

Recovering from Illness Paediatric Service

# Support for Children & Young People Coping with Illnesses

Advice for  
Education  
Providers



Gwasanaeth Rheoli Symptomau  
Symptom Management Service



GIG  
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# Recovering from Illness Paediatric Service



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# Who we are

The Recovering from Illness Paediatric Service is a service designed to support the needs of Children and Young People (CYP) who are coping with illnesses, including *Myalgia Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia, Chronic Pain and Long COVID*

The **RFI** Team works with children, young people, and their families to support them in coping with the challenges of having a health condition or dealing with symptoms that can get in the way of doing the things that matter to them in life.

Almost every child, or young person, referred into the RFI service struggles to achieve expected attendance rates in school. Therefore, a crucial aspect of the intervention plan usually relies on the **support of the CYP's school to assist the young person to access education** in a way that is most suitable and appropriate for their needs.



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# The RFI Team is made up of:

Consultant Paediatrician

Physiotherapist

Clinical Psychologist

Occupational Therapist

Assistant Psychologist

The RFI Team have designed this support package to be used within schools to help identify, understand, and support those CYP who may be struggling to access education and require further intervention.

# Health conditions covered by the RFI service

- Post viral syndrome (inc Long COVID)
- ME/CFS
- Chronic pain
- Fibromyalgia



It is important to note this guidance can be used for many children who are struggling with symptoms that may interfere with their education.



## Common symptoms

- Fatigue
- Headaches
- Nausea and vomiting
- Brain fog and concentration difficulties
- Aches and pains
- Respiratory problems
- Disturbed sleep



## Secondary symptoms including

- Low mood, anxiety and low self-confidence



# Importance of Early Identification and Prevention

A pattern of broken attendance is typically seen in children who are *struggling to manage their symptoms* and do the things that matter to them.



Typically, CYP who are struggling to balance their symptoms and education will begin to miss a few days of school at a time.

They will then return, appearing recovered.

After a few days attendance, CYP will then be absent for another few days at school.

This pattern of broken attendance will continue until the school or family flag an issue.

Usually, targets for returning to school will then be set, these may not be achieved by CYP due to their health condition.

This can make it difficult for the school and family to manage CYP's symptoms without having an impact on their relationship.



# Why do CYP with health difficulties struggle to get into school?

Children may have been struggling to do things that matter whilst living with their symptoms.

