

**Title: Chronic Primary Pain in children and young people: evidence review with reference to safeguarding**

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## **Abstract**

Many children and young people experience recurrent pain, and a minority of these experience substantial disability and distress. Some have pain that is intrusive and that does not come from an obvious medical cause, such as chronic abdominal pain, headache, or widespread musculoskeletal pain. Historically, such persisting pain has been a contested category, with labels such as 'psychosomatic' or 'medically unexplained' pain being used. Social Workers are not always able to access unequivocal medical advice about treatment and prognosis in these conditions and will benefit from being aware of the current literature. Happily, contemporary research helps to explain the physiological origin of such chronic pain states, and the personal and systemic contributors to pain-related distress and disability. This paper reviews epidemiology, cause, presenting features and treatment of these conditions, as well as issues of stigma. Successful investigation of child safeguarding concerns in this context, and of suspected Fabricated and Induced Illness, will benefit from an understanding of the typical presentation of these conditions, as they are not well understood in mainstream medical practice. We explore how parental attitudes and actions may sometimes come from legitimate concerns, yet may also in some situations come to constitute cause for safeguarding concern.

**Keywords:** catastrophizing, child safeguarding, chronic pain, fabricated and induced illness, pain management, parenting

## **Teaser Text:**

Some young people have a chronic primary pain (CPP) condition, where they experience unpleasant ongoing pain despite there being no cause easily found by doctors. Some examples would be persistent stomach pain, headache, or muscle and joint pain. Most people do not understand these conditions, including Social Workers but also most health and education professionals. This makes things harder when a Social Worker needs to support a young person with pain, or where they need to investigate child safeguarding concerns. This paper reviews literature that explains how CPP conditions can arise, what young people usually struggle with, and how to distinguish family factors that are common from those that may indicate safeguarding concern.

## Introduction

Recurrent pain is not uncommon in children and young people. Estimates of prevalence vary between 11% and 38% in a review of multiple population studies across many nations; a minority of these young people experience substantial disability and require extensive health care (King *et al.*, 2011). Whilst pain can be present in younger children, prevalence of persistent pain increases sharply in adolescence (King *et al.*, 2011). Some forms of recurrent paediatric pain are intuitively easy to understand, such as Sickle Cell Disease. However, many young people experience a Chronic Primary Pain (CPP) condition, where they experience persistent discomfort despite the fact that no pathological causes are easily found on examination. Examples include persistent abdominal pain, headache, widespread pain and Complex Regional Pain Syndrome (CRPS, (Nicholas *et al.*, 2019).

Young people with CPP can be described as children in need where their condition causes sustained disability, and CPP can be a threat to longer term development, increasing social, educational and occupational problems in young adulthood (Murray, Groenewald, de la Vega, & Palermo, 2020; Palermo, 2020). Young people with CPP commonly have parents with physical and mental health problems (Campo *et al.*, 2007). In these cases, Social Work involvement may be necessary. However, the role of the Social Worker can be challenging in these contexts, as CPP is poorly understood in medical and education settings. Where health-related safeguarding concerns arise with regard to young people with other, more common, chronic medical problems (e.g., diabetes), the Social Worker may be confident of clear advice from healthcare professionals. However, CPP conditions are poorly understood outside of specialty healthcare contexts, and do not conform to a 'medical model' whereby physical symptoms should have a readily identified and proportionate medical cause (Liossi & Howard, 2016). The lack of this 'cause' can lead to health and education professionals doubting the legitimacy of the child's symptoms and giving differing advice (Schechter & Nurko, 2019). Social Workers may struggle to get consistent opinions on diagnosis, prognosis and treatment from health care professionals. Parents and families may dispute the quality of medical care given, sometimes questioning or rejecting advice. There may even be concerns about Fabricated and

Induced Illness (FII), as suspicion of FII is often applied to subjective physical symptoms (such as pain) that seem disproportionate to their medical cause (Bass & Glaser, 2014). It can be hard to judge safeguarding risk in the context of this medical uncertainty. Young people are often painfully aware that their condition is poorly understood (Wakefield *et al.*, 2018) and will greatly benefit from encountering a Social Worker who has an up-to-date knowledge of CPP conditions.

