how the pain may be linked to other medical problems, causes of pain that may have been missed and how the pain affects you. They will develop a pain management plan that may include medication as well as other sources of support that may help.

// Clinical psychologists who may be very helpful in looking at ways to help you manage your pain so that you can live a more normal life in spite of it. Sometimes looking at things in a different way or trying a new approach can help when you cannot see a way forward. Psychologists may also identify other stresses which are adding to your pain.

// Physiotherapists who can help with exercises, manual therapies, electrotherapy, advice on posture and advice on how to manage your activity levels and improve your fitness. All of which may be helpful to make the pain more manageable. It is important that the physiotherapist has specialist knowledge of dystonia to ensure that they prescribe appropriate exercises and activities.

Pain management clinics may also include chiropractors, osteopaths, specialist nurses, occupational therapists and pharmacists.

Other ways of managing pain

Some people find one or more of the following helpful:

// TENS machines are small devices that apply a weak electric current through the skin to relieve pain by blocking pain signals.

// Physical activity

// Deep breathing and other stress management techniques to aid relaxation.

// Complementary therapies.

What is suitable will vary from person to person and depend on the type of dystonia. You should check with the person responsible for your medical care before starting a new physical activity or therapy.

It can also be helpful to set achievable goals and pace yourself – for instance by building rest, exercise, and relaxation times into your daily schedule and not overdoing it on good days. Also it may be beneficial to decrease or eliminate alcohol consumption. Pain often disrupts sleep and alcohol may further disrupt the sleep cycle.

Helpline
0845 458 6322

Website
www.dystonia.org.uk
Dystonia and pain

Some people with dystonia are concerned by the level of pain that they experience. Pain is often associated with neck dystonia and generalised dystonia and can also affect people with other types of dystonia. It is very much an individual experience and varies greatly from person to person.

In many cases, treatments that address the dystonic contractions and spasms may also help to relieve the pain. Botulinum toxin injections and muscle relaxant medications may be quite effective at reducing pain.

Classifying the type of pain you have is the first step to make, allowing you and your consultant or GP to choose the best method of pain management. Chronic conditions such as dystonia can be made up of different types of pain, and so your doctor may need to combine treatments to achieve the best possible pain relief.

Forms of pain

There are 2 basic forms of physical pain: acute pain and chronic pain.

Acute pain arises from injury, disease or inflammation. It is immediate and usually of short duration. Acute pain is a normal response to injury and can be a useful alarm signal that something is wrong.

Chronic pain is continuous pain that persists – beyond the time of normal healing. It ranges from mild to severe and can last for weeks, months or years. It can interfere with a person’s quality of life. One cause of chronic pain is long term medical conditions such as dystonia.

What causes pain

Nociceptive pain arises from stimulation of specific pain receptors which can respond to heat, cold, vibration, stretch and chemical stimuli released from damaged cells. Muscular pain is nociceptive - it is usually well-localised and often experienced as an aching feeling.

Not all pain is nociceptive. For instance, neuropathic pain is nerve pain arising within the central or peripheral nervous system. It is often experienced as a shooting or burning feeling. It is sometimes observed in people with dystonia - for instance due to pinched nerves in the neck.

Medication for pain

Some medications for pain can be obtained over-the-counter (such as paracetamol) while others require a prescription. Medications can have side effects and the appropriate type of pain medication will depend on the type of pain you are experiencing. You should therefore always discuss any changes in your medication with your consultant or the doctor responsible for your care before changing medication or starting a new medication.

A range of medications for treating pain exist - these include paracetamol, non-steroidal anti-inflammatory drugs (NSAIDs) such as aspirin and ibuprofen as well as other prescription medications. The appropriate medication will depend on the type of pain being treated and level of pain relief needed. Treatment usually starts with small doses of weak drugs that can then be gradually increased or changed to stronger drugs until you have the best possible pain relief. However, it is rarely possible to relieve pain completely by using painkillers.

Pain management

While your GP or consultant may be able to help with your pain by prescribing medication, for some patients a more specialist approach may be needed. The professionals with most experience of managing persistent pain are usually found in specialist pain clinics. These provide a comprehensive approach to pain management that addresses a person’s physical, cognitive and emotional needs. The programmes provided by such clinics have been shown to be helpful for managing pain caused by chronic conditions such as dystonia.

These clinics use a multidisciplinary approach which can include:

// Pain specialists who make a ‘holistic assessment’ of your situation including