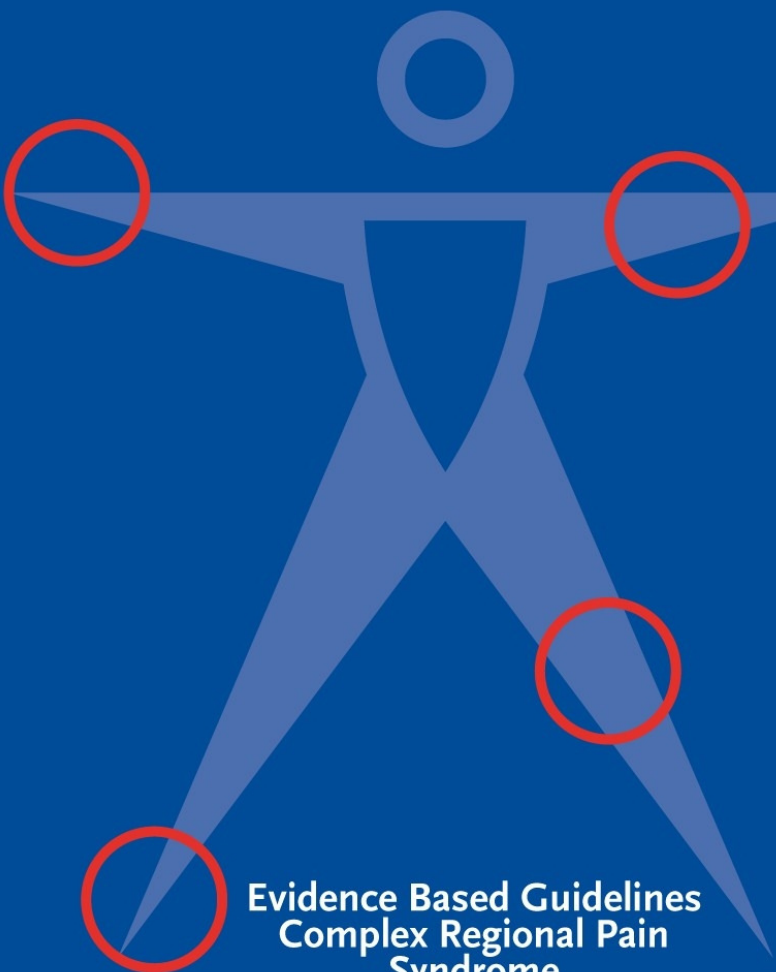


Posttraumatische

Dystrofie



Evidence Based Guidelines
Complex Regional Pain
Syndrome
type I

Patient version

Netherlands Association of
Posttraumatic Dystrophy Patients

Evidence Based Guidelines for Complex Regional Pain Syndrome Type I Patient version

Imprint:

Netherlands Association of Posttraumatic Dystrophy Patients
PO box 31157
6503 CD Nijmegen
The Netherlands
Tel. 0031 13 455 49 51
Website: www.posttraumatischedystrofie.nl

© Netherlands Association of Posttraumatic Dystrophy

2006 edition

With thanks to: Prof. J.H.B. Geertzen MD, PhD, F.J.P.M. Huygen MD, PhD

© Netherlands Association of Posttraumatic Dystrophy Patients* 2006

*In the Netherlands CRPS-I is called posttraumatic dystrophy. The patient support group, therefore, is called Netherlands Association of Posttraumatic Dystrophy Patients.

Table of Contents

Foreword	page 4
Introduction	page 5
How to use these guidelines	page 6
About the CRPS-I guidelines	page 7
What is CRPS-I?	page 10
Diagnosis and practitioners	page 12
Recommended treatments	page 14
Children and CRPS-I	page 18
Communication and information	page 19
CRPS-I and work	page 20
Prevention	page 21
Treatments in combination with scientific research	page 22
Outline of treatments / diagram	page 23
Glossary	page 24

Foreword

The Evidence Based Guidelines Development (EBGD) Guidelines on Complex Regional Pain Syndrome type I (CRPS-I) dealing with the diagnosis and treatment of CRPS-I were published in 2006. These guidelines were drawn up by a large number of medical practitioners in association with the Netherlands Institute for Healthcare Improvement (CBO) and adopted by the relevant scientific professional associations. Our association was also involved in drafting the guidelines.

The EBGD Guidelines on CRPS-I have been written to give practitioners more clarity in dealing with this condition, help them coordinate treatments more smoothly, and give the same information to their patients. The guidelines contain recommendations for practitioners to back up everyday practice.

The guidelines are the outcome of scientific research and opinions of experts, drawing on evidence to reach conclusions and recommendations. The evidence consists principally of articles on scientific studies into CRPS-I, which were assessed for their quality on the basis of EBGD assessment forms. Articles of moderate or poor quality were excluded. If you would like to read these guidelines in full, go to the CBO website (www.cbo.nl) and click on Guidelines Development.

The guidelines do not have the force of law, but contain sound scientific ideas and recommendations that have broad support and should be used by practitioners in order to provide good care.

