How can I help? Action for ME's guide for educators

This guide has been developed by Action for ME to support schools and teachers to begin to understand the serious neurological condition Myalgic Encephalomyelitis (ME), sometimes diagnosed as chronic fatigue syndrome (CFS or ME/CFS).

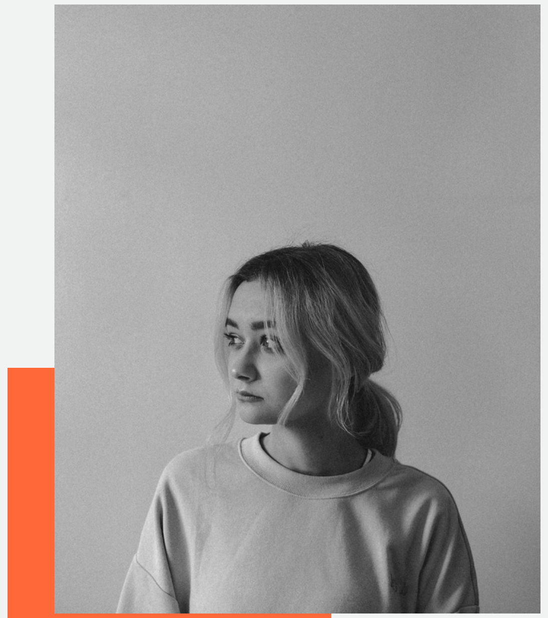
This guide offers practical advice and provides ideas for adjustments and adaptions that can be incorporated into your pupil's educational programme.

The best way to support your pupil with ME and their family is to be led by them and their individual circumstances. ME is unique for each person, and symptoms and severity may fluctuate overtime, and some young people are too ill to be in school, no matter how well they are supported.

Contents

1. ME/CFS and its impact on young people

ME/CFS is a complex, chronic disabling medical condition, affecting multiple body systems (immune and nervous systems predominately) that has no cure.



If children or young people (CYP) with ME/CFS overexert themselves at the beginning of their illness it makes it more likely that they will be unwell for longer and may be more severely or permanently affected. Careful management of activities, and rest periods tailored to each child’s situation and resources, are needed to get the best outcome for their future.

ME/CFS affects everyone differently and its impact varies widely. For some people symptoms still allow them to carry out some activities, whereas for others they cause them to be housebound/ bedbound

