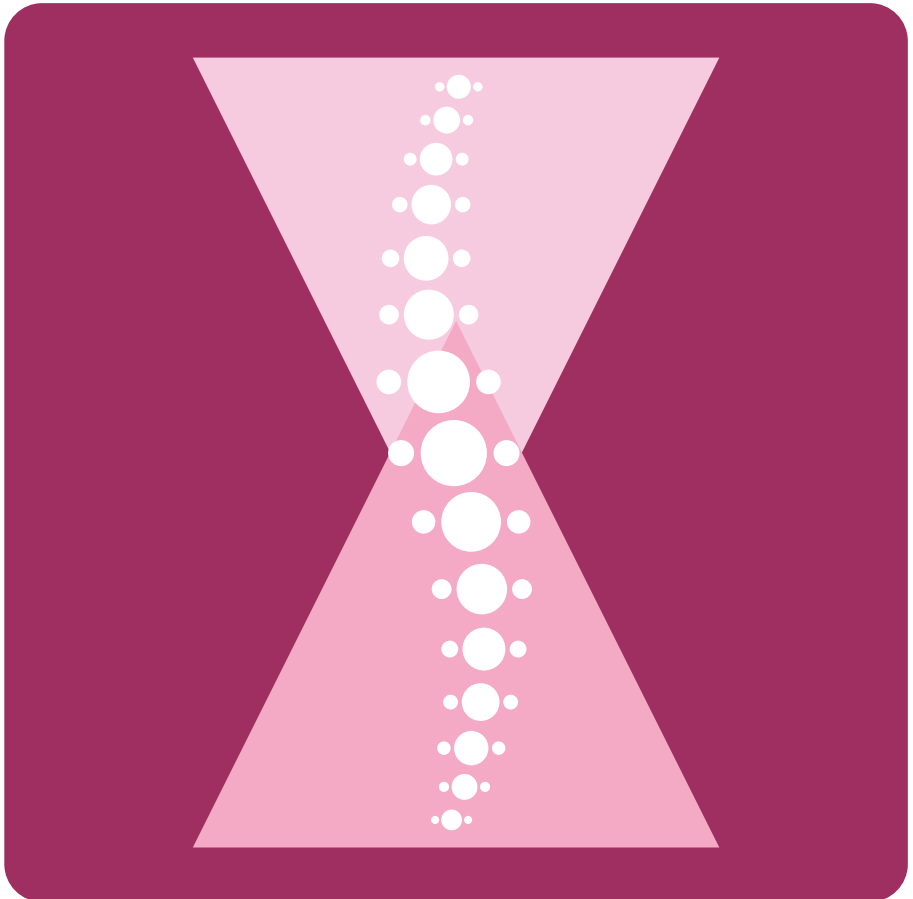


Psychological Wellbeing

After Spinal Cord Injury

Booklet 6



Psychological Wellbeing after Spinal Cord Injury

This is one of a series of booklets developed by the Spinal Cord System of Care (SCSC) Team at the NRH.

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Contents

Common Early Reactions to Spinal Cord Injury	3
Coping with Spinal Cord Injury	6
Making the Most of Rehabilitation	8
Identity	12
Sexual Identity	14
Resilience	16
Post Traumatic Growth	17
Hope	18
Managing Stress	19
Managing Pain	21
Pain Management Tips	23
Impact of SCI on Families	25
What Helps?	26
Financial and Other Supports	27
Supports After Discharge	30
Advocacy	31
Common Terms	32
Frequently Asked Questions	34

Common Early Reactions to Spinal Cord Injury (SCI)

“I just didn’t want to know anything about spinal cord injury for a while. I couldn’t take it in”
(Tommy, L1 Incomplete injury)

This booklet describes some of the psychological consequences of spinal cord injury (SCI). In the beginning, the main focus is usually on physical changes. It may take some time to fully consider the psychological effects.

Everyone experiences SCI or illness differently. There is no ‘right’ way to react and no ‘one-size-fits-all’ approach to dealing with SCI. However, there are common emotions and feelings which are part of a typical or ‘usual reaction’. Traumatic spinal cord injury is usually sudden and unexpected and it can take time to make sense of what has happened. Soon after injury it is common to feel shock, numbness, or disbelief. Non-traumatic spinal cord injury may be less sudden or unexpected but can also lead to shock and disbelief.



“I knew immediately there was some serious damage done”
(Sam, C6 Complete injury)

Mixed emotions are expected at the early stages as you think about what SCI might mean for your life. Feeling sad, angry, scared, lonely or out of control are typical reactions. Uncertainty can produce anxiety and confusion. Disappointment and regret are also common. You may also feel a sense of relief or feel lucky because you have survived a traumatic event.

After SCI, many people worry about what the future will be like. Others will focus on just taking one day at a time. It can be hard to imagine at this early stage how things can possibly work out well for you. It is common to feel that it will be impossible to cope or to achieve all your hopes and plans.

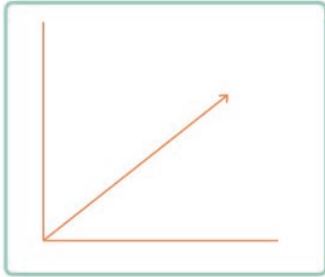
It can take a long time to understand and adjust to the many changes that can happen as a result of a spinal cord injury or illness.