However, CPP conditions are increasingly well scientifically understood. The historical label of chronic primary pain being a ‘medically unexplained’ condition (Forum for Mental Health, 2011) cannot be maintained in the face of the growing research literature. Professionals can most helpfully assess and intervene where they understand what is typical, and atypical, in these conditions, as well as evidenced treatment approaches. This narrative review, based on literature in the English language up to March 2021, aims to support Social Workers to understand CPP conditions, to (1) better support young people with them and (2) to be able to judge health-related safeguarding concern more confidently.

### *Prevalence*

Anecdotally, some health and education professionals hold the view that recurrent pain in children is uncommon, and therefore suspect or questionable. Social Workers can make more informed judgements by referring to the literature. Whilst most children and young people reach adulthood without regular pain experiences, such patterns are surprisingly prevalent; a UK birth cohort sample showed a recurrent pain rate of 21.1% at age 17 (Caes, Fisher, Clinch, Tobias, & Eccleston, 2015). The impact of this pain is uneven – only a minority of young people are more severely affected and require the most help. In terms of health care expenditure, 5% of the paediatric chronic pain sample accounted for 30% of healthcare costs due to chronic pain in an American sample (Groenewald, Essner, Wright, Fesinmeyer, & Palermo, 2014). Headache is the most common paediatric chronic pain condition, followed by abdominal pain and various forms of musculoskeletal pain (categories of CPP pain conditions, from the World Health Organisation (WHO), can be seen in Table 1 (Nicholas *et al.*, 2019). Young people with chronic pain are readily found in hospitals, for instance, those with

headache in neurology departments, and those with abdominal pain in gastroenterology services; in a Dutch hospital, 51% were struggling with school absence, 40% with difficulties with socialising and 34% with disrupted sleep (Konijnenberg *et al.*, 2005). Chronic pain in childhood confers risk for adulthood. In an extended follow up of young people who had been treated for chronic abdominal pain, 35% still met diagnostic criteria for similar problems as a young adult, and 48% had chronic pain in other locations (Palermo, 2020). Similar results have been found for back pain and widespread pain; thus, some young people do seem to 'grow out' of this difficulty, yet many do not, indicating the imperative for effective treatment at the earliest stage. The trajectories of the most severely affected young people are critical; the direct and indirect healthcare costs of a young person having severely disabling chronic pain have been estimated at £21k per annum (Sleed *et al.*, 2005, adapted for 2019 prices).

#### *Nature and Cause of Chronic Primary Pain conditions*

In Chronic Primary Pain conditions, great distress can coexist with few visible causes for it. This can be hard to understand, for the patient, relatives and professionals; unfortunately, the young person is often aware of this incomprehension (Wakefield *et al.*, 2018). Social Workers can reassure young people and combat stigma by understanding the nature of these conditions. Acute pain is more intuitively understood, where we experience discomfort that is proportional to the trauma (a broken ankle hurts more than a twisted ankle) and where that discomfort fades as the problem heals. Chronic secondary pain is also relatively easily understood, for example, where a musculoskeletal injury causes pain for more than three months, or persistent pain is provoked by a clear underlying medical cause (e.g. juvenile arthritis, sickle cell disease). However, CPP is diagnosed where pain persists for over three months, and where there is no readily identifiable medical cause; the pain itself is the primary presenting problem.

