

## Chronic Pain Toolkit

### 1 Definition:

**Pain** - tummy, headaches, muscular, joints, often chronic –

Chronic pain is pain that lasts beyond 3 months. It is often present in the absence of any obvious pathology or disease process. We do not understand exactly what causes pain and why some children have it and others do not, but the main factors that maintain chronic pain in the present are musculoskeletal imbalances (such as muscle tightness and weakness, adaptations made in response to pain, e.g. limping) and a process of pain sensitisation in which the pain centres in the brain have become more sensitive to normal stimuli such as touch, movement and temperature. A good metaphor for this is a fire alarm, which goes off in the absence of fire. Similarly, the pain response is activated at a very low threshold of sensory stimulation. Often, imaging and blood tests are completely clear despite very high levels of pain. This is because the pain is not caused by pathology or damage to the body, but instead by pain communication or processing problems. The severity of pain and disability is often dependent upon the level of threat perceived by the person. For example, a child with severe abdominal pain may be very worried that someone may bump into him or her. The threat of this happening may directly increase the pain experience or it may make the person more wary to move around the school or in fact to go to school in the first place.

Chronic pain can have a major impact on the child's life, in terms of their sleep, eating/appetite, activities, ability to concentrate, socialising and their psychological functioning. A child's emotional state is directly affected by the pain, but often in turn affects the child's pain experience. It is wrong to suggest that pain is 'psychological' and referring to it as such is both untrue and unhelpful.

## **Diagnoses you might hear of relating to Chronic Pain**

Idiopathic pain  
Fibromyalgia  
Ehlers Danlos Type 3  
Complex Regional Pain syndrome  
Headaches / migraine

## **When someone has Chronic Pain it is common:**

For medicine/pain medication not to work  
To see lots of different doctors and have lots of examinations  
For X-rays and scans to show up as normal, as if there is nothing wrong  
For the pain to be in one place, several places or all over the body  
For the pain to change throughout the day or from day to day  
For people not to understand what it is  
To feel sad and worried about having the pain

Many young people find their own ways to manage pain until it disappears. However, some have pain that continues - despite their strategies – to disrupt schooling, family life and social contacts and these young people require support from specialist services.

Chronic pain is unlikely to be “cured” and the child or young person will instead be supported in “managing” the pain. A key concept is that a young person should not allow their experience of pain to dominate their lives. They can acknowledge their pain and yet still engage in activity. Levels of stress are always likely to have an impact on pain levels

and it is very likely that there will be points in the journey when the young person has pain flares or find it more difficult to manage. But an effective chronic pain rehabilitation programme can have a good success rate.

Treatment is usually a combination of (some of) graded exercise/psychology/CBT/ occupational therapy/physiotherapy/medication. A multi-disciplinary approach is often appropriate with an aim to return to normal activity in a graded, paced way through understanding of pain, exercise, building up daily routines and anxiety management. In some children and young people medication can be helpful, but in most cases it is not. There is no research evidence for any particular type of medication for chronic pain.

It is very important that children and young people who have chronic pain should attend school and the aim will usually be for them to build up to returning there full-time and to sustain this.

## **2 Key Points:**

For pupils who are diagnosed with Chronic Pain, it is important to accept that the condition is likely to be long-term. It is also important to say that the course of the condition will be different for each individual and there will be much variation between them. Therefore any plan that is put in place needs to be “bespoke” rather than “generic”.

**The relapsing and remitting nature of chronic pain makes them difficult to plan for in schools and can lead to the idea that it is “all in the mind”, “attention-seeking” or “malingering” in some parts of the school system. The variability in the pain experience can be hourly, daily, weekly, monthly. It is crucial that the pupil feels believed about their symptoms and that the evidence base of accepted best practice is used as a basis for planning (not personal judgement).**

Having accepted that chronic pain is likely to be chronic and long-term, the focus for schools should be on the management of the pupil’s access to learning during this time, rather than the prospect of a cure. Once a bespoke plan has been made for an individual, it is important to stick to it and to remember that doing too much can be as much of a problem as doing too little, with the impact of too much activity being felt later in the day or sometimes the next day.

