Peer power

Becoming disabled is a truly life-changing experience – and one best faced with the help and support of others, writes Emma Bowler

It might surprise you to know that only 17 per cent of disabled people were born with their disability. That means a whopping 83 per cent of disabled people become disabled after they are born.

Alongside being a journalist, I've worked with disabled people for nearly 30 years now – in the charity sector, in the media, and as a counsellor.

What interests me is how some people seem to adapt more positively to becoming disabled than others.

For example, think of our previous *Lifestyle* cover star Martine Wright, who was injured in the 7/7 London bombings; or Frank Gardner, the BBC's security correspondent; or basketballer Ade Adepitan, campaigner Heather Mills and Paralympian Jonnie Peacock – to name just a few well-known examples.

These inspiring individuals have all found success as disabled people. But there are also millions of us 'ordinary' disabled people who are quietly, but positively, getting on with our lives – working, raising children, playing sport, going on holiday and so on.

I've also come across many others who find it hard to come to terms with living with a disability, or even never seem to, rather than just existing with it and making the best of things. So what makes the difference? What helps people make a positive transition instead of a negative one?

First thoughts

Every year, around 1,000 people's lives are changed through spinal cord injury (SCI) in the UK. Lady-Marie Dawson-Malcolm is one of them. She sustained an SCI through domestic violence in 1992 and her injury left her tetraplegic.

MOTIVATION
Knowing your family can help you, and that your family need you, too, can be a source of strength

Like many, Lady-Marie's initial thoughts were bleak: "I felt I was just going to be at home, not being able to do anything, not being able to work," she recalls. "I just thought I was going to be dependent on people all the time."

A former physical training instructor of the 31st Royal Signals Regiment, Lady-Marie found motivation through her daughter who was only six months old at the time of her injury. "I wanted to be there for her and felt I had to be positive for her," she says.

"I'm also a very spiritual person and I had great family support. These both helped me. At one point there was talk of me going into a nursing home and my mum said 'no way, she's not going there'. The fact that my family were there for me was really important."

Lady-Marie says coming to terms with a life-changing injury is a process, and developing resourcefulness has been vital: "You go along, and you develop strategies and new ways to do things. As my daughter grew, she started nursery, then school. I just had to find a way to deal with those things and learn to juggle carers for me and nannies for her."

> There are others out there going through the same thing

People become disabled in all kinds of ways every day. Every week, for example, 150 people in the UK become an amputee. Kevin Thrift became a below-knee amputee after developing a tumour in his ankle. In the week between diagnosis and the operation, Kevin spent time imagining what it would be like to lose a leg and reading about being an amputee:

"I went onto YouTube to watch an amputation to see how it was done," he says. "I wanted to know what they were doing. I think it helped me understand it better and move on."

Positive attitude

For Kevin, developing a positive mindset was also important. "I thought 'you only live once'," he says, "and I felt like I had in some ways been given a second chance. I realised that if I couldn't put the leg back on, I would need to get out of bed and start living life again."

Another thing Kevin has found invaluable is peer support – and in particular, talking to other amputees. He says that an amputee visited him while he was waiting for his operation: "He spent a lot of time next to the bed, giving me advice, telling me not to worry," Kevin says. "That was very helpful."

After his operation, Kevin continued to find peer support useful. "A lot of stuff I've picked up about being disabled is from people waiting in the Disablement Service Centre – the place where you go to get your leg made and fixed," he says. "You sit next to people in the waiting room, and of course you get talking.

"I asked one chap about a sore on my leg and he said just put antiseptic healing cream on it. Within a week it had gone down. He told me that if my leg gets sweaty, to use talc or antiperspirant, and to use plasters to cover any blisters. They don't always give you these tips when you go to hospital, and it's these little things that can go a long way."

ASK PEERS
Volunteer services can put you in touch with people who have had similar experiences

Kevin now works as the membership and volunteer visitor officer for the Limbless Association. The Limbless Association offers various support services, including a free helpline, an informative website, and a volunteer visitor service where amputees are paired up with someone roughly the same age and with similar interests, with the idea of offering long term support to the new amputee.