#### *Historical models of pain*

There is now some scientific consensus about how chronic primary pain states arise. To appreciate this, it helps to first identify two 'older' models of pain that are now seen as incomplete or incorrect. The first, unhelpful, model is that the pain system in the human body is a passive receptor of information. In this view, there is one direction for information; for example, nerves in the periphery detect a problem (e.g. a stubbed toe) and this is relayed via the spinal cord to the brain, where the 'pain experience' arises. From this picture, the assumption arises that there should be no pain without some obvious damage somewhere in the body. This has been recognised as at best oversimplified, and at worst wrong, for decades. Common clinical experience shows it to be incorrect, such as in cases of phantom limb pain after amputation (Melzack and Wall, 1965).

A second model is that chronic primary pain states are 'psychosomatic' phenomena. Although the term 'psychosomatic' is often used with confidence, as if it is a clear concept, it is not. A review of the pain literature showed that there is no consensus about what this word means (Crombez *et al.*, 2009). For example, it may mean (1) that the person is labelling the physical aspects of an emotion, incorrectly, as pain. Alternatively, (2) in other more psychodynamic accounts, they might be experiencing the eruption of an unacknowledged emotion or stress that is manifesting as a physical symptom (via unobservable unconscious mechanisms). There is no agreement as to the correct account. In the paediatric context, sometimes the concept involves attributing pain to parental (usually maternal) emotional struggles. Despite compelling case reports and intuitive appeal (Freud and Breuer, 1895), the 'psychosomatic' picture of pain struggles under scrutiny. Reviews in the adult and paediatric pain literature have shown the idea of 'somatisation' to be conceptually weak and to evade clear definition (Wakefield *et al.*, 2018). The implication, that the painful sensations of CPP would disappear precisely in sync with resolution of certain personal issues, is seldom seen in paediatric pain practice. Also, although the idea is not intrinsically stigmatising or belittling, casual use of this concept has contributed to the stigma around CPP conditions, as will be described below.

After decades of research, including neuroimaging and basic science work exploring the nervous system in animals, persistent pain in the absence of an obvious stimulus can no longer be described as ‘medically unexplained’. The pain system is not a passive ‘relay’ of information from the periphery to the brain (Legrain *et al.*, 2011). Instead, ‘pain nerves’ (nociceptors) connect to the spinal cord at the dorsal horn where a ‘filtering’ of their information takes place. As ‘pain signals’ ascend to the brain, a range of different neural structures process the sensory, evaluative, and affective aspects of pain, and in turn they exert ‘descending control’ back down to locations such as the dorsal horn which can enhance or diminish further signals (Bourke *et al.*, 2015). This dynamic system of feedback explains common phenomena such as pain habituation, where a repeated stimulus becomes less bothersome over time, and also pain sensitisation, where the stimulus becomes worse.

For example, decades of research have clarified a process termed Central Sensitisation (CS), an “amplification of neural signalling within the CNS that elicits pain hypersensitivity” (p55, Woolf, 2011). This mechanism gives a clear example of how persistent pain can happen without ongoing physical damage. CS manifests as hypersensitivity to touch, lingering pain sensations when the stimulus is absent, and spread of sensitivity away from the initial site of pain. Stimuli of the same intensity become more painful over time. This phenomenon has been shown to be present in a range of CPP conditions (Bourke *et al.*, 2015). Whilst it is beyond the remit of this review to cover the neuroscientific and clinical literature in this area, it is important to know that these well-defined mechanisms exist; they can helpfully be explained by metaphors that are often used in clinical practice. For example, CPP can be described as a “software problem rather than a hardware problem”, where people can see that severe problems can arise even if a computer is functioning correctly (Coakley and Schechter, 2013). Alternatively, it can be useful to draw a parallel with autoimmune medical conditions, where the body’s own natural defences “overreact” and cause problems, in the absence of any other disease process.

A contemporary understanding of CPP allows professionals to avoid dismissing the pain experience or resorting to poorly defined ‘psychosomatic’ explanations. However, evidence nonetheless shows

that the role of emotions, coping, and parent family factors remain pivotal to the *impact* of pain and its treatment.