No matter how emotionally strong you are, the trauma of SCI can shake your sense of yourself. It can bring up lots of questions about the meaning of life, the things you took for granted before it happened and the value of friends or family. It also asks you to find coping skills you may never have needed before.

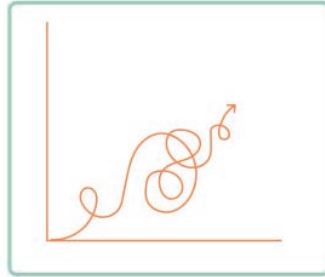


Everyone who experiences SCI will have met other challenges in their lives. Even if those challenges were small in comparison, the same skills can be used to cope with life after SCI. At the NRH, your treating team can help you to identify personal strengths to support you during rehabilitation and into your future.

Life



What I Planned



What Actually Happened



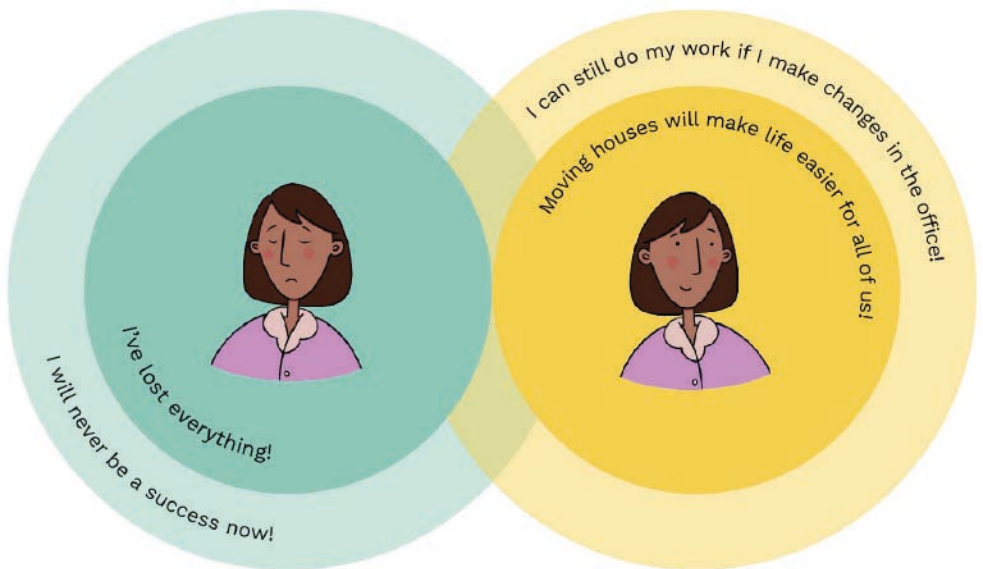
Coping with Spinal Cord Injury

"I've tried to do everything in my life well. I'm going to do disability well"

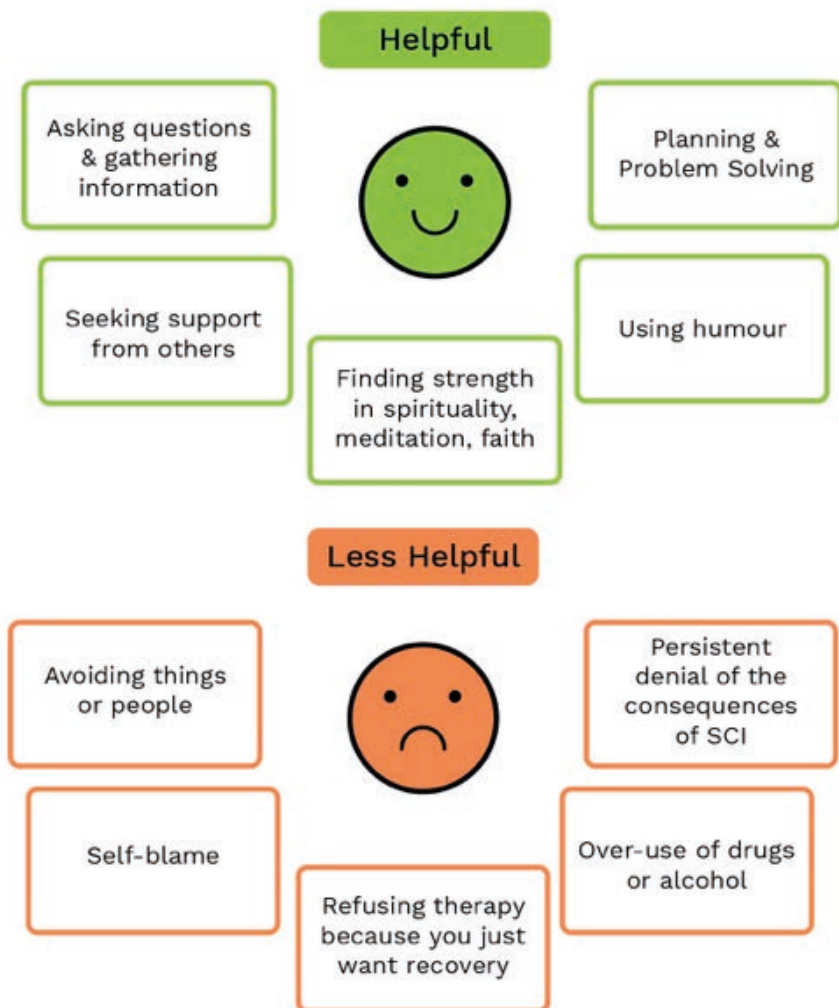
(Maura, C5 Complete injury)

SCI changes the way that your body works. Depending on your level of injury, these changes can affect your independence, your confidence and your lifestyle. It can feel like a huge loss of the life that you had planned.