We hope that this patient version will give you a good understanding of the treatment options available and will help you decide on the right treatment in consultation with your practitioner.

Netherlands Association of Posttraumatic Dystrophy Patients
I.L. Thomassen-Hilgersom, chairwoman

Introduction

It is estimated that 5,000 to 8,000 people a year develop CRPS-I in the Netherlands (total population 16 million). Most patients recover well, but about 20% experience lasting impairment and pain. The condition has a considerable effect on quality of life. CRPS-I usually requires intensive, long-term treatment.

If you have developed CRPS-I following an accident or operation on an arm or leg, you will probably come into contact with various medical practitioners. This could include your GP but also a surgeon if you had an operation or suffered a fracture resulting in CRPS-I.

You may be unable to carry on doing your present job, or you may need changes to your working hours and/or duties. You might also need alterations to be made to your home. It is also possible that you might experience emotional difficulties or tensions in your relationships. CRPS-I has a considerable impact on your quality of life and may entail psychosocial consequences.

Practitioners have devised guidelines in conjunction with the Netherlands Institute for Healthcare Improvement (CBO) because of the wide range of different treatments that were available and the need to coordinate these treatments more effectively, if only because CRPS-I is such a complex condition. The guidelines describe what constitutes the best care and what treatments are recommended. The guidelines will lead to more equality of care, more clarity of treatments, and more uniformity in the information given to patients.

You may be given a form of treatment that is not covered in these guidelines because your personal circumstances require it or because you are taking part in scientific research into a particular treatment. It will sometimes be necessary or desirable to opt for treatment that differs from the guidelines offered. In that case your medical practitioners will explain why and describe the treatment fully. But in principle you will normally be treated according to the guidelines.

This patient version is a shortened version of the EBGD Guidelines on CRPS-I and only covers the treatments recommended in those guidelines.

All other treatments that were assessed and found wanting are not included in this version.

This version contains an introduction, the recommended treatments, a summary outline of the treatments, a description of the practitioners that may be involved and the treatments that are recommended only in the context of scientific research.

There are many synonyms for CRPS-I, the most common of which are: posttraumatic dystrophy, reflex sympathetic dystrophy and Sudeck's dystrophy.

How to use these guidelines

You can use this patient version of the guidelines to prepare for your appointment with your practitioner. You can consider the treatments that are available and you could, for example, take these guidelines with you to the appointment. If your treatment differs from those described in the guidelines, you will be in a stronger position to discuss this with your practitioner. Do not hesitate to ask your practitioner if you have any questions about CRPS-I or treatments. Only he* can explain exactly what the treatment is and what effects it might have.

You might find it useful to take someone with you to an appointment so as to be sure that you do not forget any questions or mishear/misunderstand anything that was said to you.

* or of course she

About the CRPS-I guidelines

The guidelines have been drawn up in the light of scientific research and the views of experts in the field of CRPS-I in order to define what the best care should be. The guidelines are designed to support the daily practice of doctors, physiotherapists, occupational therapists and psychologists.

Who drew up the guidelines?

The guidelines were the initiative of:
Netherlands Society of Rehabilitation Specialists
Netherlands Society of Anaesthesiologists

WITH THE SUPPORT OF:
Institute for Healthcare Improvement CBO

IN COOPERATION WITH:
Royal Dutch Society for Physical Therapy
Dutch College of General Practitioners
Dutch Professional Association of Psychologists
Dutch Orthopaedic Association
Dutch Multidisciplinary Association for the Study of Pain (Dutch chapter of the IASP)
Netherlands Society of Neurosurgeons
Netherlands Association of Posttraumatic Dystrophy Patients
Netherlands Association for Occupational and Industrial Medicine
Dutch Association of Occupational Therapy
Netherlands Society of Surgery
Netherlands Society of Paediatric Medicine
Netherlands Society of Neurology
Netherlands Society for Plastic Surgery
Netherlands Society of Rheumatology
Netherlands Society for Insurance Medicine

Working method followed by the project group on Complex Regional Pain Syndrome type 1

In autumn 2003 a project group was set up, consisting of representatives of all the medical and paramedical disciplines involved in CRPS-I, epidemiologists, the Netherlands Association of Posttraumatic Dystrophy Patients and the Institute for Healthcare Improvement CBO.

The project group spent two years discussing scientific research and the findings of experts in order to produce treatment recommendations.

Subgroups were set up to discuss specific subjects or treatments, which were then debated in the project group as a whole. Conclusions and recommendations were discussed and formulated as a result of this process.

The guidelines have now been produced with the support of all the scientific professional bodies concerned, and we hope that they will make a contribution to good care and treatment.