### *Chronic Primary Pain as a stigmatised condition*

The neuroscience of CPP states is not widely understood, either in the general population or in most aspects of the healthcare system. Thus, when Social Workers encounter a young person with CPP and their family, it is wise to anticipate their previous experiences, which can include disbelief and invalidation. Young people with CPP often encounter the idea that their pain is exaggerated, non-legitimate, or caused by emotions or family dynamics. Although the idea of ‘psychosomatic’ pain is not necessarily designed to belittle, it implies the idea that the patient (or parent) is mistaken in their awareness of what is going on in their body and mind, and that a health professional can know better, on brief acquaintance (Wakefield *et al.*, 2018). It is easy for an observer to see the distress and family dysfunction that often accompany CPP states (summarised below) and to assume these are causal, thus diminishing the significance of the child’s actual pain experience.

Comprehensive literature reviews have summarised the presence and impact of stigma in adult and adolescent CPP (De Ruddere and Craig, 2016; Slade *et al.*, 2009). Adults with CPP feel disbelieved by family, professionals and colleagues. Healthcare professionals see such pain as less severe, where it is not associated with visible tissue pathology, and are more likely to suspect deception. People with CPP are seen, by health professionals, as deserving less help and sympathy (De Ruddere and Craig, 2016). Authors refer to the “sometimes institutionalized beliefs that dissembling of chronic pain is commonplace” (p. 1608, De Ruddere and Craig, 2016). Qualitative work with young people shows experiences with healthcare professionals such as “they’re rude and they think you’re faking”, “They’d be like ‘Nothing is wrong with you’” (Wakefield *et al.*, 2018).

### *Typical presentation of CPP in young people*

CPP prevalence increases with age and is higher in females, with both pain levels and disability peaking in adolescence. A review of international studies showed CPP in children to be associated



with lower socio-economic status, mood problems, and other chronic health conditions (King *et al.*, 2011). An American study, using a nationally representative cohort, showed that risk for CPP was increased by being female, white, experiencing healthcare barriers, having safety concerns and being exposed to violence (Tran *et al.*, 2020). Thus, the paediatric CPP population may well be disadvantaged, as well as being stigmatised.

The role of culture and ethnicity in the experience and expression of paediatric CPP is poorly understood. An authoritative review in 2009 found insufficient data to make any conclusion (Fortier *et al.*, 2009). Subsequent studies have suggested ethnicity differences in particular contexts, such as in experimental pain induced in a lab (Lu *et al.*, 2013), or the pain that young people experience after common surgeries (Rosales *et al.*, 2016). However, neither of these contexts necessarily generalise to the lived reality of CPP.

The different types of paediatric CPP can be explored using the new ICD-11 (World Health Organisation) diagnostic categories, seen in Table 1 (Friedrichsdorf *et al.*, 2016; Nicholas *et al.*, 2019). Where CPP is severe enough for patients to seek treatment, the pain condition may be accompanied by other difficulties. For example, CPP is often seen with associated joint hypermobility, (sometimes known as being “double jointed” and sometimes labelled as hypermobile-Ehlers-Danlos Syndrome), though the relationship between the two conditions is unclear (Landry *et al.*, 2015). In a sample seeking specialist treatment, relatively high rates of comorbid Autistic Spectrum Conditions (ASC) and other neurodevelopmental problems were seen, often previously undiagnosed (Lipsker *et al.*, 2018).