It is important to let yourself feel those losses. Sharing your thoughts and feelings, in a way that suits you, can help you to process what has happened and to plan for the future. Talking to family and friends can help you to make sense of what has happened. Everybody has their own way of coping during difficult times.



How you understand, think about and make sense of an event will affect how you manage it. This means that if you see something mainly as a disaster, loss or a threat you can easily be overwhelmed or depressed by it. However, if you can come to see it mainly as a challenge, it brings out your 'fighting spirit' and problem solving abilities.



Making the Most of Rehabilitation

“Don’t belittle your own progress”
(Terry, T5 Incomplete SCI)

Rehabilitation:

- provides you with information and skills to help you to become as independent as safely possible.
- is based on a series of goals that are focused on your physical functioning, daily activities and wellbeing.
- means working with a team of healthcare staff to support you to understand and manage your SCI.
- also means taking time to reflect and think about the personal meaning of SCI for you and your life.

Learning new ways to do things can be rewarding, frustrating, surprisingly enjoyable and slow. Be patient with yourself. This is your rehabilitation programme. Do what you can to make it work for you.

Now, possibly more than any other time in your life, you may need to talk about how you are feeling and help to put plans for your future into place. Support can come from family, friends, and peers. Often it is helpful to speak to a person outside your circle of family and friends during your rehabilitation and after discharge.

Your treating team at the NRH will include a psychologist and a social worker who can offer professional support at this difficult time. You can also meet with a psychiatrist by appointment. Attending counselling or psychotherapy during your rehabilitation gives you an opportunity to confidentially explore your feelings about what has happened to you or your family.

While your rehabilitation team may not have personal experience of SCI, they will have had training and experience of working with people coming to terms with life changing injuries.

When asked about their rehabilitation experience, people said they found the following things helpful:

Focus on your values and priorities

Try everything in rehab even if you think it's not for you

Learn from others in a similar situation

Learn all you can about SCI and its effects

Be glad of every small gain, no matter how tiny it seems

Let yourself feel the whole range of emotions

Enjoy small pleasures like talking to peers, forming new friendships, trying new things...



Sometimes previous losses, mental health issues or life events can become important again following SCI and can affect how you react. Counselling gives you a chance to review many aspects of your life including SCI. You do not have to feel alone. Talking to other people who have experienced SCI is a really valuable way of learning from 'lived experience' and benefitting from peer support.



The early months following SCI can be a difficult time. However, it is possible to deal with SCI and to continue, or get back to, enjoying life again. In time, you may discover strengths that you did not know you had and develop confidence as you learn new skills and interests.



“Denial helps us to pace our feelings of grief. There is a grace in denial. It is nature’s way of letting in only as much as we can handle”

(Elisabeth Kübler-Ross)

Adjustment is talked about a lot in rehabilitation. It is a word that can easily be misunderstood. It does not mean giving up hope for improvement or just accepting what has happened. It means:

- taking the time to adapt and get used to a changed situation.
- recognising that this is how things are right now and finding ways to move forward in ways that are important to you.

Wishing the illness or injury had never happened is normal. Hoping for a cure is normal. However, concentrating mostly on the past or on how you want things to be different can lead to depression and block the process of adjustment. Learning to think of your injury as a challenge which brings with it a set of problems to be solved is hard, but helpful.

Denial of the consequences of injury is not at all unusual in the early days. Denial can allow reality to seep in slowly.



Identity

Identity means how 'I see myself'. It is related to self-image and self-esteem and a sense of yourself as continuous throughout your life. SCI can cause a disruption or break, temporarily or permanently, in that sense of self and continuity.

Many people say that in the months after injury they experience a loss of:

- identity or purpose.
- important roles in relationships, families and workplaces (such as main earner, active sports person or reliable carer). It can be really hard to imagine being that person again.
- motivation and interest in things around you.



People also may feel confused about the identity changes or think that they are a burden to others. These feelings are natural. However, it is also very common for them to fade over time as new goals and a sense of purpose take their place.

While your life may change in all sorts of ways as a result of SCI, there is much that remains the same. This sense of 'continuity as well as change' is something that becomes more obvious with time. In the early weeks and months, the sense that 'everything is different' can be very strong and even overwhelming.

However, the sense of being 'still me' becomes stronger as relationships, activities and events become important again. You are not just the things you do but what you think, value and feel.

Roles and interests can change and be re-directed with time. Doing the things that matter to you is important, even though you may be doing it in a different way. For example, while you may not be able to provide physical support to others, you can still offer emotional support, listening, connection and kindness.



It can be useful to take time to think about your personal values. These are the things that provide you with a sense of meaning and purpose. A quick way of doing this is to imagine attending your own 90th birthday party. Think about what you would like your friends, family members or work colleagues to say about you and the way you lived your life after your spinal cord injury.