## Their difficulties may include;

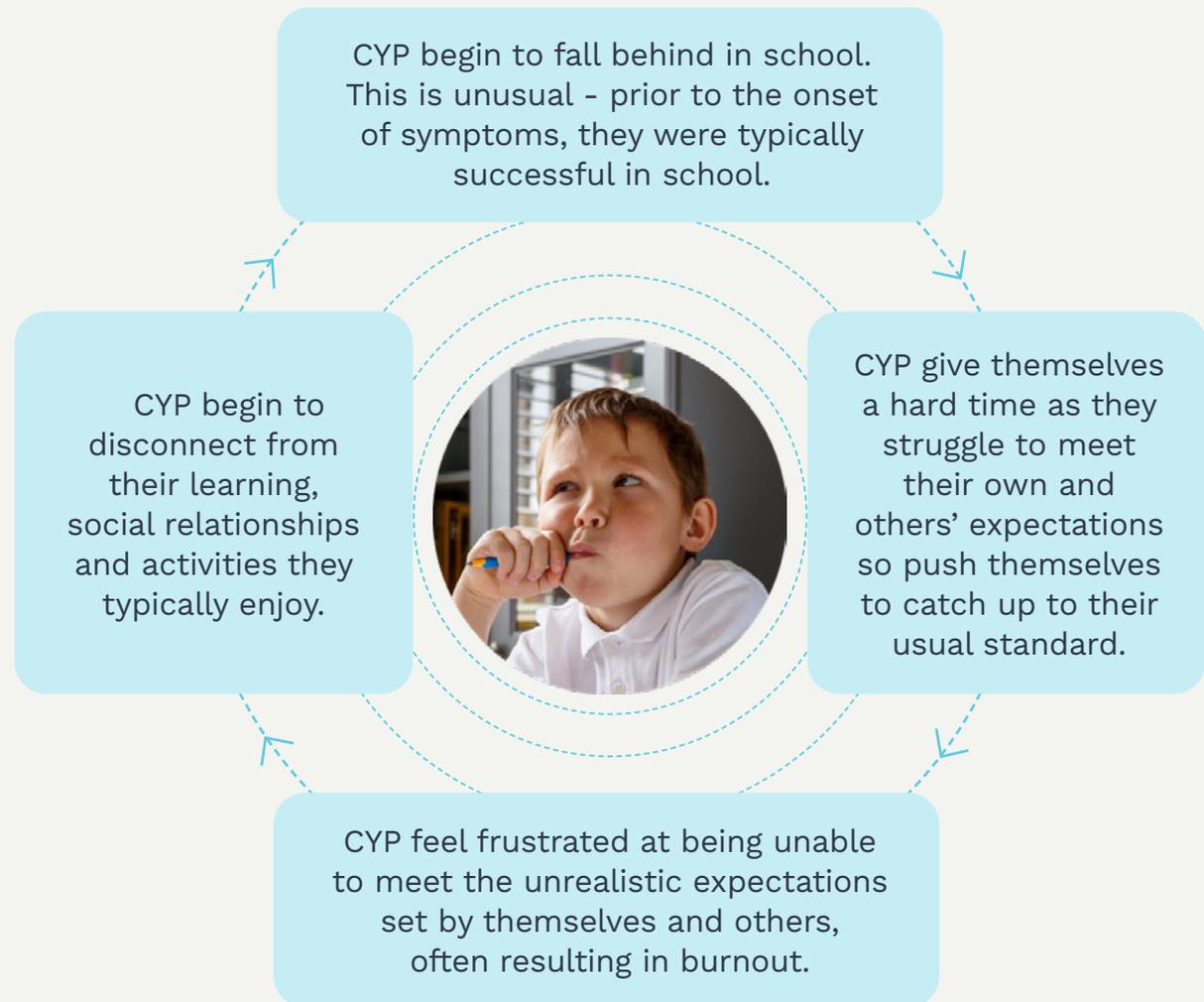
- ..... Being able to attend class for the full length of time.
- ..... Being able to concentrate for a full lesson.
- ..... Anxieties around telling others about their difficulties and falling behind with school work.
- ..... Not feeling able to do their homework outside of school hours.



# Why do CYP with health difficulties struggle to get into school?

Sometimes, **CYP's symptoms are not visible to the adults** in their lives and they can begin to feel that they are not believed or are being labelled as lazy.

**This can result in further disconnect between the child and their teachers/family.**



# Impact of Pain

Pain is a *common experience*. We know that different people can experience different intensities of pain from the same injury and that that it is not related to the amount of *'tissue damage'*.

**Pain is our body's way to protect us** when it 'thinks' we are under threat or in distress. Pain teaches us to avoid threatening situations that may cause us harm or distress e.g., if our hand gets burnt over a hot flame, we feel pain. **The pain tells us that we should not do it again and we learn from the experience.** This means that a person's experience of pain depends on the context, where the pain is, their expectations, their mood and beliefs, and of course genetics.

CYP, like adults, experience their physical symptoms such as pain as threats to their body. **They may interpret their pain as harmful to their body** and plan their lives according to what feels safe, rather than what they want or need to do in their lives. When they experience pain

whilst in school, **their brain will focus on this pain**, losing all other contextual information, and warn them to avoid the situation that has caused harm i.e., school. Their threat systems **remain on hyperalert** for any further pain that may be a sign of danger and as a result their world becomes smaller, and they feel stuck.

As adults we can **help CYP respond to their pain differently**. We can remind them that they are safe and help them understand that **their pain is trying to be useful but keeping them stuck**. We can support them to make different choices to enable them to open their lives back up and live a life they value.