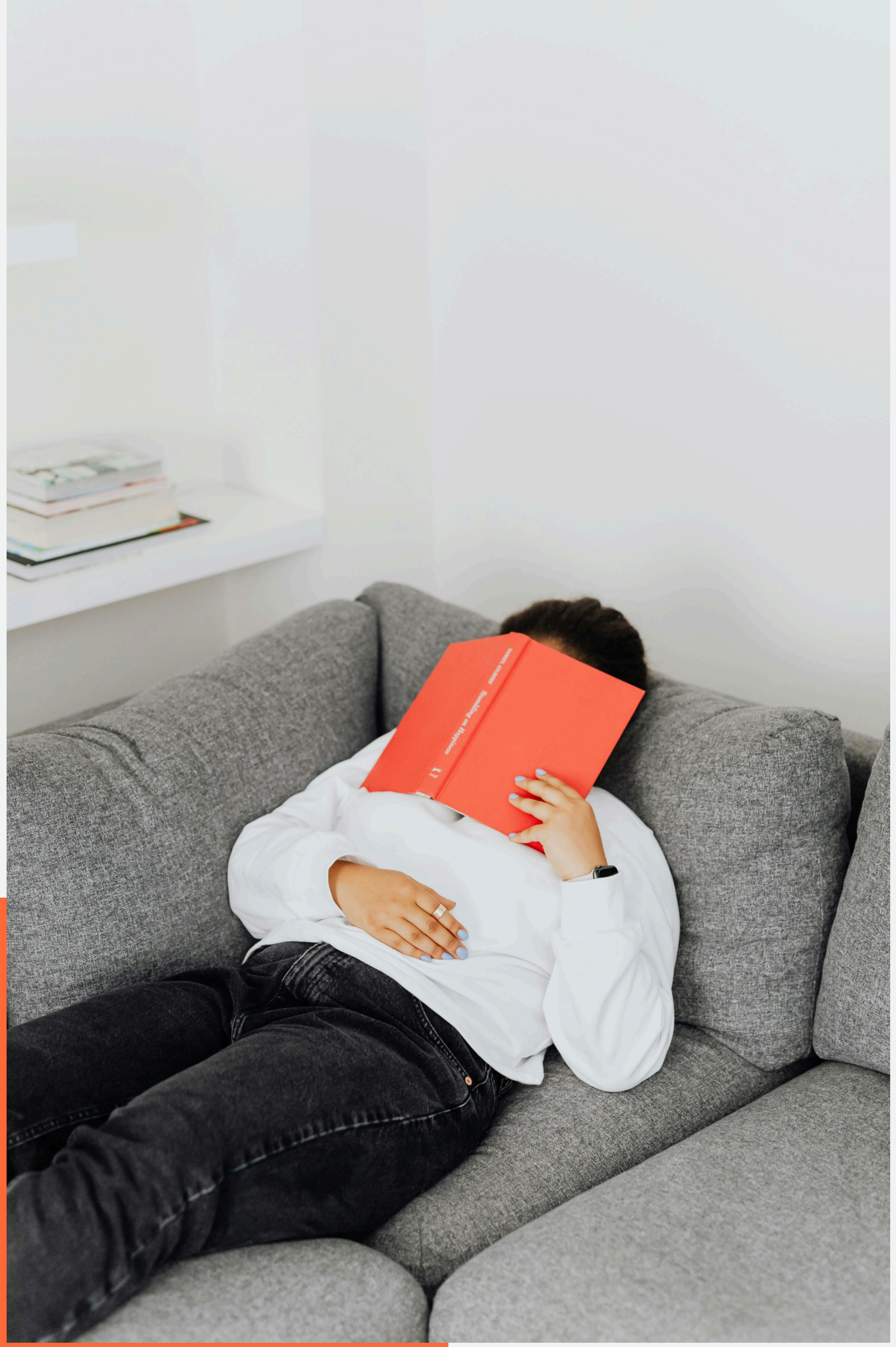
ME/CFS is a fluctuating condition in which a person's symptoms can change unpredictably in nature and severity making it a very difficult condition to manage. Even armed with energy management diaries and pacing, it remains an incredibly difficult condition to manage.

2. Explaining post-exertional malaise – PEM

ME is not just ‘feeling tired’. A key symptom of ME/CFS is post-exertional malaise (PEM). This is the delayed response and worsening of symptoms after any exertion or activity - physical, intellectual or emotional. Simple physical or mental activities, or a combination of tasks may leave someone with ME. feeling absolutely debilitated. This can happen immediately but may also take a day or two to impact, and it is not significantly improved by rest.

Without proper pacing and support there is the risk of PEM which has the potential to cause harm to a CYP’s health.

Watch this video for more info: POST EXERTIONAL MALAISE VIDEO



PEM Battery analogy

- Think of yourself/your pupils like a mobile phone
- Someone without ME/CFS charges to 100% overnight
- Someone with ME/CFS only charges to say 30% overnight
- How will the CYP you support use that 30%?
  - 5% just waking up
  - 10% on washing and getting dressed
  - 5% to travel into school.

So now they only have 10% left for the rest of the day - so they could use that for chats with friends, studying for 30 minutes or another small activity – then travelling home, but that’s all their energy gone for the day. If they push beyond that last 10%, they are likely to experience PEM and it causes a ‘crash.’

What causes ME/CFS?

We estimate there are up to 1.35 million people in the UK with ME or ME-like symptoms.

Researchers are still investigating the causes of ME, but emerging evidence points to multiple contributing factors, especially neurological and immunological ones.

Because the cause of ME/CFS is not known, many potential causes are being studied. These include infections, how the body uses energy, how people respond to infection or inflammation, and genetics.

If a pupil already has ME/CFS, getting a virus like the common cold can worsen their ME/CFS symptoms and sometimes the severity of their chronic condition.

Knowing this information, what can you do as a school to support pupils with ME/CFS?

- Allow pupils with ME/CFS to study from home if they are feeling poorly/have symptoms of a virus
- Infection control - encourage all pupils to not come into school if they are poorly, to protect the health and welfare of everyone in school.

The fluctuating symptoms of ME/CFS

While there are key symptoms that must be present for an ME diagnosis, including PEM, not everyone with ME experiences the same set of symptoms and the illness can vary enormously, including how long symptoms last.