As well as a helpline, comprehensive website and telephone counselling, the Spinal Injuries Association provides a similar peer support service. Two years ago, determined to empower others to realise there is plenty to life post-injury, Lady-Marie became a peer support volunteer with the association.

It's a service not everyone takes up – indeed, Lady-Marie didn't either – but it is one that she now recognises as invaluable: "People avoid it because they think 'this is only temporary', 'things will get back to normal', or 'there might be a cure'," she says. "They have that mindset at first, but usually there comes a time when the penny drops.

"Peer support helps people to see that there are others out there who are going through the same thing, living in the community and managing their lives. It might seem like only a little thing but I'm very coordinated in my clothing, and I keep my handbag resting on my feet. It makes a difference. People say to me that when they think they can't do something, they think of me and realise that if Lady-Marie can do it, they can too!"

Long journey

Around 5,000 people each year are diagnosed with multiple sclerosis (MS) in the UK. John Stillitz was relieved to be diagnosed with MS in 2010 as it ended years of unexplained symptoms.

Like Lady-Marie and Kevin, he has found family support invaluable. He also found a pragmatic approach suited him. "I knew because of friends who had been diagnosed with MS that things weren't going to improve, but I didn't want to concentrate on that," he says. "I was very matter-of-fact about it, I thought 'let's just move on'."

John found that it has helped to sort out the practicalities and build an 'easy' way of life for himself. For example, when he was diagnosed he moved to a bungalow. He's also found that getting the right equipment is extremely important.

"I recently got a mobility scooter that I could easily put in the back of the car," he says. "It has changed everything for me in terms of not being reliant on others. I can now go out with my wife knowing that I won't be holding her back. It has been the greatest thing in the world. I took it with me on a cruise recently and it was just magical."

The MS Society provides information

and emotional support to people with MS via a free helpline, a comprehensive website, online forums, and over 300 local groups, which can offer coffee mornings, exercise groups or just a chance to meet other people.

John found peer support from his local MS group invaluable. "I got to a point where I needed to meet other people with my problems," he says. "To say it is great fun is not quite fair, but it's such a good thing to share ideas and knowledge – a little bit of knowledge that you might have might just be the key for someone else.

"It's made me aware that I'm not alone in facing certain challenges, and I just think it makes us all feel a little bit better that we can talk openly and honestly."

Abigail Stidston, Senior Helpline Support Officer at the MS Society, nicely sums up some of the things people with new diagnoses and disabilities might find helpful.

"It's important to find out what support is available," she says. "We also urge people to ask for help from family, friends and professionals, and accept their support, which can be quite hard if you were very independent before.

"Newly disabled people need to look after themselves. Simple things, such as eating regularly and exercising, if you're able to, can be part of it. Also, do things that make you happy instead of feeling like you can't do things anymore.

"People need to give themselves time and not put high expectations on themselves that they will adapt quickly. Being diagnosed can be like a grieving process, and the person might feel anger, sadness and enter a stage of denial about what has happened to them. Hopefully at the end of the grieving process comes acceptance."

ACCEPT HELP

If you're used to independence, asking for help might be hard. The advice? Do it anyway!

Adapting to life with a disability is no mean feat. However, time and time again I talk to people who have become disabled and I hear stories of resilience, resourceful and sheer determination to turn things around.

It seems that support from family and friends, access to accurate information and advice, and above all peer support, really are the things that help people discover that there really is life after disability. ■

For more information

MS Society:
mssociety.org.uk
Freephone: 0808 800 8000
helpline@mssociety.org.uk

Limbless Association:
limbless-association.org
Freephone: 0800 644 0185
enquiries@limbless-association.org

Spinal Injuries Association:
spinal.co.uk
Freephone: 0800 980 0501
adviceline@spinal.co.uk