# Impact on a child's energy levels



## Energy Batteries

We all have our own energy batteries.

They are recharged when we **sleep, rest or refuel**, so we rarely pay any attention to them.

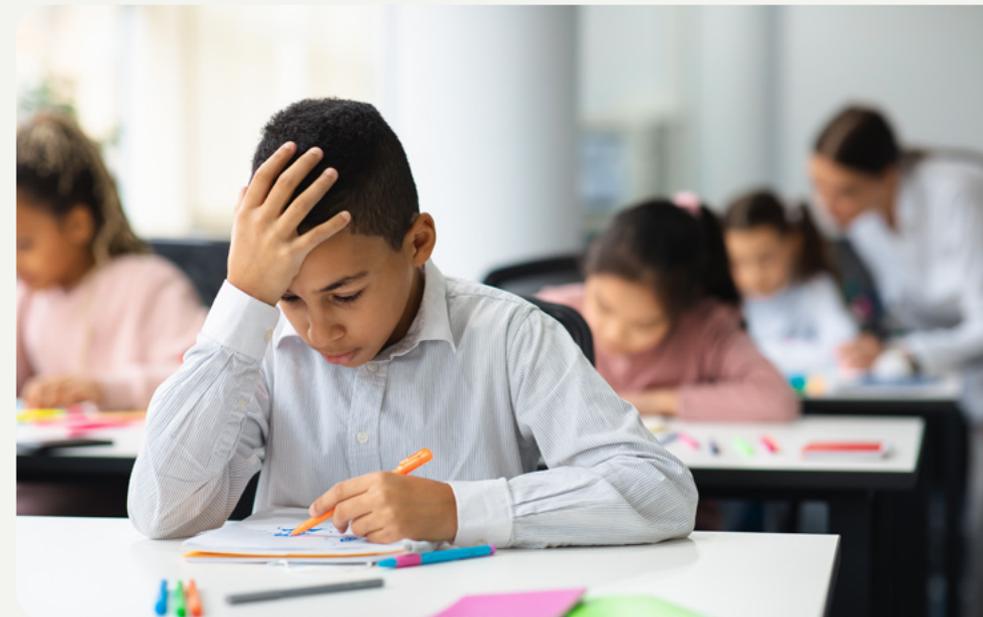
When CYP have been **unwell and/or in pain, their energy battery reduces in size**. If children rest too much or stop doing the things that matter, **they may become deconditioned**. If this happens CYP will use more energy doing the things that they have to do and have less energy to do the things that they want to do. This means that **CYPs battery uses up energy more quickly and also takes longer to charge back up again**.

This explains the typical broken pattern of attendance seen as a few days in school can deplete CYP's energy batteries, **requiring a few days rest to recharge before being able to continue**.

## Boom and Bust

Another reason we see broken attendance is due to **boom and bust**. This is where CYP may start to feel better within themselves, **resulting in them trying to achieve/engage in lots of things that they have missed out on whilst ill**.

This then leads to feelings of burnout where they have completely depleted their energy batteries, meaning **a few days recovery is needed to recharge** their batteries again.



# Process diagram to support CYP in education



Identify child in need of support



Access RFI Top Tips on Hwb for advice and contact family to arrange meeting



Encourage family to visit GP to discuss symptoms and direct them to RFI Top Tips for use at home



Meet with family and CYP to discuss needs (option for consultation between school and RFI Team)



