

# Goal three

**Staying connected:** everyone affected by spinal cord injury can connect with someone in a similar situation to themselves, to overcome challenges and achieve the goals that matter to them.

## Setting the scene

Adjusting to spinal cord injury can be overwhelming both for the person with a spinal cord injury, and their family. People can often feel isolated and alone, thinking no one could possibly understand what they are going through. No one should have to face living with a spinal cord injury alone. At Back Up, most of our services team have a spinal cord injury or are a family member of an injured person. This includes all members of our outreach and support and mentoring teams. We understand, because we have been there ourselves and we use these experiences to ensure people reach their goals.

Over the past five years, inpatient rehabilitation times have decreased. This means that recently injured people spend less time learning from others in a similar situation. Many other people with spinal cord injury will never receive inpatient rehabilitation at a specialist Spinal Cord Injury Centre. Typically this can be people with co-morbidities, those with Cauda Equina Syndrome or people with lower level injuries who can walk.

Back Up has been providing mentoring since 2005 - we know first-hand that connecting with others in a similar situation can positively influence the adjustment process of living with a spinal cord injury, both for the individual and their family. It can make the difference between surviving or thriving and that is why we will be expanding our mentoring service and developing new offers to bring people together.



## What did people affected by spinal cord injury tell us?

“It was hard coming home and not knowing what was accessible in our area. We have had to find out through our own research and sometimes disappointment. When my husband was at **Stoke Mandeville he was surrounded by people with spinal cord injury**, but when he came home he was the only one.”

“**It has been so beneficial to be able to meet**, receive support from and chat to other people with a spinal cord injury.”

“Offer follow up sessions with your mentor at potentially difficult times in the future, e.g. on the anniversary of your injury.”

## What we will achieve by 2025

■ We will provide more in-depth one-on-one support to those who are really struggling, increasing our capacity to mentor three times more people with a spinal cord injury and their family members. We will also establish a parent support programme and parent mentoring. This will involve sharing experiences and parents being provided with practical support to help them come to terms with what has happened, and adjust positively to life post-injury.

■ We will offer a ‘family rehab service’ that supports family members of those with a spinal cord injury. This begins with the acute phase through information and advice online and in-person at relatives’ days, to post-discharge, from the hospital through peer mentoring and dedicated courses.

■ We will be integrated into the NHS’s spinal services rehabilitation pathway in order to increase access to the first-hand knowledge that comes from living with a spinal cord injury. We will work in partnership with the spinal centres’ multi-disciplinary teams for in-patient support and with the outreach and out-patient teams to support those with a spinal cord injury in hospital as well as in the community.