- **Debilitating fatigue** - The fatigue that comes with ME is totally different from "normal" exhaustion. Fatigue levels can go up and down during the day, and people might suddenly need to sit or lie down very quickly.
- **Feeling generally unwell:** this may be a recurrent sore throat or flu-like illness.
- **Pain** in muscles, joints, chest or back or may be a headache or abdominal pain.
- **Sleep disturbance:** problems getting to sleep or waking/unrefreshing sleep.
- **Problems with concentration**, thinking and memory (‘brain fog’).
- **Problems with the nervous system:** very sensitive to light and sound, dizziness, poor temperature control and circulation.
- **Digestive problems:** nausea, loss of appetite, IBS-like symptoms, indigestion.
- **Intolerance and increased sensitivity:** odours, some foods (for example dairy or wheat), and some medications.

Pacing explained

Pacing is a self-management tool. It is a technique to help people with ME/CFS take control of the balance of activity and rest and learn how to communicate to other people about this balance.

Self-management is a broad description of a combination of knowledge, skills and strategies which people can use to reduce the impact of a health problem on their quality of life.

Pacing is not a treatment but more as a way of coping with the impact of ME. By pacing, a young person tries to maintain activity (physical, mental and emotional) levels within sensible limits avoids overly aggravating symptoms – a crash or PEM.

Example of pacing in school:

- Attending classes in school on Mondays, Wednesdays and Fridays
- A blended learning approach - in school and online at home
- Delayed starts to the day to allow for slow starts, due to fatigue

More pacing info on the resources page (slide 22)

ACTION FOR M.E.

Explaining ME

Need support? Call us on 0117 927 9551

What better support do you need in your education?

"More awareness about ME overall would be the best way to fix systemic issues with how education systems deal with ME".

"Adjustments and accommodations with exams and schoolwork".

"Having better systems in place for students who are too severe to attend school in person (e.g. online zoom calls)".

"A better understanding of the illness and appreciate the difficulty of managing both education and a chronic illness".

How would you explain the boom and bust cycle?

Trying to push through ME is like trying to run up an escalator that's going down. You can try as hard as you can, but you will inevitably end up crashing down at the bottom. You can determinedly sprint up that escalator again and again but you will fall harder every time

It feels like you are taking a step forward but end up going two steps back.

It's like you can't stay awake or breathe without widespread pain.

How would you explain having ME to a friend?

"Imagine a really, really long lockdown. It can be really tough as they don't see the daily challenges. Giving examples of everyday things - such as not being able to watch a long film without crashing - helps show how hard even little things can be".

"It's like the feeling you have after running a marathon and you have recovered a bit of energy, but you still lack a large amount of the energy that you started with - ME is like that, but the feeling doesn't go away when you wake up the next day".

"It's like waking up and feeling the weight of everything and every step you take just makes it worse."

Explaining ME/CFS to your doctor

ME/CFS is not a mental illness & the main goal of someone with it is to become as well as possible - ME/CFS is not a choice.

"Everyone is different".

ME is a chronic condition & currently, there isn't a cure. So, the best thing a doctor can do is help individual to manage it in the best way possible.

Any advice for other young people?

ME/CFS can be a debilitating illness and can take away many things, however, with friends and family to support you, it can be managed.

Prioritising activities that are most important to you is essential (e.g. choosing to limit social time to focus on exams, or focusing on physical wellbeing rather than schoolwork. Also, having the self-discipline to stop yourself from overdoing things is really important with pacing (this can be hard!) There is a lot of support out there, so to anyone with ME/CFS, remember there is an awesome community out there to support you and you are not alone!

ACTION FOR M.E.

Explaining ME

Written by young people, for young people

What does having ME feel like?

Having ME feels like something constantly needs repairing but you're never quite fixed.

It feels exhausting all the time and just wanting it to stop.

Waking up feels like you have already run a marathon with lead weights to your arms and legs.

What symptoms of ME affect your day to day?

"Severe fatigue, brain fog, nausea, aches/pain, headaches, sensory input and difficulty with thermoregulation".

"Dizziness, problems with sleep, feeling worse after resting and memory problems".

"Mainly pain and joint pain (and obviously fatigue)".

Sum up having ME in only a few words:

EXHAUSTION, FEAR AND HOPE

OVER-WHELMING

FRUSTRATING

Letting people know the difficulties...