Individual support plan created to be used in school



CYP supported to access education in the most appropriate and suitable method



# The School Day



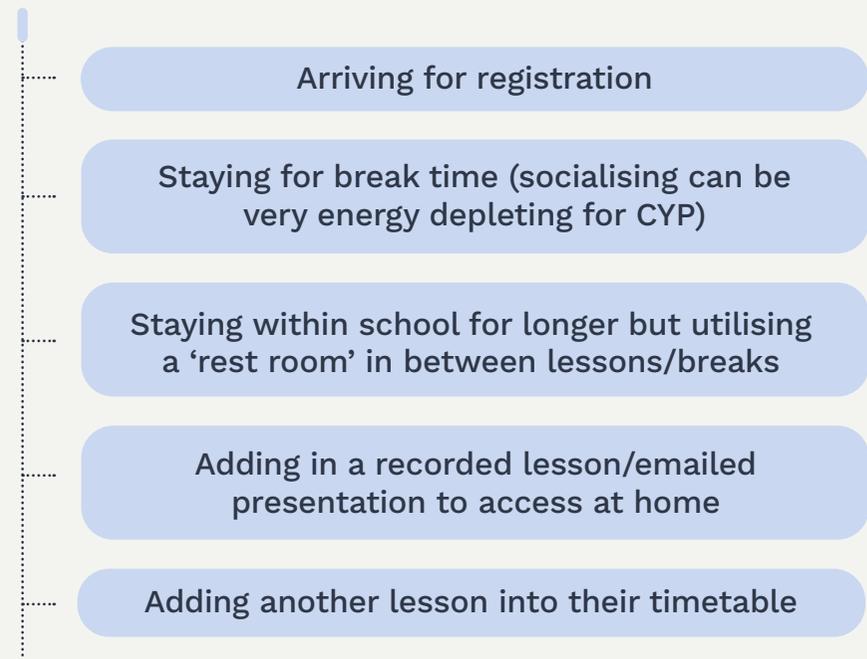
The aim is for CYP to have a regular routine around attending school – *this is really important to help prevent Boom and Bust*. Ideally, we want CYP to be attending every day to encourage them to manage their energy batteries efficiently and *learn that they can do things that matter to them*, even when they experience fatigue and pain.

An approach may begin with agreeing to attend school every day but only for a limited time. (E.g. they arrive for their first two lessons but leave at break time). Agreeing to attend school **every other day should be avoided** as this can perpetuate the boom and bust cycle by reinforcing that a child cannot engage in what matters to them.

**It is important to encourage attendance in the mornings to help CYP to establish a routine and encourage other healthy habits such as a regular sleep-wake time.** If CYP struggle to make the start of the school day, an agreement could be made that they arrive in time for their first lesson (missing registration/form time).

**When the agreed routine is achieved for a full week and this becomes manageable,** the length of time in school should be slowly increased. This helps CYP learn that they can do things even when they are experiencing fatigue and pain.

Length of time in school could be increased in different ways:



**It is important to stick to the agreed timetable.** Even if CYP feel well and want to stay in school for longer than agreed in their plan; **they should be encouraged to go home as scheduled to prevent the Boom and Bust cycle occurring.**

# KS2 Things to Consider (7-11yrs)



Option for **reduced school hours** (refer to The School Day).

A **separate 'restroom'** to be used as and when needed.  
This can be **before/during/after lessons**.

A **'Time Out' card** to be used if a child needs to step out of a lesson or activity and **take a break**.

**Lessen the cognitive load** by giving written handouts instead of having to write own notes.

**Support** to stay on task when **struggling with concentration**.

**Offered support to catch up** on missed work. To be aware that **you may be asking for too much**.

Limited homework or **homework only given when necessary**. To expect that homework may not be completed to the **best of their ability**.

To be mindful that **group activities can be exhausting** for CYP and they should be offered support throughout these.

**Access to refreshments** during lessons (snacks and fluids).

To **encourage social contact** - CYP may want to spend break time inside, which should be advised, and the option to have **a friend to accompany them should also be suggested**. (Lunchtime supervisors to also be aware of this arrangement).

**Encourage CYP to sit with peers** they feel comfortable with.

A **place to rest during P.E** or the option not to engage at all. Alternatively, **another role could be offered** so CYP feel included (i.e. referee).

Arrangements made to **support CYP to buy food** without the need to stand in a queue at break and lunchtime.

Ensure **family is aware of the structure** of the school day/timetable.

## KS3 Things to Consider (11-14yrs)

As children progress through school, their workload (including homework) increases.

