Bracing Special

We receive a lot of enquiries about bracing and have heard stories from many of you who are currently wearing a brace or who have done so in the past. Wearing a brace can be tough and there can be confusion about whether a brace is the right option and what to expect if you are required to wear one. We felt that there is a need to provide more information about bracing and to share the experiences of our members so we have created this 7 page special.

Lynda Williams
My daughter Steph was diagnosed with scoliosis when she was 12 years old. She had a thoracic curve of 29°, which after 3 months progressed to 33°. At this point something had to be done and the consultant suggested that we prepare ourselves for surgery. However, Steph was quite insistent that she wanted to try wearing a brace. She wore her brace for 21 hours every day and after 12 weeks had a 12°correction in her curve.

She continued to wear her brace, for 3½ years in total. Steph would take the brace off to do karate or dance. During this period she represented Wales and Great Britain in karate, was chosen to be part of Dance GB, and played the lead in Scheherazade at Wales Millennium Centre. More importantly Steph managed to bring her curve down to 16° in the brace and once out of her brace it has held at 20°, so she has been able so far to avoid the surgery that had been planned. Steph was nominated and chosen to run with the Olympic torch in May, 2012, in recognition of her achievements and has recently achieved the grades to go to Salford University to study prosthetics and orthotics so that she can help others to succeed.

Ellen Adkins
My name is Ellen Adkins, I am 13 years old, and I wear a Boston brace. I was diagnosed with scoliosis in January, 2014, and first saw a consultant in March. I was told I had adolescent idiopathic scoliosis with a 43° curve. I got my brace in April and I have a love-hate relationship with it. 23 hours a day is a long time to have a big plastic casing around your body! It makes you very hot, and I change my vest top at least twice a day. The brace has padding on my right ribs and they constantly feel sore and bruised. Also, my brace digs in in a few places but I have managed this by using sponges. The biggest problem with my brace is that I can’t tie my shoelaces with it on. On the other hand my brace makes me look like I’m very slim and have a nice figure—every girl’s dream! I like to decorate my brace—for example, there are lots of stickers on my brace, and on the straps, which I have velcroed to the sides, I have written ‘bent not broken’ which is my little motto! In school I have to take a friend to the toilet with me to take my brace off and on, and I take my brace off for PE. It is extremely hot in school so whenever I need to cool down I just ask my teachers, who are very understanding and allow me to leave for a while. Neither scoliosis nor my back brace has restricted me too much. I have had to give up a few things but I haven’t let this get me down and neither should you. We are bent, not broken!

Samantha Lomax
I wore a Milwaukee brace following the removal of my body plaster cast after surgery in 1980 to fit Harrington rods. I wore the plaster cast for 6 months. Mum used to put the dining room table in the bathroom and I lay down on it so they could wash my hair! To begin with I had to wear the brace for 23 hours a day, and then this time was gradually reduced until I didn’t have to wear it any more.

All the effort was so worth it as my curve was originally 72 degrees. I had halo/femoral traction and then the Harrington rods fitted, which have caused me no problems whatsoever. My curve in 1980 was down to 22°and here we are in 2014 and my curve is 23°.

Beverley Tapp
My son Lachlan was diagnosed at 18 months with infantile scoliosis, and from February, 2013, until he had MAGEC rods fitted in October, he had to wear a plaster-cast brace. The casts are effective but they are bulky, smelly, and so impersonal. Many fingernails have been broken when I have gone to tickle him and forgotten he had his cast on. Protecting other kids from being squashed or injured from colliding with him while playing together was also a concern.

The best days during the time he had to wear the cast was on a Sunday night when the old cast could come off, ready for the new one to go on the next day, and he could have a real bath and real cuddles. The 6 weeks between casts are the longest, when all you want to do is give your child the biggest hug and for them to actually feel it. On the plus side the casting worked and kept the spine where it was, with no increase in the curve, and he became a different superhero each time he had a new cast.
Bracing Special:

**Karen Simpson**

My daughter, Becky, has worn a brace for about 2 years, and just had her 9th birthday. She wears the brace on average for 23 hours of the day and it is only removed for her shower in the morning and to get her ready for bed at night. She does have to have additional physiotherapy to strengthen her core muscles because her consultant feels that they are now becoming lax, and her brace is removed for these sessions, but Becky was first diagnosed with scoliosis with a 39 degree curve. She was 10 years old when I was wrongly diagnosed and the brace was put on as quick as mine was. I felt 'floppy' as though I could move my spine easily. I once tried to bend over to pick up a feather, I was unable to do it. I had to wear the brace 23 hours a day, and although I quickly got used to it, it still completely took me by surprise. Becky was bullied or taunted about my condition, so I trained her to look for a job. I had previously worked in the travel industry so I just walked into it, and just think of the end result! Results are a lot better. If you can get in touch with SAUK when we first found out, to get more information. Becky and I are both SAUK - I couldn't tell them that I had Down syndrome because the council wouldn't accept it, and we also asked if we could speak to other girls and boys the same age as me to help me understand. We were put in touch with Mary Simons, a Regional Representative, and Martin helped us by organising regular emails and chats, and by introducing me to other families with scoliosis. Both Martin and SAUK have been a lot of help.

I asked if I could write this for Backbone so that if there are any other girls or boys out there worrying about wearing a brace, they can see that I have been through the same. I think I have been a good role model to my friends and also my friends have all been very supportive. It isn't nice but it's going to fix me.

**Thris Paling**

In 1977, at the age of 21 I underwent spinal fusion. I was in brace for 3 weeks. During those weeks I had to try to stretch my spine a little, and then I was placed in a plaster jacket. I had the operation to fit a plaster jacket, and then the worst part.... 15 weeks flat on my back! I once tried to bend over to pick up a feather, I was unable to do it. I had to wear the brace 23 hours a day, and although I quickly got used to it, it still completely took me by surprise. I once tried to bend over to pick up a feather, I was unable to do it. My sister bought me a ponytail which I wore when I went out. That was brilliant because it covered almost everything except the neck piece. I didn't buy many clothes, I was going to save the new wardrobe for when I was free from the brace! While I was in the brace I decided to look for a job. I had previously worked in the travel industry so I just walked into a travel agency in town, asked if they had any vacancies, and was asked to come back for an interview! I got the job, even though I wasn't qualified. I do think it is better the younger you are for this treatment because I don't think you would be as upset and not think you could be helping me and may prevent my scoliosis from getting worse, which is what I am focusing on and what gets me up in the morning.