"It can be really difficult to maintain social contact, especially if seeing friends is too exhausting."

"Brainfog and tiredness can cause people to be unable to focus or perform a task well, no matter how hard they try".

"When fatigue is severe, moving can be unbearable".

"Tiny little things like lifting cutlery to eat are so exhausting - I think it can be hard to portray to healthy people that even barely significant things to them can be affected for someone with ME/CFS".

What doesn't help you with managing ME?

There is a misconception that the symptoms can be pushed through - this only intensifies the symptoms and can make you more ill.

People think ME/CFS is a mental illness, or think this condition is just an excuse for being lazy.

People tell me I'm being dramatic.

What helps with managing your ME?

"Having the love and support of family and friends who can bolster me up".

"Pacing and planning".

"Reading and music".

"Regular rest/sleep".

4. Wellbeing

IF A CHILD OR YOUNG PERSON IS STRUGGLING, PLEASE REFER THEM TO OUR FREE CYP COUNSELLING SERVICE (link on resource page, slide 22)

A young person with ME/CFS wrote:

“Prioritising activities that are most important to you is essential, e.g. choosing to limit social time to focus on exams, or focusing on wellbeing rather than schoolwork”

“With the resulting isolation from peers, it is perhaps unsurprising that 97% of young people with the illness who engaged with Action for M.E.’s 2019 Big Survey said they feel socially isolated because of their condition.”

ME/CFS is an incredibly difficult condition to manage, as having such limited energy, CYP find it very difficult to see friends or do things that bring them joy.

It’s very hard to balance their mental and physical wellbeing, as well as their education. CYP are often told to prioritise their education and their ME/CFS can get worse due to the emotional load they suffer as a result of this imbalance.

Doing activities that bring them joy is paramount and this can be small things like getting creative, reading a book, speaking to a friend on the phone - whatever activity that the individual is capable of, within the confines of the severity of their ME/CFS.

This is reiterated by the NICE guidance.

Being supported holistically by school is key to managing this condition in a sustainable way:

- a CYP could attend less lessons, but come in for lunch breaks to spend time and connect with their peers
- have pastoral support, and/or counselling at school
- encouraged to prioritise creative activities and/or subjects that bring them joy
- understanding about ME/CFS and the impact it has on their life from all support staff

5. Symptoms & barriers faced by young people and support in practise

Increasing knowledge and having an empathic understanding of the impact of having ME/CFS for the individual and being flexible in the delivery of education is the easiest and most supportive way forward for a student with ME/CFS.

Remember, ME/CFS is a fluctuating condition, so having a flexible plan is a way to allow for these fluctuations and creates a contingency plan.

SYMPTOM	BARRIERS	SOLUTION
Fatigue and Post exertional malaise	• Physically getting into school to study can be a real issue • The school day is too long • Travelling between lessons can be too tiring • Not being able to concentrate for long periods of time • Feeling overwhelmed by coming into school	• Access to a designated quiet area for rest periods if in school • Flexible arrangements: online provision/work sent home/home tuition/AV1 robot • Reduced subjects/timetable • Exclusion from physical exercise and any non-compulsory lessons • An allowance for time required between lessons and/or provide buddy to accompany and carry books • Regular check ins by single point of contact - teacher/pastoral teacher/SENCO • The school/parents can seek guidance from GP, paediatrician/specialist regarding ability to attend school & issuing medical reports • Host multi agency meetings with parents, teachers, health professionals to update progress and update IHCP/care plan

SYMPTOM	BARRIERS	SOLUTION
Feeling generally unwell: this may be a recurrent sore throat or flu-like illness.	• Difficulties accessing education when feeling unwell	• Allow the student to work remotely or if feeling too unwell, to have an authorised absence to rest
Pain in muscles, joints, chest or back or may be a headache or abdominal pain.	• Difficulty navigating between different lessons • Difficulties dressing/travelling in to school	• An allowance for time required between lessons and/or provide buddy to accompany and carry books • Delayed starts to their days and shorter days/reduced timetable
Sleep disturbance: problems getting to sleep or waking, unrefreshing sleep.	• Being overly fatigued in the mornings and often early starts are very difficult	• Delayed starts to their days • Flexible arrangements: online provision/work sent home/AV1 robot
Problems with concentration, thinking and memory ('brain fog').	• Difficulties concentrating for longer periods of time • Difficulties processing the topics taught – which might cause embarrassment and anxiety • The pace of the lesson can be too quick	• An allowance for homework deadlines / suspension of homework • A reduced timetable • Chunking work – separating the lessons into manageable chunks of time so they can take breaks • A 'time out' card to enable child to leave the classroom without unnecessary attention • Regular check ins by single point of contact - teacher/pastoral teacher/SENCO to ensure studies are being kept up with at a pace that works for them • Exam provisions – quiet room, rest breaks scheduled in, delayed starts to exams