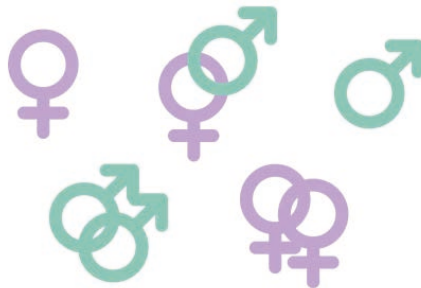
Once you know the kind of person you most want to be, you can start to think about small ways to achieve that every day. Outlining your values and setting new goals can help to increase focus and motivation.



Sexual Identity

Sexuality is a central part of who we are, what we believe, what we feel and how we respond to others. It includes all the feelings, attitudes and behaviours that make up our sense of being a sexual human being.

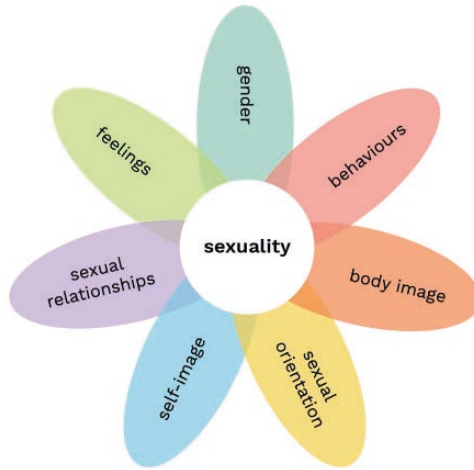
Sexual wellbeing is your level of satisfaction with sexual functioning and the importance of sexuality in your life. It includes satisfaction with both the emotional and physical aspects of your relationships.



The NRH Sexual Wellbeing Service

The NRH sexual wellbeing service provides support for patients of NRH and their partners who have experienced disability or disabling illness in their lives. This traumatic experience can sometimes change relationships, body image and self-esteem. It can also cause difficulty with sexual function, and, particularly for men with SCI, problems with fertility.

As part of a holistic rehabilitation programme, the NRH sexual wellbeing service provides an opportunity for you to discuss sexual health and wellbeing. The service is also available to partners. Some people may prefer to wait until after discharge and come back as an outpatient to attend the service.



The sexual wellbeing service provides information and counselling in a private and confidential setting, and in a non-judgemental way for the following:

- the direct and indirect impact of illness or disability on your sexuality
- information on aids and appliances to improve sexual function
- information and arrangement of appointments for fertility programmes
- individual and couple counselling
- psychosexual therapy if required
- advice and information on contraception and safe sexual practices

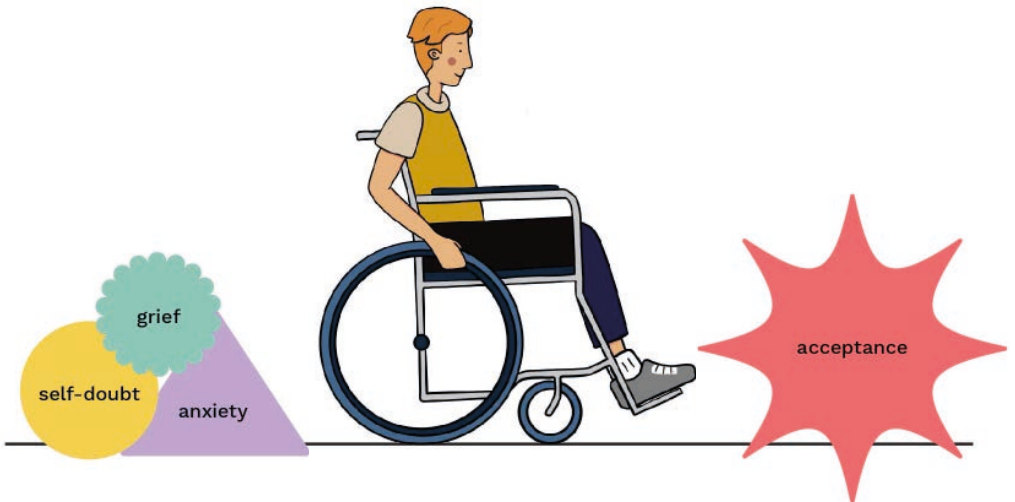
You will be informed about the service by your treating team and offered the opportunity to be referred. It is also possible for you to refer yourself to the service. Any family member or friend can also request an appointment. Contact details can be found on the NRH website or in NRH patient information leaflets describing the sexual wellbeing service.

Resilience

“You may not control all the events that happen to you, but you can decide not to be reduced by them”

(Maya Angelou)

Resilience is the ‘ability to bounce back’ from difficult events. Across the world, in response to all sorts of disasters and dilemmas, the human capacity for resilience is seen in the vast majority of people. One psychotherapist with a tetraplegic injury describes it as an ‘air bag effect’ where something, previously invisible, comes to your aid at a time of disaster. Something that was unthinkable becomes manageable because of resilience and the life force that can be seen in response to injury or serious illness.