COMPOSITION OF THE PROJECT GROUP

Steering committee

- Prof. J.H.B. Geertzen, MD, PhD, rehabilitation specialist/physiatrist, Groningen University Medical Centre, chairman
- R.S.G.M. Perez, PhD, coordinator of research into pain and pain control, Free University Medical Centre, Amsterdam, secretary
- C.J.G.M. Rosenbrand, MD, Institute for Healthcare Improvement CBO, Utrecht, senior advisor

Project group

- T. Beems, MD, neurosurgeon, St. Radboud University Medical Centre, Nijmegen
- H.R. van den Brink, MD, PhD, rheumatologist, Alkmaar Medical Centre
- P.U. Dijkstra, PhD, physiotherapist/epidemiologist, Groningen University Medical Centre
- F. van Eijs, MD, anaesthesiologist, St. Elisabeth Hospital, Tilburg
- Prof. R.J.A. Goris, MD, PhD, surgeon, emeritus professor in surgery
- W.A.J.J.M. Haagh, MD, PhD, surgeon, Maastricht University Hospital
- J.J. van Hilten, MD, PhD, neurologist, Leiden University Medical Centre
- F.J.P.M. Huygen, MD, PhD, anaesthesiologist, Erasmus Medical Centre, Rotterdam
- M.A. Kemler, MD, PhD, resident in plastic surgery, Groningen University Medical Centre
- Prof. M. van Kleef, MD, PhD, anaesthesiologist, Maastricht University Hospital
- L. van der Laan, MD, PhD, surgeon, Amphibia Hospital, Breda
- H.M. Oerlemans, MSc, senior paramedical research policy officer, St Radboud University Medical Centre, Nijmegen
- J. Patijn, MD, PhD, neurologist, Maastricht University Hospital
- J.M. Ruijgrok, MD, PhD, rehabilitation specialist/physiatrist, Maastricht University Hospital
- F.G. Slebus, MD, insurance doctor, University Medical Centre, Coronel Institute, Amsterdam
- S.D. Strackee, MD, plastic surgeon, University Medical Centre, Amsterdam

- Prof. D. Tibboel, MD, PhD, paediatrician, Erasmus Medical Centre - Sophia Children's Hospital, Rotterdam
- P. Theuvenet, MD, anaesthesiologist, Alkmaar Medical Centre
- I.L. Thomassen-Hilgersom, MSc, chairwoman of the Netherlands Association of Posttraumatic Dystrophy Patients, Nijmegen
- P.J.M. Veldman, MD, PhD, surgeon, De Tjongerschans Hospital, Heerenveen
- L.A.W. van de Ven-Stevens, MSc, occupational therapist, St Radboud University Medical Centre, Nijmegen
- A.C.L.P.J. Verhoeven, MD, PhD, company doctor, University Medical Centre, Coronel Institute, Amsterdam
- G.J. Versteegen, MSc, PhD, psychologist, Groningen University Medical Centre
- H. Wemekamp, MD, GP, Amsterdam
- P.E. Zollinger, MD, PhD, orthopaedic surgeon, Rivierenland Hospital, Tiel
- Prof. W.W.A. Zuurmond, MD, PhD, anaesthesiologist, Free University Medical Centre, Amsterdam

What is Complex Regional Pain Syndrome type 1?

CRPS-I is a condition that can cause serious problems for patients and practitioners. It normally occurs following an injury to an arm or leg, and can involve a combination of symptoms:

- circulation disorders
- signs of inflammation
- signs of oxygen deficit
- structural abnormalities in tissues
- sweating disorders
- nerve disorders

Patients report the following problems: pain, temperature difference, impaired movement, colour changes, hypersensitivity ('contact pain'), tremor, involuntary movements, muscle spasms, paralysis, atrophy, swelling and changes in hair and nail growth.

A distinction is drawn between 'warm CRPS-I' and cold CRPS-I. Warm CRPS-I affects 95% of patients. In this form the skin is red and feels hot. Only 5% of patients experience 'cold CRPS-I' from the onset of the condition: the arm/leg feels cold, the skin is blue in colour and circulation is impaired.

The most recent definition of CRPS-I produced by the International Association for the Study of Pain (IASP), reads as follows:

"CRPS-I is a set of locally occurring painful conditions following a trauma, which are mainly expressed distally and are more severe and lasting than the expected clinical course of the original trauma, often resulting in a marked motoric impairment, and characterised by a variable progression over time."

How common is CRPS-I?

It is estimated that 5,000 to 8,000 people a year contract CRPS-I in the Netherlands.

There is no clear evidence on the prevalence of CRPS-I. A range of figures appear in the literature, and it depends on the criteria used for diagnosis. CRPS-I occurs most frequently following a wrist fracture, but wide variations have been reported, with incidence figures ranging from 1% to 37%. Early problems with the cast indicate that CRPS-I may occur. A higher pressure in the plaster cast is measured in CRPS-I patients given a plaster cast following a distal radius fracture. It is unclear whether this higher pressure is due to the swelling or whether the higher pressure causes CRPS-I.

There are other groups of conditions that can lead to CRPS-I, including other fractures, soft tissue injuries, bruising, stroke, heart attack and as a complication following surgery.

Are any particular groups predisposed to the condition?

CRPS-I is most common in Caucasian (white) people and is two to three times more common in women than in men. There is some indication that hereditary factors have a part to play.

Relapse

About 9% of CRPS-I patients experience a relapse, that is a new bout of CRPS-I following an initial complete recovery or a period largely free from symptoms. This is most likely in young patients with 'cold dystrophy'. Relapses usually start spontaneously and with few symptoms. Relapse or expansion of CRPS-I can occur in the same limb or in a different limb.