SYMPTOM	BARRIERS	SOLUTION
Problems with the nervous system: very sensitive to light, sound, odours and foods and can have dizziness and headaches	• Lighting in school can be overwhelming • Busy classrooms can be too noisy • Busy lunch halls can be too noisy/overstimulating	• Allow students to take breaks when they need it (quiet room) • Consider lighting in classroom, can it be dimmed? • Allow noise sensitivity headphones in class • Lunch breaks to be in a quiet place
Poor temperature control and circulation.	• It can be too cold/warm in the classroom	• Allow the student to wear their own clothes and take breaks if needed
Digestive problems: nausea, loss of appetite, IBS- like symptoms, indigestion.	• Not having the right access to toilets or feeling too unwell to attend school • Needing to eat small, frequent meals and snacks for energy management	• Toilet/hall/lift pass • Authorised absence from school • Flexible provision: online learning, work sent home • Authorised snacks/drinks so they can manage their energy levels better
Impact on mental health	• The physical symptoms of ME/CFS, that a CYP can experience, can take a huge toll on their mental health. This may result in anxiety and in some cases feelings of depression, but this is because of the illness’s impact on their lives and which is not the cause of the illness.	• Regular wellbeing check ins by single contact at school that they like/choose themselves • Pastoral support • Being told by the teachers/support staff that the YP is believed, understood and seen – empathic understanding is a powerful tool • Referred to AFME free counselling service for CYP

