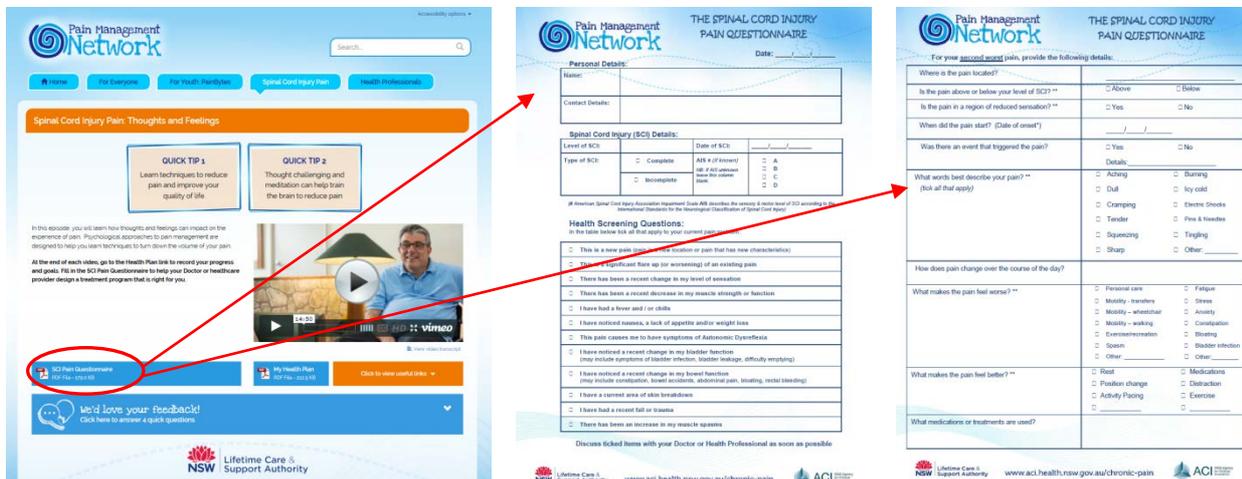


Living with a spinal cord injury means that you will probably have a different relationship with your healthcare providers than you would if you were just going to your GP with a short term illness for example. Your role in managing your health and well-being will be more pro-active where you will be very much involved in making decisions about things that affect your health and your lifestyle. Sometimes you may find that you need to provide education to your healthcare team regarding health issues that can arise after SCI. These issues could include autonomic dysreflexia, bladder routines, bowel care, pressure injury prevention or chronic pain.

It is important that you know where to direct members of your healthcare team to get more information regarding SCI if/when they need it. Websites that provide comprehensive evidence-based resources for health professionals working with people with SCI that you can confidently recommend to your health care team include:

- 🔗 Spinal Cord Injury Rehabilitation Evidence (www.scireproject.com)
- 🔗 Paralyzed Veterans of America (www.pva.org)
- 🔗 International Spinal Cord Society E-learning (www.iscos.org.uk ; www.elearnsoci.org/)
- 🔗 NSW Agency for Clinical Innovation (www.aci.health.nsw.gov.au/networks/spinal-cord-injury)

It is important that you learn ways to work with the different members of your healthcare team to get the best results. When it comes to communicating with your team about pain, there is certain information that is essential for your health professional to know. This information helps them to identify the type of pain you have and this will help you to get the best results from your treatment plan. Download the **SCI Pain Questionnaire** from the website, fill it in and take this with you to appointments with your doctor, case manager or health care provider to help start the conversation about your pain.



The image shows three screenshots related to the SCI Pain Questionnaire. The first is a screenshot of the Pain Management Network website with a red circle around the 'SCI Pain Questionnaire' link. The second is a screenshot of the questionnaire form, showing sections for Personal Details, Spinal Cord Injury (SCI) Details, and Health Screening Questions. The third is a screenshot of the questionnaire form, showing sections for Pain Characteristics and Pain Management.

Important things to communicate to your doctor include:

- Where is your pain? Is the pain located above or below the level of your spinal cord injury?
- Has the pain changed recently or have you noticed any other changes eg: have you felt unwell or noticed changes in your strength or sensation?
- What things make your pain worse?
- What pain management strategies have you tried? What strategies were most helpful?
- What would you like to be doing more of if your pain were better managed? What are your goals?
- What was happening in your life when your pain first started?

Members of your pain management team may include:

General practitioner (GP) - Your GP or local doctor is usually your main healthcare provider. He or she is often the first point of contact for someone with persistent or chronic pain.

