

## PA52 Pediatregydd, Ysbyty Athrofaol Cymru (Saesneg yn unig)

Senedd Cymru

Y Pwyllgor Plant, Pobl Ifanc ac Addysg

Absenoldeb Disgyblion

Ymateb gan Pediatregydd, Ysbyty Athrofaol Cymru

Welsh Parliament

Children, Young People and Education Committee

Pupil absence

Evidence from Paediatrician, University Hospital of Wales

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Nodwch eich barn mewn perthynas â chylch gorchwyl yr ymchwiliad, sydd wedi'u grwpio'n 5 thema

### 1. Rhesymau

There are an estimated 10 700 pupils attending schools in Wales whose persistent school absence (attendance < 90%) is attributed to pain or chronic fatigue, yet there are no coordinated and coherent pathways of care in Wales for paediatric rehabilitation including for pain and fatigue.

The persistence of pain, fatigue and other symptoms is not usually explained by an underlying condition and there are often multiple contributing factors including adverse childhood experiences and neurodiversity. Due to this level of complexity its management is not well suited to routine paediatric model of care and there are many gaps in knowledge, expertise and confidence across all paediatric services.

Further hypotheses to explain why chronic pain and fatigue affect school attendance include:

- an avoidant response to pain resulting in functional impairment and difficulty coping with the demands of school
- parents finding it difficult to negotiate school attendance in CYP expressing pain
- CYP with pain are more likely to have psychological and physiological co-morbid conditions, including depressive and anxiety symptoms, known drivers of school absenteeism
- parents may have maladaptive cognitive (e.g. catastrophising) and behavioural (e.g. protective) response to their child's pain, possibly resulting in further functional disability

Because of the increased perception of threat from COVID during the pandemic and reduced participation in activities there has been an increase in persistent pain in some pupils, whereas in others home education has felt safer and more contained and the experience of pain has reduced. These point to beneficial and adverse effects of school.

### 2. Risgiau a chanlyniadau

Persistent pain, lasting continuously or intermittently for at least three months, affects 8 to 40% of children and young people. In 5% of this population it is severe, affecting quality of life and is associated with poorer outcomes in terms of educational and degree attainment, employment and income. Surveys by the Office for National Statistics has shown persistent pain to be associated with higher levels of disability in people aged 15-34y than for mental health complaints and the WHO has cited persistent pain as one of the top five

causes of disability in adolescents. At least 20% of persistent pain in adults has its origin in childhood and adolescence.

### 3. Effaith

see above

persistent pain is also associated with higher levels of deregistration and clinical experience indicates the home schooling is associated poorer outcomes from persistent pain

### 4. Effeithiolrwydd polisïau

There are no coordinated and coherent pathways of care in Wales for paediatric rehabilitation including for pain and fatigue and no effective integration with schools even though schools present an extremely valuable resource and structure for rehabilitation.

There are many and diverse services for adults with chronic pain and fatigue and many Welsh and other guidelines, including by the National Institute for Clinical Excellence, have been written for this population. Although there is little or no reference to children and young people and no signposts to resources to support the management of children and young people the guidelines still provide a suitable framework.

There is an ideal opportunity to codesign new systems and pathways of care with patients and parents along with education, primary and mental health care, social services and communities.

### 5. Arall

This has been written by Dr Nick Wilkinson, Ceri Reed and Dr Helen Fardy.

Nick is a paediatrician who has set up new models of care in rheumatology and chronic pain across the UK for a combined population of 14 million,

Ceri is Director of Parents Voices in Wales, a grassroots social enterprise company supporting parents and carers whose children and young people have challenges with mental health and/or neurodivergent conditions,

Helen is a paediatrician, currently working as an Associate Medical Director with the Welsh Health Specialised Services Commissioners we recommend.

Our contribution is summarised as follows:

There are an estimated 10 700 pupils attending schools in Wales whose persistent school absence (attendance < 90%) is attributed to pain or chronic fatigue, yet there are no coordinated and coherent pathways of care in Wales for paediatric rehabilitation including for pain and fatigue.

The persistence of pain, fatigue and other symptoms is not usually explained by an underlying condition and there are often multiple contributing factors including adverse childhood experiences and neurodiversity. Due to this level of complexity its management is not well suited to routine paediatric model of care and there are many gaps in knowledge, expertise and confidence across all paediatric services.

Patients and families are often bounced between services and receive conflicting explanations and advice. This leads to further harm through inappropriate care, patients and families disengaging and symptoms becoming entrenched or further amplified.

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Schools present an ideal resource to support effective rehabilitation strategies provided there is access to multidisciplinary teams and school-based health care especially if delivered in the format of health coaches. This helps teachers in their understanding and to provide the right environment for patients and families to self-manage and feel empowered.

as a result we recommend

1. The establishment of a paediatric rehabilitation leadership team and strategy for Wales with an initial focus on chronic pain and fatigue.
2. Families to be part of the public involvement and coproduction of developing new systems of high value care along with schools, primary and mental health services and communities.
3. Equitable local access to multidisciplinary therapy support including specific employment of paediatric physiotherapists, occupational therapists and psychologists
4. Consideration of school-based health coaches to work alongside the Whole School approach to mental health, multidisciplinary teams and primary care and paediatrics
5. Inclusion of pain, fatigue and paediatric rehabilitation in a cross Government policy on mental health and neurodiversity in young people and the Neurodevelopmental Action Plan of Welsh Govt June 2022
6. A training and support program in rehabilitation, pain and fatigue across all paediatric services and initial teacher training
7. The development of age specific tools to support staff, patients and families and presented in formats to accommodate different learning styles
8. Consideration for the establishment of a national paediatric directorate for children and young people's healthcare service to oversee effective integration into paediatric care; ensure equitable resource allocation and avoid duplication of services; coordinate collaboration between education, mental health, social services, charities and community action.

A document entitled "Pupil absence associated with pain and fatigue Jun 2022" has also been submitted via email to further make the case with supporting scientific evidence.