### *Impact of CPP syndromes*

Although CPP can affect varying parts of the body with different symptom patterns, there are common patterns of struggle and disability that all involved professionals should understand. Young people with CPP often experience low mood. They are more likely to be socially isolated and bullied (Kashikar-Zuck *et al.*, 2007), and where severely affected they are often ‘behind’ their same-aged

peers in their capacity for independence (Eccleston *et al.*, 2008). Sleep problems and disturbance of daily routine are common, worsening daily fatigue and diminishing the ability to concentrate (Clinch and Eccleston, 2009). Where young people are frightened to move, they can become sedentary and physically deconditioned, which feeds back into worsened pain and disability (Logan *et al.*, 2012). School attendance and performance become difficult (Alsaggaf and Coyne, 2020). Education professionals find it no easier to understand CPP syndromes than anyone else, and sometimes struggle to understand the 'activity cycling' seen. 'Activity Cycling' refers to a pattern of alternating 'good' and 'bad' periods, including overexertion in relatively low-pain phases, which is followed by increased pain symptoms. A young person can seem more physically capable and more cheerful on one day, and have limited mobility and affected mood the next.

Low mood and anxiety are increased in young people with CPP; depression, anxiety and Post-Traumatic Stress Disorder are all seen at elevated rates. In young people hospitalised for CPP, 44% meet diagnostic criteria for a mental health problem (Coffelt *et al.*, 2013). Young people have also reported positive aspects of dealing with their CPP, feeling that it can make them more mature and understanding than their peers (Jordan *et al.*, 2018).

Family strain is common in CPP, as in many other chronic paediatric conditions (Palermo *et al.*, 2014). Parents are affected by caring responsibilities, worry about their affected child, and experience difficulty in balancing the needs of siblings (Palermo *et al.*, 2014). Families may be managing more than one person with health problems; in one sample of treatment-seeking young people with CPP, 44% of their mothers also had a chronic pain problem (Birnie *et al.*, 2020). In a sample of young people seeking treatment for abdominal pain, their mothers had approximately a five-fold increase in likelihood of anxiety or depression (Campo *et al.*, 2007). Information on fathers is minimal, though qualitative work has begun to explore their experiences (Jordan *et al.*, 2016).

#### *Mechanisms of pain-related disability and distress*

Although chronic pain in young people is not uncommon, there is variability in how much disability and distress it causes. Individual and family responses to the pain usually determine distress and disability more clearly than the intensity of the pain itself (Crombez *et al.*, 1999). Social Workers will benefit from understanding which coping styles are currently understood to improve, or worsen, disability.

### *Fear of Pain*

Young people who are more frightened of their pain function less well and are more distressed (Fisher *et al.*, 2017). According to the Fear-Avoidance Model of pain, fear of pain is likely to lead to avoidance of movement and challenging activities, which will in turn lead to a cycle of increased disability and lost confidence (Asmundson, Noel, Petter, & Parkerson, 2012). Child and parent beliefs about pain, such as that chronic pain is evidence of physical harm or could result in permanent injury, predict worse functioning (Simons *et al.*, 2015). A child's pain-related fear is likely influenced by parental fear of the child's pain and by how the parent responds to their own health problems (Birnie *et al.*, 2020).

### *Coping*

Research has often grouped pain coping styles into *passive* (rest, withdrawal), *active* (problem-solving, seeking support) and *accommodative* (self-encouragement and re-framing the situation; (Walker *et al.*, 2005). Passive coping is quite understandable in the chronic pain context but has consistently been shown to be unhelpful, increasing disability. Changing this is often seen as a goal in treatment (e.g. van der Veek, *et al.*, 2019). In contrast, active and accommodative coping have not been consistently shown to be helpful, against prediction (e.g. Walker *et al.*, 2007). This leaves a question about which coping styles should be 'recommended', which may be partly answered by the concept of acceptance.

### *Acceptance of Pain*

In CPP, pain sensations are often unavoidable, particularly in bad moments. However, most humans nonetheless attempt, naturally, to minimise their pain (e.g. medication, physical rest) and stop activities that cause it. In the chronic pain situation, these attempts are usually either only briefly effective, or come at the cost of an important activity (i.e. stopping school or seeing friends, as these efforts cause pain). The concept of pain acceptance includes a young person's ability to (1) let pain be present without immediately trying to terminate or reduce the experience, and (2) to persist with important activities even with pain present. The ability to 'accept' pain is associated with more positive functioning and mood across all domains, and with a positive response to treatment (Gauntlett-Gilbert *et al.*, 2013; Kemani *et al.*, 2018) .

