



Chronic Pain : Possibilities and impossibilities of pain rehabilitation

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Already in our early life we learn that pain is a warning signal. Pain is a sign that something is "wrong" in our body. If you feel pain, you are going to a doctor. The doctor looks for the reason of the pain and gives a treatment to take away the pain. Unfortunately this does not always work.

For many people pain is persistent and never will ease off.

People with a neuromuscular disorder often have chronic pains.
Research shows that dependant of the disease 30-70% suffers from them.

The results of a survey by Spierziekten Nederland show that pain, next to fatigue, is the most important reason for problems during daily activities for people with neuromuscular disorders.

Also half of the people with Hereditarily Spastic Paraplegia (HSP) have chronic pain ; the unknown reasons are a problem.

Is the reason partly caused by the disease itself, or because of overloading through a different, disturbed normal gait caused by the muscle weakness ?

This is (still) unknown ; little research has been done of pain in muscular disorders.

Previously pain was not considered to be a symptom of the disorder and it was thought that only a few people had chronic pain.

Unfortunately, same as for other forms of chronic pain, also for people with a neuromuscular disorder no real solution exists.

At present there is no medical treatment that can take away the pain completely. The patient often gets to hear "you have to learn to live with it".

This seems an easily given but difficult to realise advise. But is this possible ? And how ? And what can I do ? Maybe a specialised pain rehabilitation centre can help you, as in the last few years a lot of new knowledge about chronic pain has developed.

We now know that pain is a complex phenomenon in which physical, psychological and social aspects play a role.

Physically there could be too much or too little movement.

Pain has an influence on your mood : the more depressed and sad you feel, the more pain you will feel.

Also the people around you can have an influence on your pain.

If people avoid you because you cannot join them when you suffer from your pain, that in return may increase that pain.

Also it will not help you if everybody always wants to assist or take care of you, or continuously warns you to be careful.

In the treatment of pain attention must be paid to all of these three aspects.

The treatment is given by a multidisciplinary treatment team.

Pain rehabilitation programs are set up to learn patients to function better with their pain.

Important for the result of the program is that the patient is very well informed beforehand about what will happen, and what the possibilities and impossibilities are.

In the case of a pain-rehabilitation program the terms "cognitive" and "behaviour" therapy are often used.

The term "cognitive" also relates to the way of thinking about and perception of somebody's pain.

It is known that certain ideas or views can have a negative influence on one's functioning. Thoughts like "if I move more I could damage my body even more" will result in the person being less active and avoiding certain activities.

Also the idea that you can't do anything about your pain causes a feeling of powerlessness or helplessness, and may enhance the feeling of pain.

The word "behaviour" is used to indicate what a person does and doesn't do (anymore) because of the pain, or the way of doing things in itself.

Over time you develop some habits to deal with the pain. Moving will become different or may be with the aid of some sort of equipment (e.g walking aids).

You may stop doing certain activities altogether.

Through the rehabilitation program thoughts and habits that people have developed and adapted can possibly change.

Maybe you can develop other thoughts and get more knowledge and insight of the pain to help you deal in a different way with it and thus reducing it.

Another possibility is that you may benefit from changing the way you do activities or planning activities and leisure time in a different way.

Of course changing of habits is not easy, and that's why the team will help and assist you with it.

A rehabilitation team consists of a rehabilitation doctor, ergo therapist, physiotherapist and psychologist.

Often also a social worker, movement therapist and nurses may have a role.

The treatment process may last about three months.

In the first weeks the treatment can be 3 to 5 times a week and will decrease gradually towards the end. Pain rehabilitation aims at optimising the quality of life.

This is a wide understanding in which many factors play a role. It is also a very personal matter. What is very important for one person may be just a side issue for someone else.

That is why a pain rehabilitation program does not provide a readymade solution. Together with the team every patient will set the goals that are relevant and important.

It is essential to tell what is important for you and what wishes you have to match your requirements as good as possible. The rehabilitation team can assist in making choices by indicating the pro's and con's of them.

Rehabilitation does ask for an active participation. As a patient, in the end, you are responsible for your own results and will decide which goals are to be achieved.

Without doubt you must have a good motivation to progress in spite of the pain still being there. This also means accepting the idea that there is no solution to cure the pain, but explore all possibilities. You have to do new try-outs and try and think if doing things differently can be successful.

It is not always easy. Not only the physical reactions can be annoying, but also nasty thoughts and feelings can trigger unpleasant reactions.

A lot of persistence is required to , in the end , benefit from all the efforts and improve your situation ; optimum cooperation with the team is essential for it, with open and honest respectful and trustful communication at all times.

Pain rehabilitation can support learning how to deal and handle the pain and the effects on your functioning. Unfortunately there are still no readymade solutions. Every pain problem is unique and requires customized solutions.

A lot of motivation, patience and strength from you and the people around you are required.

To learn to live with pain is always difficult, but very often there will be more alternatives than you could think of, providing chances that you may grant yourself !