Natural course and stagnation

CRPS-I can occur at any age, from early childhood to extreme old age, but is most frequent in the 20 to 50 age group. Most patients recover fully or retain some residual symptoms.

It usually takes quite a long time for patients to recover. Sometimes treatment ceases to be effective and patients are left with symptoms and impairments; they have difficulty coping with the residual impairment and/or pain.

Children and CRPS-I

Few reports have been produced on children with CRPS-I, but they can also develop this syndrome. CRPS-I is most likely to occur in the leg, and girls are more at risk than boys. The progress of CRPS-I seems to be more gentle in children, and most patients recover fully. However, they are more likely to experience a relapse.

Diagnosing CRPS-I and practitioners

No firm consensus has been established in the Netherlands or internationally with regard to how this condition should be diagnosed.

Doctors/practitioners can diagnose CRPS-I using Veldman's criteria:

1. four or five of the following symptoms:

- unexplained diffuse pain
- difference in skin colour
- diffuse oedema
- difference in skin temperature
- active movement impairment

2. symptoms develop or worsen on exertion

3. symptoms are present in an area larger than the area of the first injury or surgery, and always distal to the first injury.

Scientists undertaking research are advised to describe patient groups using Veldman's criteria and/or IASP criteria and/or Bruehl's criteria, which are very comprehensive. If you take part in scientific research, you will be told more about this.

Additional diagnostic tests such as X-rays, MRI scans, three-phase bone scans, etc., are not required by practitioners in establishing a diagnosis.

Practitioners

Practitioners should start by administering drugs to reduce the (inflammation) symptoms, improve the circulation and treat the pain.

The first medical practitioner treating you will normally be your GP or the consultant who established the diagnosis. Other practitioners may become involved later on depending on how your CRPS-I develops.

These could include: a physiotherapist, a pain specialist, a neurologist, a rehabilitation specialist, an occupational therapist and a psychologist. If you have a job, an insurance doctor or company doctor will also be involved in your care.

CRPS-I is a complicated condition that needs to be approached from various angles. This is why you may often come into contact with various practitioners or in a setting with a multidisciplinary approach. Your symptoms, complaints and impairments will determine which particular practitioner treats you at any given time. However, it is important that one practitioner takes the lead role and is always aware of all the treatments you are undergoing and what effect they are having.

It may be that you will see these various practitioners in the same hospital or treatment centre. But as medical care systems sometimes vary in different regions, you might also have to go to another centre for treatment. It is impossible to say in advance whether this will be the case.

Practitioners who might be involved in your care

GP or consultant

Your GP, a surgeon or a consultant might be the first practitioner to diagnose you when you first see a doctor about your symptoms. He or she will start by prescribing drugs to treat your (inflammation) symptoms, circulation problems and pain, and will refer you for physiotherapy.

Physiotherapist

You might be referred to a physiotherapist if you are experiencing: pain, violent reactions to effort, movement disorders, loss of strength, sensitivity disorders, coordination disorders and inability to cope with the condition.

Occupational therapist

You might be referred to an occupational therapist if you are experiencing: pain, swelling and movement disorders, sensory disorders, difficulty looking after yourself, working and relaxing, and inability to cope with the condition.

Anaesthesiologist/pain specialist

This is normally a team of practitioners comprising an anaesthesiologist/pain specialist, physiotherapist, occupational therapist, psychologist and a social worker. They will discuss what care you need. You can also express your own views as to what care is important to you at a particular time. The pain specialist is normally the case manager and is kept informed of all treatments given. It is important that all practitioners involved know what is being done.

Psychologist

A patient might be referred to a psychologist if there are discrepancies between his or her objective symptoms and his or her (pain-related) behaviour, if he or she fails to recover despite receiving correct treatment, or if he or she says that the condition is having a marked impact on his or her psychosocial function.

Rehabilitation specialist (rehabilitation medicine treatment)

The rehabilitation specialist works together with various practitioners (physiotherapist, occupational therapist, psychologist, social worker) to devise and administer a course of rehabilitation treatment. The rehabilitation specialist will also consult other medical specialists at regular intervals to coordinate treatments. It is important for one practitioner to take the lead and act as the case manager. He or she will have regular contact with the patient and all the practitioners involved in his or her care.

Recommended treatments

This chapter describes the treatments for CRPS-I which appear in the guidelines and which you might receive. Not all treatments will be appropriate for you. However, this information might help you prepare for discussing suitable treatments when you see your practitioner.

If you do not tolerate a particular treatment or drug, tell your doctor. You might find some treatments easier to tolerate than others.

It sometimes needs a bit of 'fine tuning' to find out what treatment suits you.

Drug treatment and invasive treatment

The purpose of drug treatment is to control pain, inhibit inflammation and if necessary stimulate circulation.

Scavengers

Practitioners are advised to administer scavengers (substances that capture free radicals) in the acute phase of CRPS-I as they appear to have a beneficial effect on CRPS-I symptoms.

