

Communicating and building your healthcare team

Key messages

- Be pro-active in making decisions about the management of your pain
- Know your rights and responsibilities
- Become an educated member of your healthcare team

Introductory notes

Living with a chronic condition means that you will have a different role with your healthcare providers than you would have if you had a short-term illness. Your role in managing your condition will be a more pro-active one where you will be involved in making decisions about many things that affect you, your healthcare management, your family, and your lifestyle.

Every day people are involved in making decisions that will affect how they manage their lives. Learning more about yourself, your beliefs, and what is important to you will help you to make choices that are right for you and that you are comfortable with. Deciding what things you find acceptable, and what things are not, will help you with your decision-making. For instance:

- Do you prefer a female or male healthcare provider?
- Would you feel comfortable asking your healthcare provider for a second opinion about treatment and management?
- Should you find another healthcare provider if you are not happy or satisfied with your treatment and management?
- Are there particular management strategies that have not yet been explored?
- What strategies can be used to make visits to your healthcare provider more effective and improve outcomes?

These are all situations that require you to use decision making skills to get the best outcomes available to you. You don't have to make decisions on your own. If you feel overwhelmed or unable to make an informed decision, you can share the responsibility by working together with other members of your family, your support network, or healthcare team. Learning to be more assertive and developing good communication skills will help you feel more comfortable in communicating with your healthcare providers and other people who are involved in your care.

Know your rights and responsibilities

Everyone in your healthcare team, including you, has certain rights and responsibilities that come with being part of the team.

You have the right to access healthcare providers who:

- Know about your pain, or are willing to learn about it
- Believe your pain is real
- Will treat you with respect and dignity
- Are willing to work with you to find the best treatment and management of your pain

You also have the responsibility to make sure that:

- You have the knowledge and skills, or are prepared to learn the knowledge and skills, to work successfully with your healthcare team members
- You are willing to try various treatments or strategies
- You utilize the healthcare system in the most effective way

Expectations

When you engage someone to work with you in a partnership such as a healthcare team, it is reasonable for you to have an expectation of what that person can contribute to your care. At the same time that person will also have certain expectation of what your role is in the partnership. It will be important for you not to have unreal expectations of yourself or your healthcare providers. Setting realistic goals will be important because your providers do not have a magic cure. They are there to support you and to work with you in managing your symptoms and improving your wellbeing and quality of life.

Become an active and educated member of your own healthcare team

There are many ways that you can improve your ability to become an active and educated member of your healthcare team:

- Learn about your rights and responsibilities
- Communicate openly with your healthcare providers
- Communicate openly and thoughtfully with family and friends
- Educate yourself about pain
- Take charge of your situation. Ask about risks and benefits of treatments so that you can make informed decisions
- Ask your GP if you are eligible for a care plan to manage your chronic condition. If you are eligible and meet the criteria, you may be able to receive government assisted access to other healthcare providers, such as physiotherapists, psychologists, dieticians, and the like
- Do not be afraid to request a referral for a particular type of treatment. Your healthcare provider may not have considered it for you
- If you are not satisfied with your current
- If your current healthcare provider is not meeting your pain management needs, consider another opinion
- Learn problem solving skills and techniques to manage flare-ups
- Set achievable and realistic goals
- Try not to isolate yourself. Instead, meet other positive people who live with chronic pain and have things in common with you.

Consultation specific

- Ask for a long consultation
- Be aware that you will need more than one appointment to manage your pain
- Plan ahead before you attend the consultation
- Think about why you are consulting a specific healthcare provider and what you expect from them
- Prioritise what is most important
- List current concerns
- Take a list of questions
- Take someone with you to take notes in the consultation

- Indicate to the healthcare provider why you have come to see them when you arrive for visit
- Indicate the main outcomes you would like from the consultation – for example, determining the cause of the pain; strategies to better manage the pain; or a combination of both
- Be clear about how you would like your healthcare provider to work with you; and what their role is to help you better manage your pain
- After the consultation, reassess your time with your healthcare provider. Think about ways to improve your next visit so that the consultation may be helpful.

Describing your pain

Describing your pain to a healthcare provider can be very helpful in diagnosis, treatment and management. Below are some words you could use to describe your pain at your consultation.

