

Helping children with musculo-skeletal chronic pain syndromes: the Rheumatology department multidisciplinary team approach

Information for children and families

Great Ormond Street Hospital
for Children NHS Trust

This leaflet explains how we treat children with chronic pain syndromes at GOSH, using a multidisciplinary team consisting of a clinical psychologist, occupational therapist and physiotherapist.



How are chronic pain syndromes described?

At GOSH, we refer to children has having 'chronic pain'. This terms includes a variety of conditions including: pain amplification, reflex sympathetic dystrophy (RSD), chronic regional pain syndrome, neuropathic pain and diffuse or localised idiopathic pain syndrome.

How is chronic pain diagnosed?

Diagnosis is made on the basis of history and clinical examination, and the exclusion of other painful conditions, such as arthritis. However, children can have chronic pain alongside other conditions. One common finding is that children with chronic pain are often hypermobile (double-jointed), which may mean that they are more likely to have repeated injuries and then to develop chronic pain. Other sensations, such as extreme sensitivity to touch, heat or cold, numbness, and temperature and colour changes are all common and part of the body's way of reacting and coping with chronic pain.

How is chronic pain understood?

Pain is complex. All pain experience is influenced by both physical and psychological factors. Your child's pain may, or may not, have begun following a specific event such as an injury, viral illness or stressful event. Your child may have reacted to the pain by doing less physical activity, which has led to reduced muscle strength and stamina, increased fatigue and feelings of frustration and hopelessness. All these factors will have turned the volume of pain up further, creating a vicious cycle. It is also common for children to show a pattern where they do too much and then too little. This only keeps the pain going.

Even if no obvious cause for the pain is identified, your child is experiencing real pain; it is not 'in their head', 'all psychological' or 'made up'. As there are lots of factors involved, chronic pain often does not respond well to pain medication.

How is chronic pain treated?

Getting better can take time and requires lots of effort from you and your child. There are no quick fixes and we realise that this can be frustrating for families at times. Our emphasis is on improving coping rather than curing, and on improving function and quality of life rather than getting rid of the pain. A key message is that chronic pain is not a sign that your child is doing any damage to their body.

We use the skills of a physiotherapist, occupational therapist and clinical psychologist, who all work closely together. Input from therapists in your child's local community is essential to successful management, especially in the longer term. Unfortunately, it may not be possible to access input from all these professionals in your community and there may be a waiting list.

In the longer term, it is important to be aware that without appropriate treatment, persistent periods of not using muscles and joints can mean that a child ends up becoming dependent on a wheelchair.

How can a clinical psychologist help?

Typical aspects of assessment and treatment might include:

- **What your child, and other family members, think, feel and do about pain.**
- **Ways to cope effectively with pain,** for example distraction, relaxation, or helpful ways of thinking about the pain.
- **Reducing the impact of pain on everyday life,** such as improving sleep, appetite, anxiety, low mood, frustration, managing other stresses and worries.
- **Reducing your child's use of pain medication.**
- **Parenting a child with chronic pain:** helpful responses when your child is in pain (for example, encouraging them to use coping strategies, or not making pain the focus of family life), keeping boundaries and expectations for your child, and identifying support for you as parents.

How can an occupational therapist help?

Typical aspects of assessment and treatment might include:

- **Goal setting:** working with you and your child to set meaningful physical and functional goals to work towards achieving.
- **Education about managing activities:** following a graded return to everyday activities such as school and sport. This may include helping you and your child to prioritise and pace activities and so avoid 'activity cycling' (over-doing it and under-doing it).
- **Daily activities:** supporting a gradual return to full functional independence. We tend to discourage use of aids and appliances if possible, instead preferring to work with you and your child on how to overcome pain in order to complete tasks and attempt tasks despite the pain.

How can a physiotherapist help?

A typical assessment and management could include:

- An examination of your child's joints to determine how far and how well they move and to examine specific muscle strength as well as look at balance and gait.
- A progressive resisted home exercise programme, that starts very gently (only a few reps and no weights) and gradually but consistently increases in difficulty (often building up to 30 reps and then adding weights). It is important to have a daily progression rather than weekly progression as this minimises any pain increase due to over exercising muscles. The exercise programme should primarily be completed at home by the young person on a daily basis (with the support of the local therapist as necessary).
- Muscle strengthening into the full movement that each joint has is very important to ensure that each joint can be used properly.
- Balance and co-ordination training are also important parts of the exercise programme.
- Pain relief techniques such as heat, ice and TENS may be helpful.
- Supportive footwear is often a good idea, and the use of ankle boots with good shock-absorbent soles often provides excellent support for flat or painful feet.
- Temporarily stopping sports at the initial stage of treatment often helps with regaining control over the pain, but should be re-introduced when strength and stamina have been regained.

For more information about chronic pain syndromes and the Rheumatology department multidisciplinary approach, please telephone our helpline on 020 7813 8581

Notes

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