These scavengers are:

- 50% DMSO cream (dimethyl-sulphoxide) to be applied five times a day to the skin of the affected limb
- N-acetylcysteine effervescent tablets, 600 mg three times a day.

DMSO:

If you have had CRPS-I for less than a year, it is recommended that you apply 50% DMSO five times a day for three months.

If you have had CRPS-I for more than a year and have not used 50% DMSO five times a day before, a one-month course can be considered and continued for three months if it proves beneficial.

N-acetylcysteine, 600 mg three times a day for three months, is recommended if you have 'cold dystrophy' as it appears to be more effective than DMSO.

Patients used to be given mannitol infusions, but there is insufficient evidence that mannitol is an effective treatment. It is recommended that it should be given only in the context of a trial until research has found that it is effective in reducing oedema.

Improving the circulation

It is thought that calcium-channel blockers improve the circulation in the limbs of patients with 'cold dystrophy'. Tests will be carried out to investigate the effects of these drugs once you have been taking them for a week. The treatment will be stopped if no effect is observed.

Pain medication

Pain control in patients with CRPS-I presents challenges both to the practitioner and to you, the patient. The WHO (World Health Organisation) ladder is followed including the first and second level for pain medication.

This means that the first pain medication prescribed for you is paracetamol 500 mg; one of the reasons for this is that it has few side-effects.

Anti-inflammatory painkillers are prescribed to inhibit inflammation.

These substances are also called NSAIDs (non-steroidal anti-inflammatory drugs).

Antidepressants

You would be given these drugs not because you are depressed but because they have a positive side-effect on pain treatment.

A trial course of amitriptyline or nortriptyline can be considered if you are suffering continuous neuropathic pain.

Anticonvulsants

You would be given these drugs not because you are having epileptic seizures but because they might reduce pain.

A trial course of carbamazepine, pregabalin or other antiepileptics can be considered if you are suffering from occasional neuropathic pain.

Gabapentin

There are indications that gabapentin administered at doses of 600 to 1,800 mg every 24 hours in the first eight weeks can cause some reduction in pain symptoms. There are also indications that it reduces contact pain and hypersensitivity. Treatment should be stopped if the pain has not lessened after an eight-week trial period.

Treatment of movement disorders

It is recommended that patients with dystonia, myoclonia or muscle spasms should be started on:

- oral baclofen according to the standard dose increase pattern
- diazepam or clonazepam, which should be slowly titred based on the therapeutic effect and side effects of the drug in order to achieve a good dose/effect balance.

Invasive treatments

Sympathetic blockade

There are some limited indications that percutaneous sympathetic blockade in the neck/back (ganglion stellatum or lumbar region) may be effective; this treatment may also have a beneficial effect on improving circulation in the affected limb. Percutaneous sympathetic blockade with locally-acting painkillers can be considered for patients with 'cold dystrophy' who do not respond to vasodilating drugs.

Other intravenous treatments

There are indications that intravenous administration of a sub-anaesthetic dose of ketamine reduces the pain experienced by CRPS-I patients. There are indications that intravenous administration of 10-20 mg ketanserin reduces pain.

Spinal cord stimulation (ESES, epidural spinal electrostimulation)

Spinal cord stimulation is a treatment in which an electrode is placed in the epidural space (this lies between the inside of the bony spinal canal and the hard spinal cord membrane) behind the spinal cord at the level of the nerve roots which innervate the painful area. The electrode produces an electrical current that causes tingling, a sensation that suppresses the pain.

The precise mechanism of action is not known. This treatment is uncomfortable and very expensive, so it is reserved for patients who meet strict criteria for undergoing this procedure and in whom trial stimulations have resulted in a marked reduction in pain.

Patients who undergo this procedure after careful selection and successful trial stimulation experience a lasting reduction in pain and an improved quality of life. However, there is no improvement in function.

Spinal cord stimulation is administered to carefully selected chronic patients who have not seen any reduction in pain from previous treatments.

Amputation

Amputation can be considered (very carefully) in order to improve quality of life for patients suffering serious and recurrent infections together with severely impaired function. This procedure should ideally be performed in a specialised centre.

Physiotherapy

Patients with CRPS-I are less able to bear weight on the affected limb and experience pain. Small efforts can lead to a significant increase in all types of symptoms, especially pain.

Patients respond to this by:

- 1) immobilising the affected arm/leg and using it as little as possible
- 2) taking part in strenuous exercise in an effort to improve the limb's fitness. This in turn results in severe pain and the patient thinks that he or she has to exercise harder.

The key to recovery lies in carefully moving and learning to use the affected limb again. A more pain-focused approach appears more suitable for patients who have recently developed CRPS-I. You should exercise as often and as much as you can bear the pain. Cut down on the amount of exercise you do if you experience a lot of pain, and step it up if the pain reduces.

A short-term increase in symptoms such as pain starting one or two hours after treatment is not regarded as harmful. You can continue to exercise.

The pain-focused approach results in a reduction in symptoms in the acute phase.

Under the time-focused approach you should exercise and move the arm/leg in spite of the pain that develops.