Realistically, the plan for meeting the needs of the pupil may need to include arrangements for days when the pupil is too unable to attend school, days when they can manage only some time in a learning base / medical room / library and days when they can attend some or all lessons as usual alongside their peers. The plan will need to be very flexible and responsive and there will need to be good communication (probably daily) between school and home in deciding what to aim for on any particular day. Because of this, it is useful to allocate an individual worker in school who will be the single point of contact. That said, the ultimate goal should be to enable full school attendance and participation. The key aim is to be getting the body used to spending an agreed and increasing amount of time in school. For this reason it is best to think of being in school every day between 9 and 12, for example, if 3 hours is the agreed aim, rather than tracking the pattern for particular subjects which will happen in a random pattern within the timetable.

### **General approaches**

The key aim is to be getting the body used to spending an agreed and increasing amount of time in school. For this reason it is best to think of being in school every day between 9 and 12, for example, rather than tracking the pattern for particular subjects which will happen in a random pattern within the timetable. How quickly the plan builds up is a matter for the clinicians to advise on, but probably no more frequently than every two weeks.

Take the chronic pain seriously and acknowledge the reality of the pain experience. Variable activity levels do not indicate that a child is faking. It is reasonable to make demands of children and young people but it is unhelpful to dismiss the feeling of pain. Acknowledge the pain, but encourage the young person to move beyond a focus on it by directing their attention elsewhere.

Encourage or expect full school attendance (unless there is a different graded plan in place or has to attend medical appointments)

Consult with parents and the young person as to what they want other pupils to know

Try to allow children with chronic pain to manage their own condition, lead a full school life and be included in activities and normal social interaction with their peers as far as possible

Pupils leaving schools at an unscheduled time is undesirable so it may be useful to identify resting places in school if a pupil experiences symptoms.

Pain needs to be acknowledged but pupils should be encouraged to try to work through it at a sensible pace and discouraged from avoiding activities altogether.

Try to avoid a confrontational approach as much as possible. Parents may express themselves forcefully at times, but most of them are simply strongly advocating for their child in the absence of other ways that they can be helpful to reduce their child's pain. It may be helpful to try to find an 'advocate' within the school the parents and / or the child trust or like. This is likely to improve buy-in and engagement and reduce tensions.

### **3 Information and Assessment to inform planning for the individual**

#### **Home School:**

Relevant information regarding past attendance, achievement, behaviour and future targets. Any SEND needs in addition to Chronic Pain

What are difficult activities within the school?

What are difficult lessons within the school?

Is it difficult for the child to navigate the corridors?

Is it difficult for the child to go up or down the stairs?

Is it possible for the child to go to the toilet? Do they require access to a toilet that is not too far away?

Is the child able to engage in PE?

What has been the impact of chronic pain on the child's mood? Is the child seeing a counsellor/psychologist? If not, should they be seen by the school counsellor?

What has been the impact of the chronic pain on the child's social functioning and ability to be with their friends?

**Clinicians:**

Likely length of treatment

Effects on attendance & learning, including any mobility, appearance, mood issues, from diagnosis & treatment

Care Plan/ general information about therapeutic approach and the language used

**Updates from formal meetings when held eg TAF, and from any other professionals involved**

**Other sources of information:**

Oxford Centre for Children and Young people in Pain Kings College London Cumbria Project [www.uclh.nhs.uk/](http://www.uclh.nhs.uk/)

See also video presentation by Konrad Jacobs via OHS website

**4 Impact of Condition on Learning**

Worrying about pain and focusing on it instead of on their learning

Inability to concentrate

Avoidance of activities that cause anxiety, including school or lesson attendance

Anxiety in trying new things

Tiredness

Feeling frustrated and irritable

May be particularly sensitive to perceived criticism

May be self-critical and experience loss of self-esteem

Loss of interest and motivation

Feelings of isolation/impacts of less social contact

Difficulty making decisions

<b>5 Interventions</b>	
<b>Support strategies/Interventions</b>	<b>How this might be recorded in IHP</b>
<p>The pupil is not fit to have contact with school or to learn. You have been asked by the health professionals involved to remove all pressure. This will be very rare.</p> <p>Allocate individual worker to build relationship. Schedule regular meetings. Might begin at home, neutral location then into school. Work to be sent home and collected/feedback given by teachers.</p> <p>Try on uniform/pack school bag. Visit school out of hours for a walk round e.g. have meeting with individual worker at end of school day. Come in to collect and return work at the end of the school day.</p>	<p>The school will provide a choice of simple activities for home which will only be offered to the pupil if they request them. Parents will keep in touch with the school weekly to say whether or not other resources are needed. A meeting will be arranged once health professionals advise us that the pupil is ready to have more contact with school.</p> <p>X will be allocated (name) as an individual support worker who will meet with X weekly to begin with. Work at an appropriate level from subject teachers will be provided and completed work collected in this meeting and feedback given. The individual worker will communicate with the parents/carers regularly and involve them in planning.</p> <p>X will visit the school after the end of the school day and re-familiarise/de-sensitise herself to the school site by walking around it with the support of parent/member of school staff. X will meet with (individual worker) after school to collect work from teachers and return completed work and receive feedback. X will wear school uniform when on the school site.</p>

Agree a graded return to school programme if the pupil has been out of school for some time. Consult with the child, parents and medical professionals.