Tender	Sharp	Cold
Throbbing	Blinding	Scary
Agonising	Prickling	Dull
Nagging	Tugging	Excruciating
Burning	Numb	Horrible
Irritating	Exhausting	Cramping
Annoying	Draining	Tearing
Smarting	Nauseating	Punishing
Piercing	Unpleasant	Scalding
Gnawing	Radiating	Sore
Stabbing	Dreadful	Pulsing
Shooting	Heavy	Bothersome
Itchy	Pounding	Pins and needles

Identifying other additional information can also be useful to communicate to your healthcare provider. The following are examples of questions you could answer yourself and take them to your healthcare provider for discussion during your consultation.

Additional information regarding your pain

- Where is your pain?
- Have you had a diagnosis?
- What makes your pain worse?
- What pain management strategies have you tried that helped?
- What pain management strategies have you tried that did not help?
- What would you like to be doing more of – but may be finding it difficult to do as a result of your pain?
- What was happening in your life, and around you, when your pain first started

Select your pain management team

Your GP or local doctor is usually your main healthcare provider. He or she is often the first point of contact. There are a range of other healthcare providers who may be able to help you manage your pain and minimise the impact it has on your life. Trying to work out which type of healthcare provider is best for you can be confusing and difficult, not to mention

expensive and time consuming. However, it can be helpful to have a team of healthcare providers that you feel comfortable with and have confidence in.

Whoever you decide to include on your healthcare team, qualities of effective health professionals include someone who:

- Knows about chronic pain and how to manage it (or is prepared to learn)
- Believes you are in pain
- Listens carefully to your concerns
- Encourages you to ask questions
- Is comfortable when you disagree
- Works with you to develop a pain management plan
- Works with you to set realistic goals in order for you to regain function in important activities and skills
- Provides information about risks and benefits of each pain management strategy that is recommended
- Tells you when they do not know something about your pain or management.

Remember: This is your team. If you are not satisfied with the way a health care provider communicates with you or treats you, it is important to either try to discuss this with them, or try someone else.

Decide who to include on your team

The following will give you some information about the different kinds of health care providers that people with chronic pain might see. Who you might see will vary depending on the type of pain you have and who you find the most helpful. Whoever you decide to include in your pain management team, remember that this is your body and your pain – you are the only one who really knows what your pain is like and how it is affecting your life. Your health care team should work with you and should communicate with each other.

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 ongoing pain. A general practitioner provides person centred, comprehensive and coordinated whole-person healthcare to individuals and families in the community, on a continuing basis.

A good GP is someone who:

- You feel comfortable with and trust. You feel you can ask them anything and you have confidence in what they tell you.
- Understands chronic pain and has experience in managing pain similar to yours or is willing to learn. Not all doctors have been trained to manage chronic pain.
- Is willing to listen to you and spend time talking to you. This might be about what you are experiencing, how pain is affecting your life, and what your management options are, including any possible side-effects.
- Will communicate with other members of your healthcare team, where appropriate, so that you receive co-ordinated healthcare.

Medical specialists

There are a number of different medical specialists that you may be referred to for diagnosis and/or pain management, depending on the type of pain you have. They can include, but are not limited to, the list provided below.

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 and surgical treatment of bone, muscle, and joint problems.

Pain specialist

Specialises in the diagnosis 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 syndrome, FMS) and chronic fatigue syndrome (CFS). They help investigate complex medical conditions.

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

Allied health professionals are people who provide a variety of services that may help you with different aspects of living with chronic pain. They can include, but are not limited to, the list provided below.

Occupational therapist

Can help you adapt your environment and show you ways to make activities of daily living, such as housework and personal care, easier, and provide advice on useful aids or equipment

Physiotherapist

Can provide advice on exercise, posture and ways to relieve pain, as well as use treatments to maintain joint and muscle movement.

Psychologist

Can teach you different ways of thinking about and coping with pain

Rehabilitation counsellor

Can help you with employment and retraining issues. A rehabilitation counsellor can help you navigate your way through complex rehabilitation systems

Social worker

Can provide support and help with different aspects of your life that may be affected by your pain, such as your family life, income and housing, and other life problems.

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 by some people with chronic pain. It is important to understand that like any treatment there can be benefits and side effects. The skill of the practitioner is going to be critical. The practitioner is responsible for informing you of any risks. Refer to 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.

Summary

You have been provided with some information about the different kinds of healthcare providers that people with chronic pain might see. Who you might 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 by being prepared when you interact with your healthcare providers, you are starting to take 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 and practice them. Work out which strategies are most helpful and talk it through with those around you.