The two treatments can be mutually beneficial. You will notice that initially you are cautious when exercising, taking care not to exceed the pain threshold, but as time goes on you exercise without paying attention to the pain.

Absolute immobilisation of an arm/leg is not advisable, because careful movements of the affected limb are the key to your recovery.

You will perform exercises with the physiotherapist, and it is also important for you to do exercises at home, including self-massage.

You are advised to start exercising as soon as possible in order to restore function. In the acute phase, the physiotherapist will work out what degree of exercise and movement is feasible for you in terms of exercise and movement. Restoration of function will be the starting point of the treatment in the later, chronic phase.

TENS (transcutaneous electrical nerve stimulation) can be tried as an additional treatment for CRPS-I patients. Patients who benefit from TENS should continue with it.

Occupational therapy

The occupational therapist will teach you how to cope with impairments and teach you new skills so that you can be more independent. He or she may start a course of careful stimulation to treat 'contact pain'. A splint may be made to support or protect the affected area if necessary. Ideally you should not wear the splint all the time, and should try to cut down on its use.

Occupational therapy has a positive effect on functional disorders and is recommended for patients with CRPS-I affecting the hand or arm.

Psychology

It was long thought that CRPS-I was caused or maintained because there was something 'wrong' with the patients as no clear objective somatic cause could be found.

This view was not upheld by any of the scientific studies we assessed.

There is also no indication for the idea that CRPS-I patients fit into a specific personality structure.

It is not clear whether the cause and/or progress of the symptoms is determined by mental factors, or whether the mental factors should be seen as the consequence of CRPS-I, and in particular the pain symptoms.

However, patients can become depressed as a result of being affected by pain and impairment. Medication and psychological treatment are desirable in such cases.

More attention has been paid to the role of movement anxiety in recent years. The patient is excessively worried that certain activities might lead to tissue damage. We now know that patients with other chronic pain syndromes experience an increase in impairment and pain if they suffer from this form of anxiety. Talk to your practitioner if you are worried about moving. Cognitive behavioural therapy can be an effective way of treating movement anxiety, possibly resulting in a decrease in anxiety, pain and impairment. A psychologist can help you deal with the consequences of your symptoms for your personal life.

A patient might be referred to a psychologist if there are discrepancies between his or her objective symptoms and his or her (pain-related) behaviour, if he or she fails to recover despite receiving correct treatment, or if he or she says that the condition is having a marked impact on his or her psychosocial function.

Children and CRPS-I

Little research was found into children and CRPS-I, and even less is known about specific drugs and invasive treatments available for children.

It is important that drug dosages are calculated with care and that (medical) support is given to children while they have the condition. It is also desirable for a paediatrician to be closely involved.

Physiotherapy for children

Physiotherapists are often involved in the treatment of CRPS-I in children. The treatment is often similar to the model used for adults, with pain reduction and improved function the main objectives. There are indications that physiotherapy is helpful for children. Children are at greater risk of relapse.

Occupational therapy for children

Occupational therapists are also involved in the treatment of children. The overall objectives are the same irrespective of whether the patient being treated is a child or an adult.

Psychology

As with adults, there is also no clear indication in the literature of a possible psychological or personality-related cause in the development of CRPS-I. If psychological treatment is desirable, it is recommended that it should be given by a psychologist specialised in children or adolescents. It is also thought of as desirable for parents or relatives to be involved in treatment.

Communication and information

Your practitioner should give you information about CRPS-I and the treatments available. You also have a role to play in the treatment. You can tell the practitioner about any problems you are having with a particular treatment or any drug side-effects you are experiencing. The information you give the practitioner is just as important. It helps the practitioner understand what issues you see as problems. This can also apply to mental and social aspects, where specific support is desirable.

You might feel some uncertainty about CRPS-I. The cause of the condition is unknown, and it is impossible to predict how it will develop or how you will react to treatments. That is why it is so important for you and your practitioner to communicate effectively about this condition. CRPS-I can be a very disabling condition that has a strong impact on your physical, mental and social well-being and can affect your family.

Support

Most people with CRPS-I experience impairments and pain, and notice that they are less capable of performing physical activities. This impairment in your abilities can have a negative effect on how you feel. You might become frustrated as you are no longer able capable of doing certain activities.

It is therefore important that practitioners pay attention to possible emotional and social problems. This means that any problems of this nature which you encounter can be recognised and dealt with earlier. Practitioners should ask you about things that affect your quality of life, such as:

- your ability to carry out everyday activities (such as housework, work, hobbies)
- your feelings (anxiety or depression can impair your quality of life)
- the quality of your social life (for instance, whether you still have contact with other people)

Who does what?

Your GP or consultant will probably be the first practitioner to look at your emotional symptoms and physical impairments. But in principle all practitioners should consider these issues. If you have severe CRPS-I and serious emotional problems, then emotional support and treatment should form part of the overall treatment. Your GP/consultant may refer you to a social worker or a psychologist for further support depending on the nature and severity of your symptoms.

CRPS-I and work

CRPS-I is associated with impairments such as muscle weakness, impaired movement and coordination problems that can make it difficult for patients to carry out everyday activities or to work.