This might begin by doing work set by subject staff in learning base, building up amount of time gradually e.g. an hour a week, an hour a day, 2 hours a day. Think about getting to and from the learning base (or lessons at a later stage)

NB Some pupils will be ready to go straight into lessons and this should be encouraged.

Prepare for returning to lessons

Identify a starting point for attending lessons with other students – best subject or teacher/a group with a friend - and gradually increase the time spent in lessons. May need support from individual worker to do this (in the lesson/sitting with/sitting apart, just outside the classroom, to be found in an appointed place if they are particularly anxious e.g. after a long absence.)

X will attend school for 2 hours a day for the first 2 weeks of the plan, with the aim of gradually increasing to full time. The plan will be reviewed regularly and decisions as to the pace of reintegration made in the light of current progress.

X will have work set by subject staff and be given support to work on it for 2 hours each day in the learning base. Subject staff will supply other work that can be done independently at home. X will be met at the school reception at an agreed time by a member of staff and walked over to the learning base. A member of staff will take her back to the school reception at the end of the session.

We will organise a meeting for X to meet her new form tutor and also encourage her to reconnect with her friends, initially by text.

X will begin to start some lessons with other students. We will start with Art as this is her favourite subject and she has a supportive relationship with the teacher. We will add in other subjects in negotiation with X as she feels able to do more.



<p>Review and agree next stage of plan at appropriate intervals.. Accept that progress will be slow and that for some periods (maybe often) the plan will remain the same. Give time to talking about how new things are likely to happen/think about eventualities and make plans for them/counting down “In ten minutes we’re going to...” “ In two weeks’ time it’s going to be ...”</p>	<p>X’s timetable will be reviewed monthly and in negotiation with her. A flexible part-time timetable will be agreed with some time in school and some time working independently at home. We will work with X to make sure that she knows what to expect and to flag up extracurricular events she may wish to be included in.</p>
<p>Support the pupil in managing their pain</p>	<p>Staff will acknowledge the young person’s pain when it is expressed, but will encourage them to focus beyond it by directing their attention elsewhere. There will be a pain management plan in place.</p>
<p>Support mobility around the school if this is an issue for an individual</p>	<p>X is to be allowed to leave the classroom 5 minutes early to avoid busy corridors. She will be allowed to use the lift rather than the stairs.</p>
<p>Minimise strain in case of back or neck pain</p>	<p>X will be given a locker to keep her school books in. X will be provided with an extra set of textbooks to use at home X is to sit facing the teacher in the classroom</p>
<p>Encourage good posture and ensure that tables, chairs and equipment are an appropriate fit for the individual. (An</p>	

Occupational Therapist may be able to advise in complex cases.)

If pain affects handwriting adaptations may be needed

Some flexibility or adaptation may be needed around PE lessons

Do not be quick to send a young person with pain home. Agree a management plan with the child, parents or medical team.

X will work at a table of appropriate height and be offered a block to raise their feet. They will have a footrest when sitting on the high stools in the Science room.

X will be offered rest breaks in exams. Staff are aware that X's handwriting may be untidy when she is tired and that this does not mean that she is being careless. She will be encouraged to take her time. Staff will help with longer note-taking work by providing photocopies.

X will be responsible for pacing herself during PE lessons but will try to participate when possible. X will inform staff if she needs to rest and staff will be aware that this may be the case. Staff will encourage X to participate in other ways if the physical activity is too much e.g. by refereeing or keeping score where possible, or by adapting the activity for her.

X is experiencing bad pain in lessons she can approach staff to request time out in the medical room or to work in the Learning Base. She is to be allowed 30 minutes (?) rest and should then return to class. If X is unable to return to class after 30 minutes parents are to be called and X is to be taken home for the rest of the day (and to continue with the agreed timetable for the next day).