Post-traumatic Growth

Many people describe a surprising result of SCI: post-traumatic growth. Post-traumatic growth is the positive psychological change that can happen as a result of injury. It might include:

- coming to appreciate family and friends, or life itself, in a different way
- finding a new interest or activity
- meeting a group of people that become friends and peers

In general, post-traumatic growth means that, after dealing with the trauma of injury, people become aware of new strengths and abilities within themselves.



Hope

It is said that *'hope springs eternal'*. We all need hope to bring us forward in life. We can hope for short and long term goals and we can hope for things we don't really expect to happen. We may buy a lotto ticket without actually believing that we will win the lotto, but still we hope.

After SCI illness or injury, the ordinary hope in our life becomes disrupted, and a different hope slowly takes its place. At first, the hope may be for survival. This may be followed by a longing or hope that life will return to what it was before your illness or injury. Family and friends may support you in holding on to that hope. It may be part of your day to day coping to hope that you will get back to your life before SCI.

The hope for recovery can exist side by side with other more immediate goals, like getting through your rehabilitation, getting home for a weekend, getting back to work, and spending time with your family.

Over time, the hope and longing to get back to your life before your injury or illness may be replaced by hope for a good life, despite injury or illness. Many of the hopes you had before SCI may remain strong, even if altered or re-directed to new things.



Managing Stress

“I just think about how far I have come”
(Emma, C6 Complete)

There are many ways to manage the stresses that come with SCI. While you may not be able to get rid of stress, you can find ways to reduce it. Different things work for different people. Some practical suggestions include:

- Find ways to relax your body. This can include breathing exercises, muscle relaxation exercises, mindfulness, and massage.
- **Pacing** is important. Learn to plan your time and activities to take account of your energy levels and abilities. Prioritise the things that matter most to you.
- Explore the ways you cope with stress. Find what does, and does not, work for you. Be open to thinking about other things that might help.
- Take exercise. Regular exercise is one of the best ways to manage stress. Spinal injury alters the way you take exercise but it's very important to find exercise that is suitable for you.
- Take good care of yourself. Get plenty of rest. Eat well.
- Look out for **negative automatic thoughts** and try out new ways of thinking. Work on letting go of things you cannot change. Learn to say “no.”
- Express your feelings. Not being able to talk about your needs and concerns can create stress and make negative feelings worse. Talk, laugh, cry, and express anger when you need to, with someone you trust.

- Write it down. It can help to write about the things that are bothering you.
- Ask for help. People who link in with their network of friends and family manage stress better. Consider seeing a counsellor or therapist if negative feelings or thoughts continue to bother you.
- Try to find humour in situations. Laughter reduces stress hormones.
- If you are having a bad day, think about how much progress you have made since you first became ill rather than focussing on how you used to be before SCI.



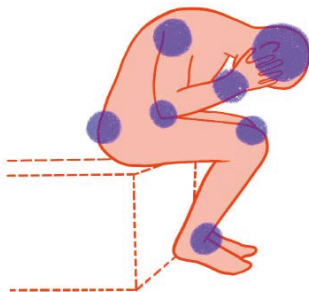
Managing Pain

“Paralysis does not stop you living your life...but pain can”
(Liz, T12 complete)

Pain can be one of the most difficult consequences of SCI for many people. Different types of pain can develop after SCI including **musculoskeletal** and **neuropathic** pain. People with SCI can also get **visceral** pain (depending on your level of injury, visceral pain can affect your internal organs, like pain from your lung or from a kidney stone).

The difference between **acute** and **chronic** pain is the most important thing to understand. Acute pain flares up and fades away with or without treatment and in a relatively short period of time. Chronic pain continues after the expected time for recovery and is always present to some extent.

While treatment and pain relief are still important, chronic pain needs to be managed on a daily basis. Learning to live with pain is a very difficult thing to do. It takes time to change your thinking about pain in order to help you to manage it well. It is natural to think that there must be medication that can reduce pain but sometimes medication can only help dull the pain or doesn't help at all.



Increasing medication, without taking other actions, can sometime lead to a cycle of dependency and distress. It is very hard to believe that there may be no cure for chronic pain. It is understandable that feelings of isolation, depression and anxiety are common in people with chronic pain.

Neuropathic pain comes from damage to the nervous system (in this case your spinal cord). It cannot be seen on a scan or linked to a specific part of your body. Chronic neuropathic pain is very real. Just because the source of the pain cannot be easily seen does not mean that it is not real.

Some people describe neuropathic pain as a burning sensation - **"I feel like my legs are on fire"**.

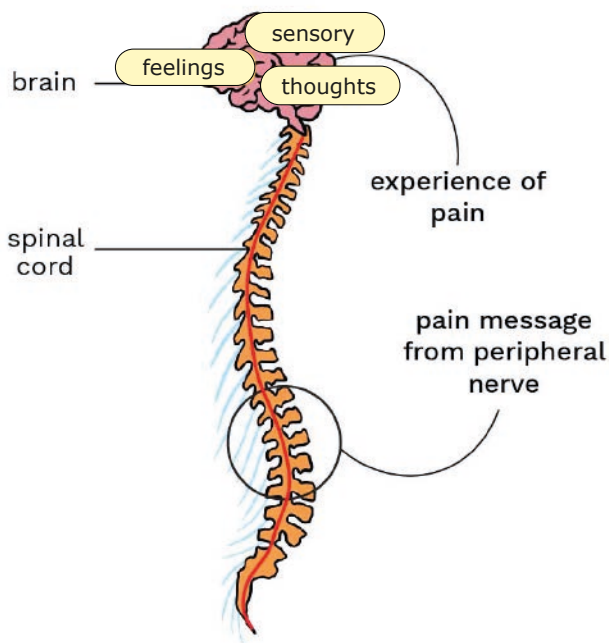
Others describe extreme cold or freezing sensations - **"My leg feels like it is in a bucket of ice"**.