In addition, many patients continue to experience pain at low and/or high temperatures, lack of muscle strength and loss of dexterity long after first developing CRPS-I.

Only 35% of patients say that they no longer have any impairment in routine tasks such as work and leisure activities.

These limitations and symptoms might mean that you are hindered in the work place if your job involves physical exertion, and you might find it difficult to hold down a job.

It is important for you to receive help in getting back to work. Help can take the form of adjustments to your workplace or changes to your duties. Your employer has an important part to play, and the company doctor can help you ease your way back into work.

Prevention

Prevention of CRPS-I can be subdivided into primary and secondary prevention. Primary prevention is the prevention of CRPS-I in patients who have never had CRPS-I. People in this group who have a wrist fracture are advised to take 500 mg of vitamin C for 50 days.

Secondary prevention is the prevention of a recurrence of CRPS-I in patients who have already had the condition.

If you have CRPS-I or have had it in the past and need to have surgery on an arm or leg, it is important that steps are taken to prevent you from contracting CRPS-I again or to stop it spreading.

The measures taken will reduce the risk of relapse.

You can talk to your doctor about what steps might be taken if you have to have an operation. You can take the information below with you when you see him or her. Your practitioner can find comprehensive information in the EBGD Guidelines on CRPS-I.

Experts have devised the following recommendations in relation to surgery:

- it is best to wait until the signs and symptoms of CRPS-I have abated before conducting surgery on patients with CRPS-I

- regional anaesthesia techniques and epidural anaesthesia should be used if possible.

This does not apply to operations intended to eliminate an underlying factor that may be responsible for the CRPS-I:

- * keep the operation as short as possible and minimise the amount of blood removed from the patient's body
- * adequate pain control before, during and after surgery is recommended
- * surgery to a cold arm/leg with oedema is not recommended.

Your practitioner can find more medical information in the EBGD Guidelines on CRPS-I. You would be well advised to talk to your doctor about what steps might be taken if you have to have an operation.

Treatments in combination with scientific research

The expert group recommends that a number of treatments should only be carried out in connection with or in the context of scientific research. Some of these treatments were carried out before 2006, but in the light of the conclusions it is now recommended that they should only be administered in the context of trials so that the effects can be clearly understood. It may be found that a treatment which used to be given is no longer standard practice, perhaps because there is insufficient evidence of its effects or because it is still risky.

In addition to the recommended treatment guidelines, you may also come into contact with new treatments within the context of a study. In the context of a trial, the specific treatment remains unproven. .

Mannitol infusion (scavenger, or substance that captures free radicals)

Until there is evidence that mannitol is effective in reducing oedema, it is recommended that this treatment only be given in the context of a study.

Intrathecal baclofen

Dystonia is a principal feature of the condition and the usual therapy with orally administered drugs has not been effective.

Bisphosphonates

These substances are administered to treat conditions such as osteoporosis, and appear to have a beneficial effect on inflammation symptoms in cases of CRPS-I as well.

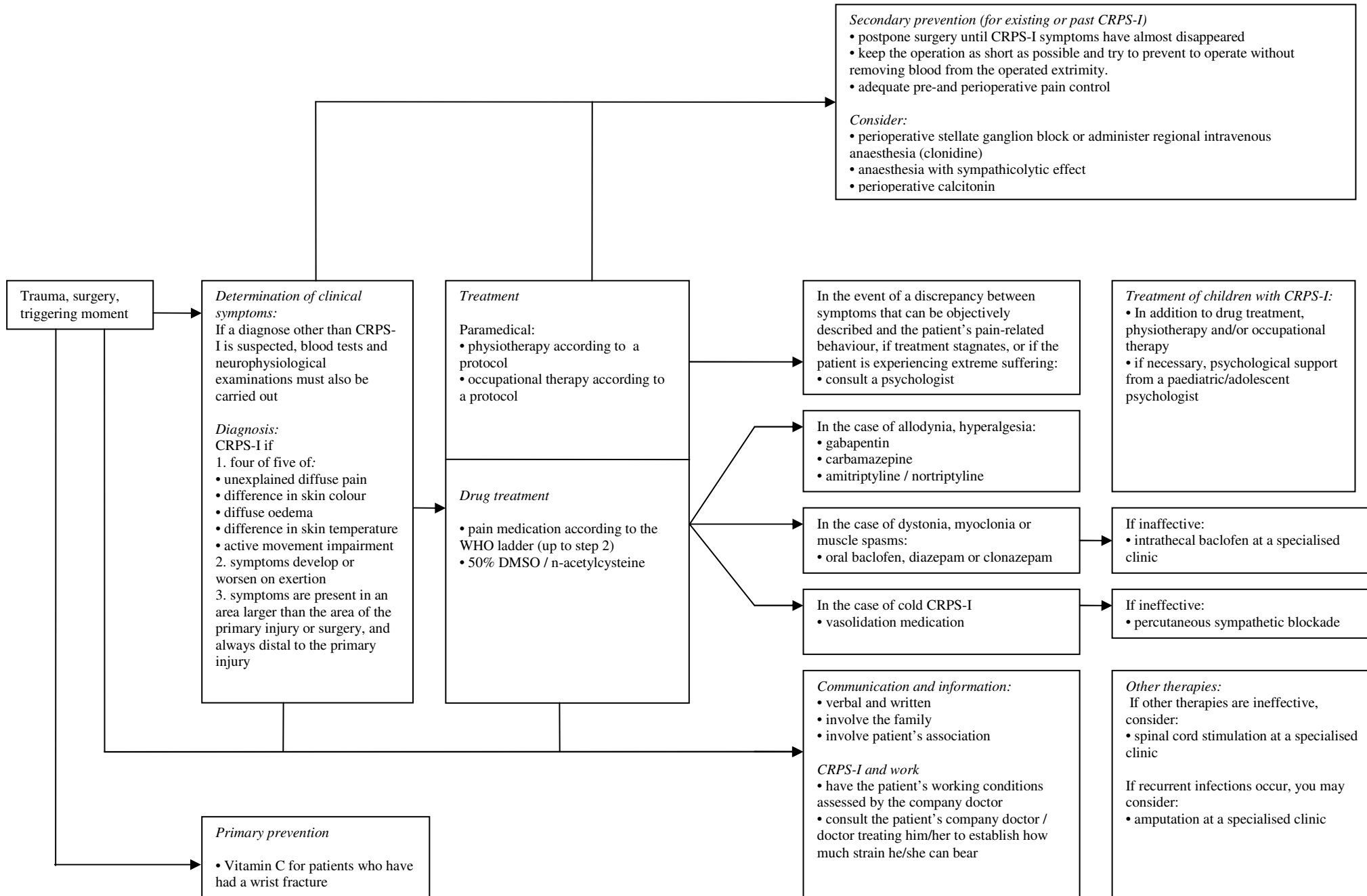
Intravenous administration is preferable as they are often poorly absorbed from the stomach. It is recommended that for the time being this treatment should only be applied in the context of a trial as aspects such as dosage, length of treatment etc. need to be clarified.