Ask the pupil/family to make a personal "Distraction Box" which includes things to use to self-soothe at times when the pain is particularly bad (make a nice box, allow ipod, puzzles, mindful colouring, sensory or fiddle toys, handcream...etc). It's important for the pupil to take X will make herself a Distraction Box including activities to do if she is experiencing bad pain. It will be stored in the medical room and X will be given access to it if "time out" in school has been needed. The pupil should take responsibility for choosing and supplying what it contains. This will be useful if the pupil needs "time out" in school

Work on specific problems that inhibit progress - seek advice from clinicians if the problems require it or seem intractable.

Think about incentives and rewards - these could come from school or family and should be individually tailored.

X will ask for pain killers if the pain is bad, or be reminded that this is an option. The medication is stored in the school medical cabinet and will be administered according to the school's Medical Policy

X may ask for permission to move and stretch

We will seek clinical advice about... or

X will create a box containing things to do if they need to have time out in school.

X has been working on managing to participate in PE in school. We will support the way of working her consultant has suggested (give details if possible)

As time in school increases and includes break or lunch make a plan for these unstructured times if needed. Arrangements to be as normal as possible to encourage social interaction and foster independence and self-confidence. It should be rare that special arrangements are needed.

Teachers should be made aware of how the pupil might present at difficult times. Pain, fatigue and anxiety may cause changes in behaviour, including withdrawal, poor concentration and frustration or aggression. The pupil and the teacher may need a quick means of communication that can be used easily in lessons.

Using praise and reflection

X is to have a reward when she has managed to attend her individualised programme for a week. She has chosen to have a trip to the swimming pool with her cousin.

X will come to the learning support base at break and lunch time if she is in school at those times. She will be encouraged and supported to socialise with other students (Circle of Friends) in the learning base.

Staff will be made aware of how X's pain may sometimes lead to changes in her behaviour and be sensitive to this where appropriate.

Staff will be aware that she has a time out plan (and how it works) and may ask for medication. Staff will give positive feedback when X has done well. X has written a list of things for staff that are helpful or not helpful to her in lessons (What I want my Teachers to Know). This will be communicated to staff.

X will carry traffic light cards to indicate to staff how she is feeling. (Green - all well, Amber – might need support, Red – needs to leave lesson and go to medical room to rest)

<p>It would be helpful for school staff to use a common language with the pupil, especially if they are having "talking" therapy by linking in with therapist e.g. "scary thoughts/cognitions /skills/challenges".</p> <p><b><i>Use the term "pain flares" to describe episodes of pain (and remind the pupil that pain flares "subside")</i></b></p>	<p>Staff will give praise at appropriate times to reinforce effort and attainment, particularly to recognise when X has pushed through pain remained in school or persisted with</p> <p>Staff will try to use language that is accessible and familiar to X in school, drawing on the words and terms she is using in CBT or other.</p>
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<p><b>6 Scripts</b></p> <p>Remember to talk to the child not the pain - "How are you today?" rather than "How's the pain today? Wait for the pupil to raise the subject of pain if they need to, rather than asking leading questions that focus too much attention on it. Use a neutral rather than a too concerned tone of voice to avoid feeding into anxiety. It is not usually helpful to talk about your own pain to the pupil – it can show empathy but can also give out unhelpful messages ( e.g. "I've had a bad knee for 15 years and it just gets worse")</p> <p>"We understand that you are in pain and that school is sometimes difficult for you. But we have worked with pupils like yourself in the past and we can support you. We can make a plan with you that will help you get back to where you need to be."(reassurance/normalising the situation )</p> <p>"I can see that you're looking uncomfortable. You can let me know if you want to tell me something."</p>
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"I can see this is difficult for you, but I am confident it is a pain flare and that your body is not damaged, so I'm not worried about that. What would you like to do?"

"I'm really sorry you've got a painful tummy today...how about we look at this and see how it goes?"

"What would help you right now? How about a bit of a stretch? A walk round? A glass of water?"

"What helped you get through this last time? What can you do to make it better?"

"Let's try to take your mind off things and see how it goes..."

"I know you're worried about the pain coming back, but that might not happen...we won't know unless you try – can you think of a way of doing this differently that might be better?"

"Let's make a plan and see how it goes – if it doesn't work, we'll think about it together again"

"Let's just sit and wait, there is no hurry."

"Let's just try just the next step..."

"I can see that this is too much for you right now...can you think of a better time to try it?"