Often there is no one way to lessen pain. Living well with chronic pain means doing lots of different things to make pain manageable. The aim is to reduce the effect of pain on your life. Because your brain can change and adapt over time, it is possible to learn to train your brain and reduce the experience of pain. You can learn to block some of the pain messages that go to your brain.

The real challenge is to live your life despite the pain rather than stop living life because of the pain. **Self-management** is what people do on a day-to-day basis to feel better and to live the life they want.

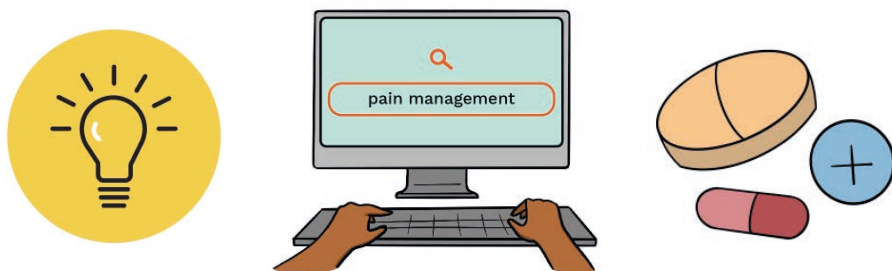
Over time the main question changes from **“Why do I have this pain?”** or **“How can it be cured?”** to **“What can I do to manage this pain so I can get on with my life?”**



Pain Management Tips

- Speak to health professionals during your rehabilitation about strategies to help you manage your pain.
- Learn self-calming, breathing, relaxation or mindfulness strategies. When your brain is more relaxed, your body hurts less. Make a habit of using these techniques on a daily basis.
- Build up a collection of active distraction techniques. Creative activity, pets, reading, watching TV, socialising, gentle exercise and massage can all help to lessen the effect of pain.
- Add physical activity to your day but be careful not to overdo it. See booklet 5 for a description of the link between physical pain and activity. Remember that 'hurt is not harm'. Your body needs to keep engaging in activities in order to create feelings of wellbeing.
- If searching for Apps or information on the internet, ensure to access those with good quality pain management information, such as Chronic Pain Ireland or Pain Management Network, Australia.
- Identify unhelpful ways of thinking that can make pain take a central place in your life. It is possible to challenge **negative automatic thoughts**. Be patient with yourself as it takes time to change the way you think about pain.
- One of the most harmful negative automatic thoughts is described as **catastrophizing**. This includes thoughts like 'I cannot live like this; I cannot work again; I cannot have a relationship; I cannot be happy unless this pain goes away'. It can lead to anxiety, isolation and increased pain.

- **Pacing** is one of the most important strategies to help you manage pain. It means not getting stuck in a cycle of bursts of activity followed by feelings of being exhausted. It means planning activities and rest periods so that your pain does not flare up.
- Set small realistic goals and give yourself credit for achieving them no matter how small they seem.
- Consider using a pain diary to track your daily pain, medication use and activities for a week. You may notice patterns that could help you to find triggers and to develop strategies to reduce the distress caused by pain
- Pay attention to your sleep, diet and alcohol intake as they can all affect your mood and your experience of pain. Keeping a food, alcohol, and sleep diary can help to identify common triggers or patterns.
- Ask for help and find ways to communicate about your pain especially to people close to you. It is tempting to avoid social situations because of pain but social situations can help distract you from pain.
- Learn how to deal with **flare-ups**. Use medication to help with flare ups. Talk to your pharmacist about your pain medications.
- Seek counselling or therapy if pain causes excessive stress, mood or relationship difficulties.



Impact of SCI on Families

When a family member has a spinal cord injury, the whole family is affected. Families cope in many different ways and respond very differently to SCI. Family members have many of the same feelings and concerns as the person who is injured. Shock, anger, hope, sadness and anxiety are all common feelings. There are no right or wrong feelings.

At first, it may be difficult for family members to show their feelings as they may not want to upset or worry you. However, with time it may get easier to talk about concerns and future plans. Being open with your own feelings and thoughts will help to encourage family members to talk honestly about their reactions.



Relationships with family and friends can change and sometimes this can be hurtful or surprising. People cope differently with new experiences and challenges, and most take a while to find ways of coping that suit them best.

Family adjustment is both individual and shared. SCI brings with it new challenges, new stresses and new roles for family too, for example, advocate, caregiver, liaising with services. Everyone will have different strengths.

During rehabilitation, some family members may be good at visiting or attending meetings, others at making grant applications or filling out forms and others at gathering essential information or keeping family and friends informed.



What Helps?