Spinal cord stimulation

Spinal cord stimulation should preferably be administered in the context of a trial except where the patient being considered for this treatment is a chronic sufferer who has failed to respond to other treatments.

Surgical sympathectomy

Extreme caution is vital when considering surgical sympathectomy. The treatment should be administered in the context of a trial so that the efficacy and possible risks can be assessed.



Glossary:

Analgesic: pain-numbing substances

Anaesthesia: numbing (part of) the body so that it does not feel anything

Calcium-channel blockers: certain vasodilating drugs that improve the circulation

Diffuse: widespread, with no particular boundary

Distal: towards the end of the limbs

Dystonia: disorder in muscle tension

Epidural and intrathecal space: the spinal cord is sheathed by three membranes with two spaces between them. The epidural space is made up of connective tissue and fat that surrounds the nerves emanating from the back.

Drugs absorbed into the fat are released slowly.

The intrathecal space contains the fluid that surrounds the brain and spinal cord.

Drugs administered here are directly mixed with this brain fluid. This means that they can act more quickly.

Evidence-based: based on scientific research

Immobilisation: making immobile

Intravenous: in a blood vessel

Invasive treatment: the insertion of an instrument such as a catheter or pump into the body

Medical history : a patient's medical history, including the patient's description of his or her complaints, symptoms, their severity, how long he or she has had them, etc.

Myoclonia: brief, rhythmic contraction and relaxation of the muscles leading to rapid synchronous convulsions of the affected muscles.

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

This pain is usually a burning, tingling sensation; sufferers often perceive contact with the affected areas of the skin to be painful and unpleasant.

Oral: by mouth

Percutaneous: through the skin

Peripheral nervous system: the nerves arising from the central nervous system

Trial blockade: a nerve blockade (created by medical intervention) of one or more autonomous ganglia (nerve heads) to see what the effects are before administering a definitive blockade.

In the context of a trial: where the effects of the treatment are the subject of scientific research at the same time

Subanaesthetic dose: a dose that dulls/kills pain but does not completely numb all feeling

Sympathetic: part of the autonomous nervous system

Sympathetic blockade: blocking a nerve that transmits pain stimuli to the brain

Sympathectomy: a definitive sympathetic blockade using alcohol, phenol, heat or surgery (surgical sympathectomy)

Details of the Netherlands Association of Posttraumatic Dystrophy Patients

Office of the Netherlands Association of Posttraumatic Dystrophy Patients

PO Box 31157

6503 CD Nijmegen (The Netherlands)

Website: www.posttraumatischedystrofie.nl

On the website you can find the English version of the guidelines for professionals, as well as the English version for patients.

Please contact the national telephone helpline or write to the office to obtain information about CRPS-I (known as posttraumatic dystrophy in the Netherlands) or the Association.

National telephone helpline: 0031 - 13 455 49 51. The helpline operates from 9.30 a.m. to midday and from 2.00 p.m. to 4.30 p.m. Mondays to Fridays.

The Netherlands Association of Posttraumatic Dystrophy has 4,000 registered members and a network of 80 volunteers.