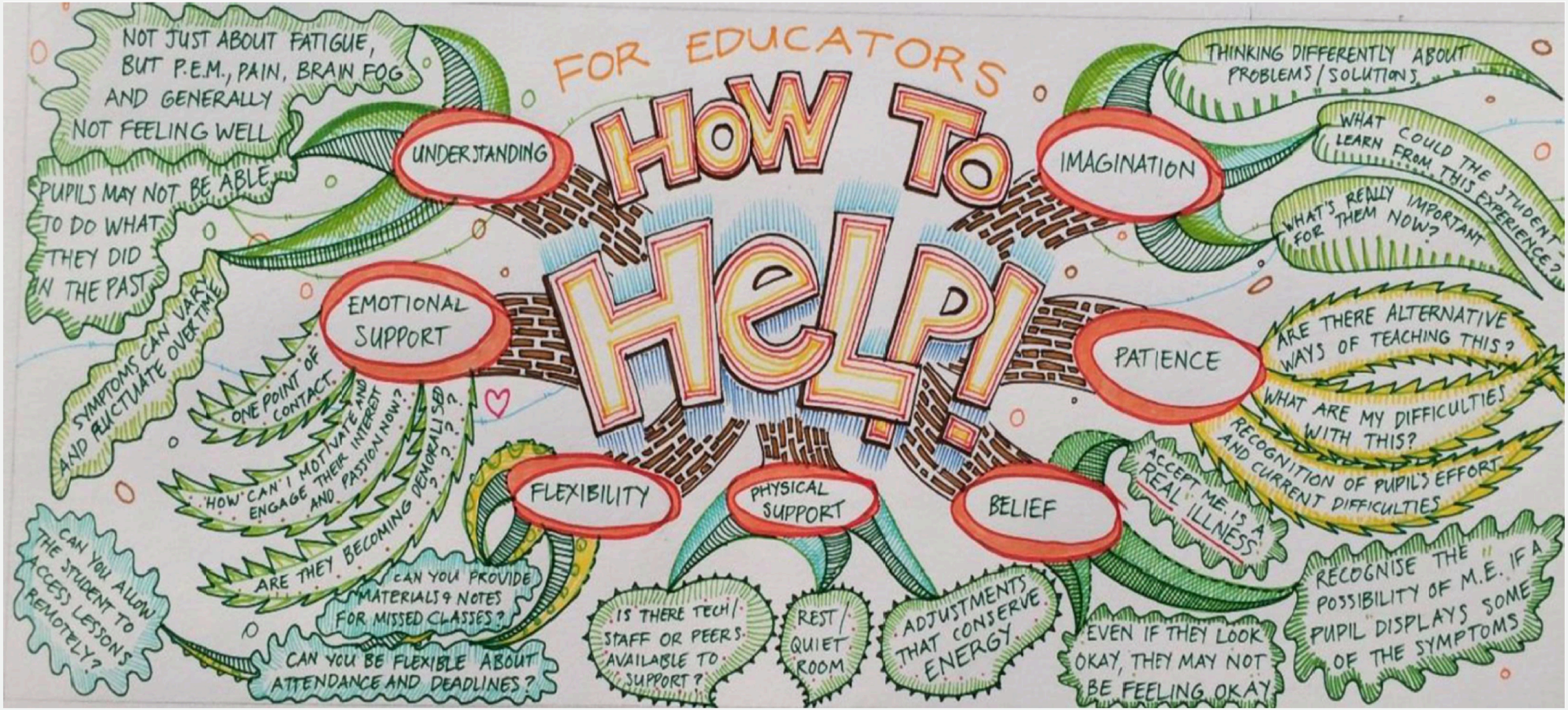
6. Educators mind map

Zoe is a music student at the Royal Conservatoire of Scotland, a world-leading performance arts school in Glasgow. Zoe developed ME at 16, just as she was preparing for crucial exams, and starting to work towards her dream of becoming a music teacher. The knowledge, understanding and support of some of her teachers enabled Zoe to continue her education, and make her dream a reality.

The mind map captures what helped Zoe manage her education and her condition. Using her experiences, this mind map can be used to help you think about what values and attributes are important when supporting someone with a long-term health condition.

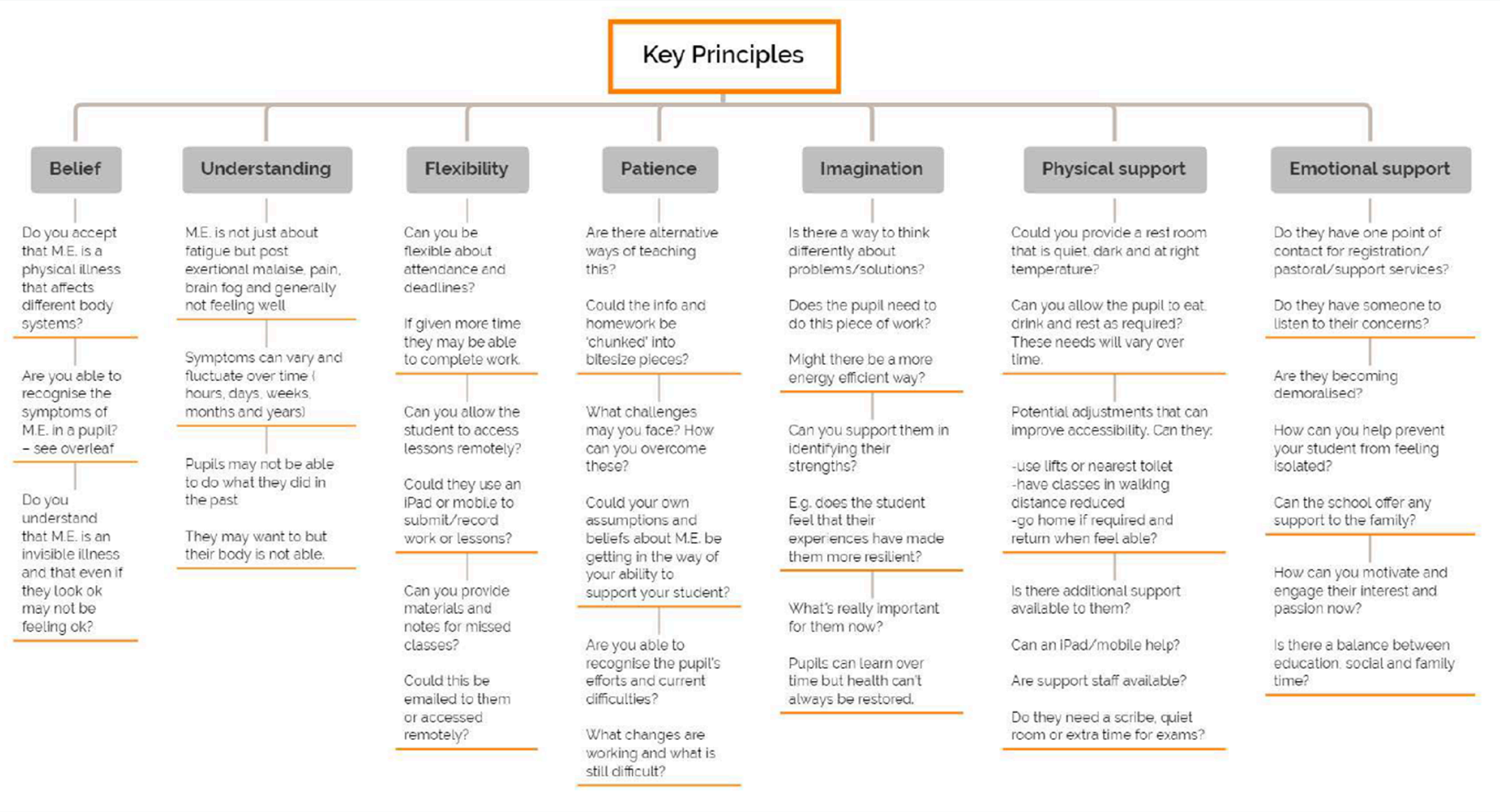
Following on from this, we have created a table of key principles (page 16) that were outlined by Zoe during this session. This table explores in more depth how you can apply these values when teaching students with ME.