Keeping family life as normal as possible

Giving yourself and your family time to adjust

Avoiding any unnecessary new commitments.
Keeping things as simple as possible

Trying to be as open as you can about your feelings and reactions

Availing of the support offered by social work, psychology, SII and others

If you don't have family close by, dealing with the trauma of SCI can be even more difficult. It can be helpful to look for support from your network of friends and peers if this is the case. During rehabilitation, support is available from members of your treating team, including a social worker and a psychologist. They can also discuss ways of coping with family members and how best to use resources after discharge.



Financial and Other Supports

What financial support is available from government when your income is disrupted?

There is no specific SCI payment. This means that all payments have to be applied for under the available Social Welfare Payment structures.

There are two types of Social Welfare Payments:

- **Social Insurance (PRSI) Payments**
- **Social Assistance payments.**

1. Social Insurance (PRSI) Payments (Benefits):

To qualify for this payment, you or your employer must have paid PRSI for you for at least two years before the tax year in which you are applying for the benefit. A certain number of contributions (stamps) are required.

Payments based on your PRSI contributions include: illness benefit, carer's benefit, invalidity pension, jobseeker's benefit, state pension (contributory) and occupational injuries benefit. If you had your injury at work, or while travelling to work, you may also be entitled to an additional disablement benefit. This payment is medically assessed.

2. Social Assistance Payments (Allowances):

Social assistance payments apply to those who do not qualify for social insurance payments because they do not have enough PRSI contributions. Social assistance payments are means tested and therefore, the total income of your household will be assessed and payment will reflect that level of income. Social assistance payments include: jobseeker's allowance, supplementary welfare allowance, disability allowance, carer's allowance, state pension (non-contributory).

Types of Payments:

Benefits (PRSI Contributions)	Allowances (means tested payments)
Illness Benefit	Jobseeker's Allowance
Jobseeker's Benefit	Carers Allowance
Invalidity Pension	Supplementary Welfare Allowance
Occupational Injury Benefit	State Pension (non-contributory)
Disablement Benefit (medical assessment)	Disability Allowance
State Pension (contributory)	One-Parent Family Payment

It is important to note that if you qualify for social assistance payment, you may also be eligible for additional social welfare payments. Contact your local Department of Social Protection office or citizens information for up-to-date information about each of the payments.

During rehabilitation, your social worker will advise you, or direct you to other supports for financial matters.



How do I apply for Social Welfare Payment?

To apply for social welfare payment, contact your local Department of Social Protection (DSP) office, Intreo centre, or citizens information bureau for the most relevant and up-to-date information.

Medical Cards (General Medical Services)

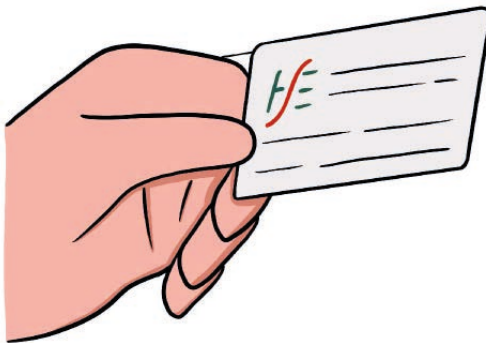
Medical Card applications are means tested. While they are based on your income, some outgoings are also taken into account.

Where there is equipment (such as a wheelchair) or high care needs, an Emergency Medical Card (EMC) can be issued for six months without any assessment of finances.

An Emergency Medical Card is issued based solely on medical grounds and cannot be extended after the six-month period.

Following this six-month period, you can apply for a full medical card. However, the approval of this application is at the discretion of the HSE. Your Social Worker can support you and your family to complete applications for medical cards.

Note: The criteria used to see if you are eligible for benefits and payments change from time to time. It is important to get up-to-date information.



Supports After Discharge

Leaving the NRH brings new challenges. The first few months after discharge are best seen as a time of transition. It will take time to adjust to the changes in your world that have been caused by SCI. Be patient with yourself during this time.

The NRH Spinal Cord Injury Liaison Nursing service is available to provide support after discharge from the NRH. You will be provided with information about this service before discharge. Your GP and the Primary Care Service in your area can support you with your health care in the community. If you require specific mental health supports in the community, referrals can be made by your treating team before discharge.



Spinal Injuries Ireland (SII) provides a range of services and supports, including counselling, grants, information and family support.

www.spinalinjuries.ie | (01) 653 2180



The Irish Wheelchair Association (IWA) provides a wide range of services, including sporting activities, to people with disabilities.

www.iwa.ie

Advocacy

Your team in the NRH will work with you and your family during your admission to address any concerns you may have. Your team will also outline possible advocacy supports available to you after your discharge. These can include patient advocacy supports that will help you to look for supports or services specific to your care needs, peer mentoring supports, and age-related supports among others.



Common Terms

Adjustment: The process of adapting or becoming used to a new situation.

Advocacy: the act or process of supporting a cause or proposal. Advocating for someone means speaking out for them, and with them, to influence decisions.

Catastrophising: to see things as much worse than they actually are. Traumatic experiences can often lead to an increase in catastrophising.

Coping: to invest conscious effort to solve personal and interpersonal problems in order to try to master, minimize or tolerate stress and conflict.

Flare-ups: a period of intense pain which is more severe than your day to day chronic pain.

Musculoskeletal pain: pain that affects the muscles, joints and bones.