Medical specialists – you are likely to have a range of medical specialists on your team – these may include:

- **Spinal specialist/rehabilitation physician** – Specialises in rehabilitation after spinal cord injury. Your spinal specialist will be involved after your initial injury as well as following up with you after discharge from hospital, perhaps as an outpatient or with a visiting outreach service.
- **Neurologist** - Specialises in the functioning and diseases of the nervous system, including the brain, spinal cord, and the peripheral nervous system.
- **Neurosurgeon** - Specialises in, amongst other things, nerves that branch out from the spine. If needed, this kind of doctor will perform surgery on the spine or spinal cord.
- **Orthopaedic surgeon** - Specialises in diagnosis & surgical treatment of bone, muscle & joint problems. Your orthopaedic doctor may need to work with your rehabilitation specialist or allied health team to help you plan for any surgery that is required.
- **Pain specialist** - Specialises in the diagnosis, treatment and management of pain.
- **Rheumatologist** - Specialises in processes that involve joints and soft tissues, including multi-system auto-immune diseases, as well as chronic pain (e.g. fibromyalgia and chronic fatigue syndrome).
- **General physician** - Specialises in caring for patients with complex illnesses in which the diagnosis may be difficult. They provide expertise in the diagnosis and treatment of problems affecting different body systems; as well as the social and psychological impact of disease.

Allied health professionals

- **Occupational therapist** - Can help you adapt your environment and show you ways to make activities such as housework and personal care easier, and provide advice on useful aids or equipment. An Occupational Therapist may be involved in advising how to set up your work environment to reduce strain on your body and may also assist with wheelchair set up and mobility skills training.
- **Physiotherapist** - Can provide advice on exercise, posture and ways to relieve pain as well as use treatments to maintain joint and muscle movement. May also be involved in wheelchair set up and mobility skills training & accessible sporting and recreation activities.
- **Clinical psychologist/psychologist** - Can teach you different ways of thinking about and coping with pain and can train you to use pain management skills more effectively in your daily routine. Can provide treatment for depression or anxiety that is also common when people live with chronic pain.
- **Social worker** - Can provide practical advice, support and help with different aspects of your life that may be affected by your pain, such as work, relationships, family life, income and housing.

Complementary and Alternative Medicine (CAM) - CAM refers to forms of health care that are used in addition (complementary) or instead of (alternative) traditional medical treatment. CAM therapies are used by some people with chronic pain and it is important to understand that like any type of treatment, there can be benefits and side effects. Just because a treatment is advertised as *natural*, *alternative* or *holistic* doesn't mean that there are no risks involved. The skill of the CAM practitioner is very important. The practitioner is responsible for informing you of any risks, but it is also very important that you know your body and have the

confidence to communicate your needs to them clearly and assertively. Remember to keep in mind any risks of medications interacting with supplements or natural remedies and take extra care of your skin if your sensation is reduced – this could mean making sure that treatment surfaces provide enough pressure relief or making sure that you don't risk getting burned from heat therapies below the level of your spinal cord injury.

Refer to the Australian Health Practitioner Regulation Agency (AHPRA) or the professional body regulating practice for advice on levels of experience, qualifications, and training required by practitioners. CAM can include, but is not limited to, the following: medical acupuncture, chiropractic medicine, homeopathy, hypnosis, massage therapy, naturopathic medicine, osteopathy, reflexology and reiki.

WARNING! Always tell your doctor if you are taking any vitamins, supplements, and naturopathy or homeopathy products – these are medicines too and may interact with your prescription medication. You also need to be particularly careful with certain therapeutic techniques. For example, **heat therapies are not recommended for use below the level of your spinal cord injury if your temperature sensation is reduced.** Treatments that could cause **burns** include heat beds, heat packs, ice packs and techniques such as moxibustion or cupping in acupuncture. Do not use heat therapies below your level of SCI.

Always communicate to your healthcare workers your SCI related health needs so that they can adapt or modify their techniques to give you the best possible treatment. **Don't be afraid to speak up during a session if you have any questions or concerns.**

You have been provided with some information about the different kinds of healthcare providers that people with chronic pain might see. Who you see will vary depending on the type of pain you have and who you find the most helpful. Remember the qualities that you would like your healthcare team to have and the importance of partnership and communication to improve your health and function. By doing your research and being prepared when you interact with your healthcare providers, you are taking an active role in your health and pain management. Do not wait for your partner, family, or healthcare providers to fix or remove your pain. Instead, be actively involved - improvements in pain and functioning happen most successfully when the person with pain is an active team member. Work together with your partner, family, and healthcare providers to find and use the most appropriate strategies and management techniques for your pain. Listen to the advice you are given and the different strategies that you are taught. Try them out, practice them and work out which strategies are most helpful for you.

Tips to get the most out of your consultation

- When booking an appointment with your GP request a long consultation
- Be aware that you will be likely to need more than one appointment to develop a pain management plan
- Be clear about what you want to achieve regarding pain management eg: do you want to be able to sit for longer periods, do more exercise or do you want to reduce your pain by 50%
- Prioritise your goals –decide on your top three goals to focus on first
- Fill out the **SCI Pain Questionnaire** and take it to your appointment with your doctor or health care worker
- Take a list of questions or current concerns
- Take notes to help remember things later or take someone with you to the appointment

General Practitioner	
Spinal Specialist	
Pain Specialist	
Case Manager	
Physiotherapist	
Occupational Therapist	
Clinical Psychologist / Psychologist	
Other	
Other	
Other	
Other	