



## 4. Support for young people

### 4.1 Young people's experiences

## Introduction

This section is all about listening to young people's experiences of going back to school after they have had a spinal cord injury. They are in the best place, having gone through it themselves, to give you advice about what to expect. Hopefully they can help make what might seem quite scary a little less daunting. Section four will have lots of real life stories, and will cover issues like what your rights are, what support is out there for you, understanding your emotions, thinking about sex and relationships, and returning to school.

Back Up has worked with many children and young people with spinal cord injuries who have returned to schools. They told us about their experiences of returning to school – how it felt, what worked well and what could have gone better. Their varied and insightful experiences are shared in throughout section four of the toolkit. Two examples are shared here.

## Danielle's Story

My name is Danielle and I sustained a spinal cord injury at T10 when I was 15 in a road traffic accident. **When I was injured I felt scared and nervous.** I had a different mix of feelings because I didn't really know what to expect. Upset. Angry.

I found it easier to talk to someone who had some experience of a spinal injury, who was roughly the same level injury as me and the same age. I had a mentor from Back Up. She has been injured for four years more than me. She helped me with any questions I had, how things were going to work like driving, different transfers (like getting in and out of the car) and things like that. I talked to her for about a year. **My mentor helped me realise that life doesn't stop, that it keeps going and that I shouldn't stop myself doing anything, as I can do anything I want to do, just adapted in different ways.**



**I was extremely scared about going back to school, not knowing what people were thinking and how I was going to get to the toilet, things like that.** I had known the school from an able bodied point of view. I had no idea what it was going to be like to return as a wheelchair user. I had to find different ways of getting about, different ways of doing subjects.

**My school was really good. They were eager to get me back.** The teachers were understanding about everything, for example if I wasn't well or couldn't go in or if I had a hospital or doctor's appointment. They understood that it was not going to be the same as before. They gave me extra time to do things.

**The school did lots of adaptations.** I had a lowered unit to use in home economics and other subjects. I could wheel it up and down so able bodied or wheelchair users could use it. The school adapted the bathrooms too and I had a personal carer to help me if I needed to go to the toilet. The school made sure I got around ok, made sure I could use the lifts.

**My advice to schools would be don't act differently because the young person is in a chair** because they are exactly the same person, apart from going from walking to sitting. That was what I didn't like – the teachers were constantly asking if I was OK.

**My advice to young people going back to school after an injury is to take your time to settle in, give it a chance and don't give up.** The longer you are there the easier it gets. It does take a while to adjust. It takes time. But you will find different ways of doing things in the school and outside the school. I had good strong support from my family, friends and my mentor. **They did not let me give up, they consistently reassured me, let me get on with things, let me be independent and did not hold me back.**

## Ben's story

I first got my spinal cord injury in 2007 I was struck down with a virus in the spine which they diagnosed as Transverse Myelitis. After two years of retraining myself how to walk again, it came back in 2009 and worsened my physical state as it took away the use of my arms and legs.

**When it first happened I was 12, and when it came back I was 14, just in the middle of my GCSE's. It wasn't really a great time to be honest.**

When I first had it I was pretty okay, I was determined to beat it, but when it came back in 2009 I coped with it quite badly. I had spent two years retraining myself to walk again, I was almost there, I was on crutches, and then it just felt like those two years were for nothing, it just wiped them from me. So I did get depression. **I did hide away from people**; I kept myself in my room for 3 months solid and felt anxious and depressed during that time.

The first time I got the virus the school wasn't really accessible as it was an old building, but they were building a new one so I didn't go back to school until that was finished.

**When I went back I was nervous because I didn't know how people would react to me being in a wheelchair.**

When the virus came back in 2009 going back to my school then was twice as bad because of the anxiety, and the depression I got. It was just so bad, I found it really hard even getting in the car let alone going into the school itself. **But the school was really supportive. They never forced me to do anything; they let me take it at my own pace.** Instead of chucking me straight into lessons surrounded by people, they let me stay in a room where I felt comfortable with students coming in and out, until I was used to being around people again before I went back into my lessons.

**The teachers asked me what I wanted.** Every week they would ask me how I was doing, is there anything else they could do for me, were the times okay for me to come into lessons, and told me to let them know when I wanted to start increasing the times I was in school. **The decisions were in my hands and that helped a lot. I controlled the process.** There was a level of trust there. If the school had no idea what I was going through and they weren't supporting me in the right way I would definitely have wanted meetings with everyone to tell them 'this is what's needed' or 'this is what you can't do'. But because I trusted them I didn't need to do this.

My friends and family were shocked when they found out about my spinal cord injury. Looking back it was probably just as hard on them as it was on me. But not once did they give up on me. **My family and friends were my rock, if it wasn't for them I wouldn't be here now. They kept me going, they would never let me slip behind, and they would always check how I was.** As time went on they got used to it and they got used to my different types of needs.

It's easy for me to say, looking back on it, that you shouldn't push out your family and friends, as much as you want to, as much as it's hard to let them in. Obviously when you're in a dark and depressive place you can't see any other way out but **pushing your friends and family away is a big mistake because you need them there. You need someone to talk to, and you need your rocks to see you through.**



Check out the Spinal Injuries Association's guide for teenagers:

[Wha'ever Guide for teenagers with a spinal cord injury](#)