### *Parent factors*

Safeguarding investigations often include an assessment of parenting impact; the pain literature provides some guidance. Although it is understandable for parents to be protective towards an acutely ill child, in CPP, protective and solicitous parenting have been shown to be associated with worse functioning in the child (Donnelly, Palermo, & Newton-John, 2020). Parents can also come to fear their child's pain as well. Parents who 'catastrophise' about their child's pain have children who are more distressed and who function more poorly. Specific parent fears about the danger of physical movement are also unhelpful (Simons *et al.*, 2015). It is also natural for parents to struggle to see their children in pain and to try to take steps to stop it. Parent Acceptance of the child's pain, using a similar definition of acceptance to above, is consistently associated with better child outcomes (McCracken & Gauntlett-Gilbert, 2011). Finally, the parent's global wellbeing has an impact on the child with CPP. Parents with higher levels of anxiety and depression generally have children who function less well with pain (Donnelly *et al.*, 2020).

### *Treatment*

Young people with CPP are usually treated with medicines, other medical interventions (such as injections of painkillers), and rehabilitative treatments involving physiotherapy and psychology.

However, the evidence for these varied treatments is uneven, and unevidenced treatments (e.g. pain-killing drugs), are still widely used in practice.

There is no evidence that analgesic medications are effective for young people with CPP, including over the counter pills such as ibuprofen, or stronger medically prescribed drugs such as morphine (Eccleston *et al.*, 2019). This conclusion partly comes from a lack of research, but it indicates that medicines should never be the sole approach to CPP conditions. It remains possible that drugs may help particular individuals. Also, many analgesics have side effects, induce dependence and can induce tolerance, where increasing doses are needed for a therapeutic effect. Where young people with CPP are on a range of different analgesic agents, it is important to question whether these are improving the young person's mood and functioning.

Interventional procedures have been invented for pain difficulties, such as injection techniques (peripheral nerve blocks and trigger point injections). However, they are seen as a "last resort at the end of the therapeutic algorithm" (p365, (Shah *et al.*, 2016) due to the risk of developing complications.

Despite medications and interventions having questionable benefits and clear risks, they are still widely used in routine practice; it is reasonable to ask why. In general, the child, family and healthcare team are motivated to try to relieve pain, and are aware that successful pain relief is achievable in other contexts (for example, post-surgery). Driven by a strong desire to help the child, medical teams may over-treat with classic medical approaches as above. This phenomenon is understood and discussed in the paediatric literature (Schechter & Nurko, 2019).

Most of the positive evidence for treatment of CPP is found for psychologically-oriented treatments, often with a component of physical activity (Hechler *et al.*, 2015). These treatments are designed to directly reverse pain-related fear, passive coping and physical deconditioning. Reviews show that such treatments can have a sustained effect in reducing disability in young people with CPP (Fisher

*et al.*, 2018; Hechler *et al.*, 2015). Some positive treatment effects persist in the long term (Zernikow *et al.*, 2018).

### *CPP and child safeguarding*

It is evident that most young people with persistent pain manage to live relatively well with this, and do not require help from services. However, some show an escalating pattern of distress, disability, use of healthcare services, and withdrawal from life and education. Many, as a result, will benefit from multiagency support.

Sometimes concern about the young person escalates to safeguarding enquiry. As noted above, severe distress and disability are not inevitable, or untreatable, in CPP conditions, and may be worsened by the young person's, and parent's approach to the problem. Anecdotally, it is common to see education or health professionals questioning whether the child's level of disability is proportionate to their pain problem, and specifically whether parents are acting in the best interests of the child's rehabilitation and independence. As noted above, physical and psychological difficulties are common in parents of young people with CPP, and this may affect their parenting approach. Social Workers may be called upon to assess whether parenting is contributing to the young person's disability, for example, by being highly protective or refusing to support the child to engage in evidence-based treatments.