ACTION FOR M.E.



Key principles in supporting a student with ME – coproduced by Zoe, a student with ME

ACTION FOR M.E.



Key Principles

Belief

Do you accept that M.E. is a physical illness that affects different body systems?

Are you able to recognise the symptoms of M.E. in a pupil? – see overleaf

Do you understand that M.E. is an invisible illness and that even if they look ok may not be feeling ok?

Understanding

M.E. is not just about fatigue but post exertional malaise, pain, brain fog and generally not feeling well

Symptoms can vary and fluctuate over time (hours, days, weeks, months and years)

Pupils may not be able to do what they did in the past

They may want to but their body is not able.

Flexibility

Can you be flexible about attendance and deadlines?

If given more time they may be able to complete work.

Can you allow the student to access lessons remotely?

Could they use an iPad or mobile to submit/record work or lessons?

Can you provide materials and notes for missed classes?

Could this be emailed to them or accessed remotely?

Patience

Are there alternative ways of teaching this?

Could the info and homework be 'chunked' into bitesize pieces?

What challenges may you face? How can you overcome these?

Could your own assumptions and beliefs about M.E. be getting in the way of your ability to support your student?

Are you able to recognise the pupil's efforts and current difficulties?

What changes are working and what is still difficult?

Imagination

Is there a way to think differently about problems/solutions?

Does the pupil need to do this piece of work?

Might there be a more energy efficient way?

Can you support them in identifying their strengths?

E.g. does the student feel that their experiences have made them more resilient?

What's really important for them now?

Pupils can learn over time but health can't always be restored.

Physical support

Could you provide a rest room that is quiet, dark and at right temperature?

Can you allow the pupil to eat, drink and rest as required? These needs will vary over time.

Potential adjustments that can improve accessibility. Can they:

-use lifts or nearest toilet
-have classes in walking distance reduced
-go home if required and return when feel able?

Is there additional support available to them?

Can an iPad/mobile help?

Are support staff available?

Do they need a scribe, quiet room or extra time for exams?

Emotional support

Do they have one point of contact for registration/pastoral/support services?

Do they have someone to listen to their concerns?

Are they becoming demoralised?

How can you help prevent your student from feeling isolated?

Can the school offer any support to the family?

How can you motivate and engage their interest and passion now?

Is there a balance between education, social and family time?

7. IHCP information

Every child with a medical condition should have an Individual Healthcare Plan (IHCP) – this is a formal agreement between parents/carers, the CYP, the school and health care professionals (GP or paediatrician) and it is the responsibility of the Head teacher and school governors to ensure that the IHCP is implemented and carried out.