"Let's try 5 minutes, and if it's still too much, talk about it and try again tomorrow".

"You've done the time/amount of minutes we agreed. That's terrific. You've worked really hard to keep going. Well done."

“It’s great that you’ve managed to do that despite not feeling so good – how did you manage to keep going? Let’s try to remember that...”

“I can see this is too much for you today - let’s take some time out and think again. Sometimes we have to try lots of times before we succeed, so let’s try to keep going and come back to this another time”

“It was really good that you managed to (do more) than last time. What made it different? What worked for you in managing your pain? Let’s remember that so you can try it again”.

“What do you think we should aim for next?”

“I know you’re in pain, let’s do something together to try and take your mind off it, if possible!”

“Well done, you’re doing so well, I know you’re hurting but you are doing amazingly well!”

“You have done amazingly well, I’m so proud of you.”

I’m going to say it’s time to finish now, you’ve done really well, but I don’t want you to wear yourself out and I think you need a break.

## 7 Progress

### Indicators of success/Identifying further development

*What might achievement and progress look like?*

Able to attend most lessons and to learn.

Able to manage some social time

Continuing to work on remaining challenges. May still need to have some time in learning base or similar as part of their routine.

Good pupil/family/support worker communication established but needing less frequent contact.

Pupils will be able to use a range of strategies to reduce/manage their pain in most situations and will be becoming increasingly independent.

When feeling in too much pain to be in lessons, the pupil will use their rest space and be able to manage themselves or to approach staff for extra support.

**N.B. Update the IHP - keep copies of previous versions or a rolling log so there is a record of the interventions you have put in place and their outcomes. Note the positives/achievements as well as on-going difficulties. Put in more support at points of transition eg ends and starts of years, changes of staff, exams, trips and visits.**

**Accept that this will be a longer-term recovery and that there are likely to be periods of regression along the way and that this does not necessarily mean failure.**

**The Pain Progress Grid below may help with assessment.**

Name

Colour

Date



Not able to come to school at all	Needing an adjusted timetable (up to 25%)	Needing an adjusted timetable (up to 50%)	Managing almost a full timetable (Up to 75%)	Managing a full timetable (Up to 100%)
Needs to be with an adult at all times, to be accompanied on and off the school site	In learning base all the time Unable to work elsewhere	Mainly in learning base, but attending some classes Needs support for moving around the school	Mainly in lessons/small amounts of time in learning base Managing most transitions by self	In lessons Managing transitions independently
Extremely anxious about pain.	Very anxious about pain	Anxious about pain	Less anxious about pain	Seldom anxious about pain
Not able to be present with any other students, needs to be in a separate space	Can be around other students in learning base, can see other students and be seen, but avoiding all interaction	Can be around other students in social time in a protected space.	Can attend lessons with extra support in or outside the classroom	Can attend lessons without extra support and manage social time
Unable to form social relationships with peers	Has some contact with one or more friends, in or out of school	Is forming connections with other peers in a protected setting	Able to work with others in the context of a lesson	Maintaining friendships
Not ready for contact with school staff	Can communicate with staff if directly spoken to	Forming good relationships with one or more members of staff eg mentor	Will engage with and respond to most adults	Has formed positive relationships with most members of staff who teach them
Able to acknowledge the presence of school staff through their body language			Able to work with a larger number of staff	
Unable to show interest or motivation in learning	Can begin work with 1-1 support	Can learn independently	Can learn independently and also small groups	Can learn alongside others in a class setting
Unable to focus at all due to pain	Able to focus for about 15 minutes	Can focus for an hour at a time	Can focus for 2-3 hours during the day	Can focus for most of a school day
Working on personalised/engagement activities	Working on bespoke work/project approach	Accessing selected parts of the curriculum, with some additional support	Accessing most of the curriculum, with less individual support	Accessing the whole curriculum
Too much pain to attempt to come in to school	Can access school with a lot of individual support	Has periods of time in school where pain is not an issue	Managing most routine things in school though will still have occasional difficult times	Can manage unpredictable or unusual events – visits, tests
Unable to challenge pain	Understands that pain needs to be challenged	Can make a plan to challenge pain and begin to execute it	Can identify skills and strategies that are helpful	Uses skills and strategies independently
Has no skills and strategies to use	Can sometimes manage their pain with intensive support from an adult	Has learnt some skills and strategies that can help and can sometimes use them	Can mostly use skills and strategies with success	Knows what to do to manage self in most situations