As CPP conditions are complex and poorly understood, it is possible for professionals both to apply too much, and too little, questioning around parent behaviour. For example, an activity cycling pattern of 'good days' and 'bad days' is common. The child may require a wheelchair at school on one day, but not the next. Parents may justify this pattern whilst teachers question it; although this may seem to raise questions about the parent's consistency of approach, in fact such patterns are common in CPP, and are not in themselves cause for concern. However, if parents (who are perhaps themselves struggling with low mood) are defending the constant use of a wheelchair where other professionals consistently see the child as more physically competent, this may be robustly

questioned. This section of the paper, and particular Table 2, aims to provide some guidance as to what is a common feature in CPP children and families, and which factors should reasonably cause more concern,

Concerns about Fabricated and Induced Illness (FII) may arise, as FII can be marked by persisting medically unexplained symptoms of a subjective nature (Bass & Glaser, 2014). There is no research on the prevalence of FII in chronic pain populations. Anecdotally, frank fabrication of illness is rare in specialised pain settings. However, FII guidance notes a level of concern where illnesses are not actively fabricated or induced, but instead the “child’s symptoms are misperceived, perpetuated or reinforced by the carer’s behaviour; carer may genuinely believe the child is ill” (p. 8, Royal College of Paediatrics and Child Health, 2012). Clinical experience suggests that this level of concern is not uncommon in specialist paediatric pain services. Where this is the case, it can be more helpful to frame this as neglect or emotional abuse, rather than FII, as this allows robust challenge to parental behaviour but without accusation of active manufacturing of symptoms.

Table 2 includes a column, on the left, of common and ‘typical’ features of CPP, drawn from the literature and from clinical experience, and not commonly associated with safeguarding concern in specialised pain services. The right-hand column includes forms of family and parent behaviour that have previously been seen in specialist pain clinical practice, and which are *not* common or inevitable in CPP. They may compromise the development of the child’s functioning and independence. The contrast between columns may provide supportive guidance for professionals assessing safeguarding concerns.

## **Summary**

Chronic Primary Pain conditions are increasingly well understood from a research perspective, but this understanding is not widespread in healthcare and educational settings. Many young people

struggle substantially with their CPP condition and may require multiagency support; Social Workers can have a significant positive impact, particularly where they are educated about CPP conditions. Some come to the attention of services due to health-related safeguarding concerns, and these can best be assessed with an up to date understanding of the conditions, their typical impact, and the most useful treatment approaches.



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**Table 1: Chronic Primary Pain diagnoses and features**

<b>ICD-11 Chronic Primary Pain Diagnoses</b>	
<b><i>Chronic Widespread Pain</i></b>	<b><i>Chronic Primary Visceral Pain</i></b>
- Fibromyalgia	- Chronic primary abdominal pain syndrome
<b><i>Complex Regional Pain Syndrome</i></b>	- Irritable Bowel Syndrome
- CRPS Type 1	- Chronic primary epigastric pain syndrome
- CRPS Type 2	- Chronic primary chest pain syndrome
<b><i>Chronic Primary Musculoskeletal Pain</i></b>	- Chronic primary bladder pain syndrome
- Chronic primary low back pain	- Chronic primary pelvic pain syndrome
- Chronic primary thoracic pain	<b><i>Chronic Primary Headache / Orofacial Pain</i></b>
- Chronic primary cervical pain	- Chronic migraine
- Chronic primary limb pain	- Chronic tension-type headache
	- Chronic temporomandibular disorder pains
	- Trigeminal autonomic cephalalgias
	- Chronic burning mouth
	- Chronic primary orofacial pain

