make in the state of exhaustion one is in, and one has to decide which battles have been lost, for one's own sanity. Others do not readily understand this.

> **"You have to choose the battles you think you can win, or are of utmost importance; otherwise your energy levels will be totally sapped.**

Many times family/ friends would phone and ask about my son which was good, but an hour later I would feel drained as all we had talked about was my son and the pretty 'heavy' situation we were in. Many times I just would have like to have had a conversation like the 'old days' and with them talking of this and that, and funny things.

Is there any information or support network that you found helpful?

> **"The spinal charities were good in different ways at providing information.**

SIA were very helpful in legal matters, and matters of benefits. Their spinal magazines have informative articles. A representative from Aspire visited the spinal centre; he was a young, funny, very positive chap with a high level injury, who was a great inspiration. We had support from Disability Cornwall (our home county) who have an excellent helpline for residents of Cornwall, and a very helpful magazine.

The National Bureau for Students with Disabilities gave helpful information about returning to school although their offices are not open every day. And the Citizens' Advice Bureau representatives were very helpful when our son was in hospital at setting up benefits

Back Up helped with fighting the examination board that were refusing to accept our son's practical grades in sports sciences as he could no longer physically do the sports, and could not see that this was discriminatory. The excellent thing about Back Up is that they were the one charity who actually contacted us and asked if they could help with issues about my son going back to school, and were pro-active in helping. It was wonderful, as after trying to cope with such an awful accident, and its outcomes one needs a bit of nurturing and being offered help rather than the constant struggle of seeking help and answers.

Was there a particular kind of support that you wanted but could not find?

It would have been great to have a ‘one stop’ shop of information combining information on issues of going back to school, what benefits are available, and how personal injury settlements might affect these things.

Planning to go to university has also been time consuming and a bit of an unknown. It would be good to have a plan for how disabled students can apply for university grants. It is always the unknown unknowns that scare one. One always worries that one has not found out everything, that one has not done something that one should have done, because of ignorance.

What are your child’s aspirations for the future?

> “**My son is now on a gap year in which we have spent five months in Ethiopiea and done a ‘pilgramage’ to Lourdes.**

He is going to Norwich University in September 2012 to study Business Economics and would like to run his own business eventually. He would like to find a disability sport in which he could excel, at the moment plays powerchair football. He wants to travel extensively, to lead a full and active life and be happy!