*In addition to the KS2 advice, advice specific for KS3 and KS4 could include:*

Option for **partial timetable** to include only lessons that will be continued at GCSE level.

**Locker or place to leave schoolbag or books** during the day.

**Option to use a lift** (if available).

**Permission to leave lessons early** to avoid busy corridors

**Access to medication** (if needed) and where this will be held

**Emailing presentations** out that are used in class

Consider **seating plans to allow CYP to leave the classroom without disruption** (causing embarrassment)

**Access to a computer** rather than needing to write



# KS4 Things to Consider (14-16yrs)

To only be expected to **complete work contributing towards GCSEs/coursework.**

**Reduced subjects** that require examination.

Apply for **extra time in exams.**

Access to a **scribe or laptop** to complete exam.

Use a **separate room** to complete exams.

**Refreshments** during exams.

**Permission to move around** in the exam room if CYP has a separate room.



# Difficult Thoughts and Feelings around Returning to School

CYP may begin to feel *anxious or distressed* about returning to school after some time away.

It is important that we support them with these difficult feelings and help them to transition back into the school environment.



## What does anxiety or worry look like?

Struggling to concentrate

Quickly becoming angry or irritable, and being out of control during outbursts

Constant worrying or having negative thoughts

Feeling tense or fidgety, or using the toilet often

Tearful

Hovering near teacher/asking to go home (if pacing is going well, CYP should not be asking to go home due to their symptoms)



### How can we support?

#### Listen and validate feelings

Making time to be emotionally available to **listen and offering a safe space** for CYP to share their feelings.

#### Linking with family

**Checking in with family** to ensure support is given from all directions.

#### Keeping hopeful

**Looking to the future with confidence.** It is important to recognise this is not invalidating the negatives.

#### Encouraging routine and structure

#### Helping to connect

Friendships may have 'moved on' whilst CYP have been away from school. Try to provide a safe base for CYP to **reconnect with their old friends, or make new ones.**

**To help CYP to feel included while they are absent, a weekly check-in email could be arranged by their teacher.**

This could let CYP know that they are missed by their peers and give them a sense of what has been covered during their time away from class.



# What Next?

Here are some recommended apps that can be signposted to CYP and their families who are *struggling with their symptoms*.



Click on the icons to find out more.

<b>Headspace</b>  meditation and wellness	<b>Calm</b>  meditation for stress and sleep	<b>The Pain Toolkit</b>  understanding and managing pain
<b>HappiMe</b>  self-esteem, confidence and happiness	<b>SafeSpot</b>  coping strategies for difficult situations	<b>Mindshift</b>  anxiety

## Useful websites for adults caring for /working with CYP:

**melo** 

Helping you look after your mental wellbeing.

Visit **melo.cymru** — mental health and wellbeing resources, courses, helplines and local opportunities. Delivered to you by Aneurin Bevan University Health Board.



 **MindEd**   
cleaning to support healthy minds

**YOUNGMINDS**   
fighting for young people's mental health

**Click here for more useful Cahms resources (including websites, books, videos and more)** 

## Further Support

If the individual you are supporting develop any new symptoms, their symptoms appear to get worse, or you are still concerned, *please advise the family to contact their GP to access further support.*

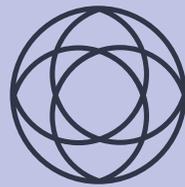
Alternatively, you can request an individual consultation with the RFI team by contacting:

[ABB.recoveryfromillness@nhs.wales.uk](mailto:ABB.recoveryfromillness@nhs.wales.uk)

**The Educational Psychology Service** (situated within the additional learning needs/inclusion department of your Local Authority) **are also available to provide help and advice to schools and families** about children who may be experiencing some of the difficulties described in this booklet. **Please see the Local Authority Education web pages for contact details**

If an individual you are supporting continues to struggle with anxiety or difficult thoughts and feelings, **you may wish to contact the in-reach team within your school.** Together you may discuss whether a referral to the local **SPACE** Wellbeing panel in your area is appropriate.





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