**Table 2: Judging safeguarding / FII concern**

<b>Common feature of Chronic Primary Pain, not a necessary cause for concern</b>	<b>Factor that may increase safeguarding concern</b>
<p><i>Symptom Fluctuation</i></p> <ul style="list-style-type: none"> <li>- Child can function and mobilise better on some days than others</li> <li>- Requires more mobility aid on some days, less on others</li> </ul>	<p><i>Symptom misrepresentation</i></p> <ul style="list-style-type: none"> <li>- Parent denies a witnessed example of good functioning</li> <li>- Says child 'can never' do an activity that has been witnessed</li> </ul>
<p><i>Symptom patterns</i></p> <ul style="list-style-type: none"> <li>- Child struggles with sensitivity to stimuli such as touch / wind (CRPS), loud light and noise (Chronic Widespread Pain and others) and specific foods (Abdominal Pain, IBS)</li> <li>- Family make some changes to environment and routines to accommodate this</li> </ul>	<p><i>Symptoms as barriers</i></p> <ul style="list-style-type: none"> <li>- Parents attempt to limit child's contact with distressing stimuli, resulting in restricted lifestyle and reduced opportunities for independence</li> <li>- Changes made to 'protect' child compromise the family home, affect siblings, reduce healthy parental functioning outside the home</li> </ul>
<p><i>Parent struggling emotionally around condition</i></p> <ul style="list-style-type: none"> <li>- Parent struggles to tolerate seeing their child in pain</li> <li>- Struggles with lack of 'proper medical diagnosis'</li> <li>- Strong desire to reduce child's pain</li> <li>- Some dissatisfaction with one or two health or education professionals</li> </ul>	<p><i>Parent impeding healthcare treatment</i></p> <ul style="list-style-type: none"> <li>- Parent insists on repeated, often unpleasant, medical investigations</li> <li>- Refuses to encourage child to take on challenging physical and psychological treatment</li> <li>- Unwilling to witness child in discomfort, so applies few boundaries or expectations</li> <li>- Pattern of soured relationship with most health / education professionals</li> </ul>
<p><i>Parent and child beliefs about pain</i></p> <ul style="list-style-type: none"> <li>- Struggle to believe that 'hurt' is not necessarily 'harm'</li> <li>- Wishful thinking about a cure for pain from standard or alternative routes</li> </ul>	<p><i>Parent and child beliefs about pain</i></p> <ul style="list-style-type: none"> <li>- Belief that movement and exertion are actively harmful and 'worsen the condition'</li> <li>- Beliefs combine with other 'modern healthcare worries' (e.g. concern about WiFi, vaccines, non-mainstream dietary theory) to result in lifestyle restriction for the child</li> </ul>
<p><i>Equipment and adaptations used to enable</i></p> <ul style="list-style-type: none"> <li>- Equipment (e.g. elbow crutches) is used sparingly and allows child to access developmentally important activities on a 'bad day'</li> <li>- Giving up equipment (e.g. transitioning from walking with crutches to without) is desired but experienced as challenging</li> </ul>	<p><i>Equipment and adaptations function to disable</i></p> <ul style="list-style-type: none"> <li>- Equipment multiplies, is not removed, and child disability increases in line with this</li> <li>- Parent benefits, either financially, or in terms of their identity, from having a 'disabled child'</li> </ul>
<p><i>Social media (SM) use and support</i></p> <ul style="list-style-type: none"> <li>- Child uses SM to connect with other young people with CPP, to reduce social isolation</li> <li>- Parent seeks out advice and information on managing condition and possible treatments</li> </ul>	<p><i>Social media use and disabled identity</i></p> <ul style="list-style-type: none"> <li>- Child or parent adopts SM 'disability / pain campaigner' identity at the expense of maximising the child's functioning</li> </ul>

	<ul style="list-style-type: none"> <li>- Parent focuses on un-evidenced advice seen online at expense of engaging with evidence-based treatments</li> </ul>
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