Negative automatic thoughts: negative self talk that happens almost without being aware of it. Examples might include
'I am helpless and have no control...',
'bad things always happen to me...',
'I'm not good enough...'
'this is never going to get better...'

Neuropathic pain: pain caused by damage to your nervous system.

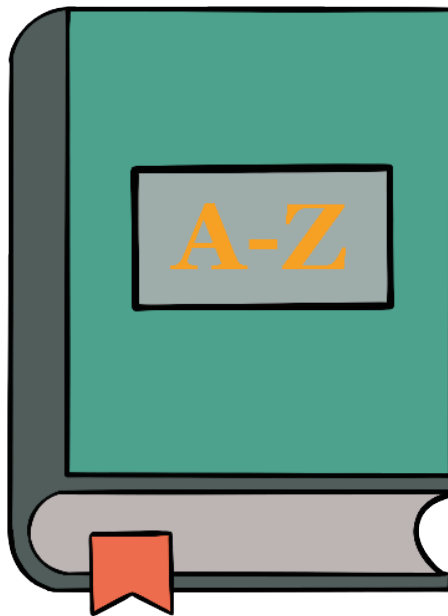
Pacing: deliberately balancing your energy and activity levels so that you avoid the vicious cycle of bursts of activity followed by fatigue or exhaustion.

Post-traumatic growth: positive psychological change that happens as a result of struggling with stressful and challenging life circumstances

Resilience: the common human ability to recover or 'bounce back' from difficulty

Traumatic SCI: a sudden injury to your spine caused by, for example, a fall, motor accident or other trauma

Non-traumatic SCI: SCI caused by medical conditions including tumours, stroke or developmental conditions



Frequently Asked Questions

Does everyone meet a psychologist and a social worker during rehabilitation?

Yes. There is a social worker and psychologist on every treating team in the NRH. Referral to a visiting psychiatrist is also possible during admission.

Are there other psychosocial supports available to me during my rehabilitation?

The Spinal Programme at the NRH includes peer support provided by people who themselves have had a spinal cord injury and completed rehabilitation at the NRH. SII is involved in delivering peer support with the NRH. The lived experience offered by peer support staff is invaluable during and after rehabilitation.

Does everyone become depressed after SCI?

No. While it is common to experience depressed thoughts or periods of intense sadness or depression after SCI, clinical depression is not typical. Most people have a resilient response, even if it takes some time to develop.

I had mental health symptoms before SCI. Will they get worse?

Sometimes SCI can lead to an increase in mental health issues. However, this is not inevitable and some people find that their adjustment to SCI can help them to also manage mental health symptoms better.

Can my partner look for support for himself or herself during my rehabilitation?

Yes. Social Workers at NRH are trained to provide family support. Family members are invited to attend a family

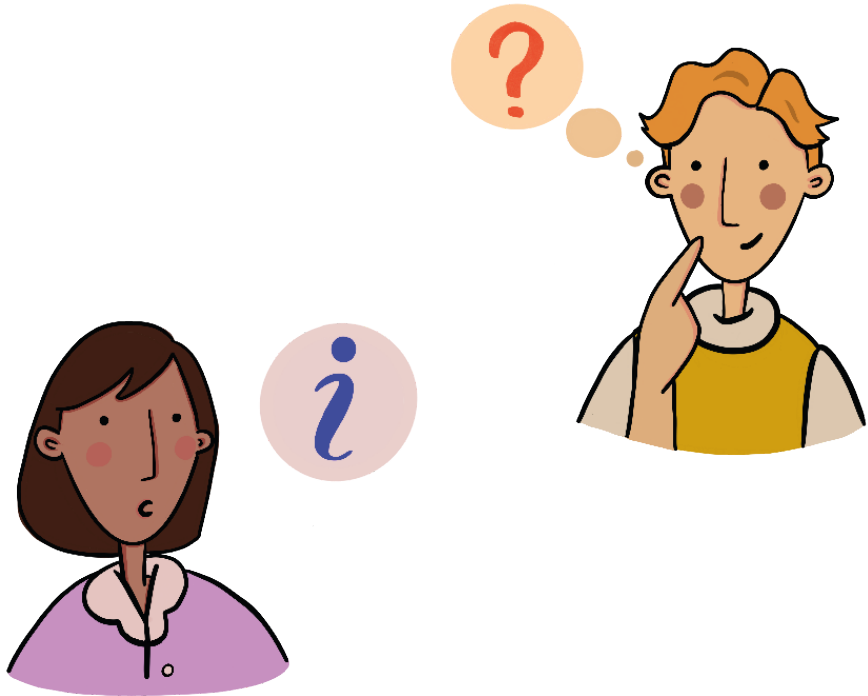
conference during rehabilitation. Family members can also request to speak to any member of the treating team and to attend therapy sessions once agreed with individual therapists.

Can I become a parent after SCI?

Yes. Questions about fertility, sexual relationships and pregnancy can be discussed during and after rehabilitation with your Consultant, the Sexual Wellbeing Service, and the Liaison Nursing Service.

Can I be a good parent with SCI?

All the worldwide evidence confirms that you can become, or continue to be, a good parent no matter what type of SCI you have. It is common to lose confidence temporarily while you develop new ways of doing things and being with family members.



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**National Rehabilitation
University Hospital**

An tOspidéal Náisiúnta Athshlánúcháin



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