The IHCP should:

- Describe the child's care needs (medical condition, symptoms and difficulties), and this organically highlights the impact it has on the young person's daily life and education (filled out by the YP/family)
- Describe how their needs will be met at school and with home study/hospital ed (filled out by school)
- Be reviewed every 6 months, or when the medical condition changes/fluctuates – to be agreed upon when creating the initial IHCP so everyone is aware of responsibilities moving forward
- Be shared with all staff, teachers, support staff and school nurse to ensure everyone involved in the care of the student is aware of their condition, the impact it has on their day-to-day life and their current and future needs
- Identify training needs for teachers and support staff specific to the medical condition of the child/young person.

Templates and resources to support you as a school for implementing an IHCP are on the resources page.

7. EHCP information

There may be adaptions/provisions for a CYP that your school cannot provide, without getting additional funding from your Local Authority, (beyond the individual SEND budget you can apply for each year) e.g. home tutoring, a schedule that suits the individual needs and online provision, a comprehensive platform to learn from home.

In these cases your school/the family can apply for an EHCP from the local authority which brings in an extended budget, specific to the individual needs and which is a legally binding agreement that supports young people until the age of 25.

Example: The young person could extend the length of time for studying, e.g. GCSE's and A-levels can be spread over 2-4 years, and young people can re-take years etc.

EHCP's are sometimes quite hard to get, and they can take a long time as there are multiple stages (the Local Authority are meant to complete this within 20 weeks), which is why school's taking the time to support families with the process is very valuable. The stages are:

1. EHCP needs assessment
2. A draft EHCP is drawn up
3. Initial EHCP is created
4. EHCP is implemented

8. Legal info and responsibilities

1. The 15-day rule If a student is absent for 15 or more consecutive or cumulative school days due to illness or disability, schools are required to notify the local authority.

The local authority duty:

- to ensure the child receives a suitable education, which may include providing alternative arrangements: home teaching, a hospital school or teaching service, a combination of both.

Your duties:

- let the local council know if the child is likely to be away from school for more than 15 school days (doesn't need to be consecutive)
- give the local council information about the child's needs, capabilities and the programme of work
- help them reintegrate at school when they return
- make sure they're kept informed about school events and clubs
- encourage them to stay in contact with other pupils, for example through visits or videos

2. Have a medical support policy in place
This should be an active document, giving clear processes and actions for teachers and support staff to implement and be readily available for parents. It should:

- understand the impact it can have on a child's ability to learn
- make clear that every child with a medical condition is different and should be treated as an individual
- Implement an IHCP.

3. Supporting students without a formal diagnosis
Schools do not have to wait for a formal diagnosis by a medical practitioner before providing support or implementing an IHCP for pupils.

9. Practical steps you can take as a teacher/school:

- Implement an IHCP – this means all the information and the support plan is stored in one central location, which can be easily shared with all the relevant support staff and reviewed easily
- Seek support! Speak to your local authority representative – it is their responsibility to provide the education for a student that has missed 15 days of school (consecutively or not)
- Be flexible in the delivery of the education – part time timetables, later starts, less subjects – these simple changes can make a huge difference
- Funding:

1. The adaptions and provisions needed to support a CYP with ME/CFS often costs nothing beyond element one base funding, but can have a big impact.
2. If you need additional funding to support the pupil with ME/CFS you can use up to £6,000 SEN budget per pupil - this is element two funding.
3. If you need further funding after using the SEN budget for the pupil you can apply for element 3 top-up funding, which is the financing behind the EHCP plan

Speak with your SENCO or Local Authority rep for more info on funding for your pupils

Supporting a student who has ME/CFS in education needs to:

- Have true understanding for what the condition is and the impact it has on the individual’s life
- Have the pupil at the forefront of planning their support – their voice needs to be the loudest in the room
- Be empathic to their individual needs, not everyone experiences ME/CFS in the same way
- Be flexible in its delivery – remember it’s fluctuating!
- Champion the pupil for their achievements, whatever the size!
- Be holistic in its nature – work with the young person, all support staff, their GP, mental health providers and of course the parents - and provide wrap around care and support
- Have a single point of contact that the young person likes and trusts - this is a really valuable way of maintaining the support put in place
- Be mindful that ME/CFS affects their immune system, are there ways you can support students with compromised immune systems? Not coming in to school when poorly, allowing

Need to know more? Get in touch with the Information & Support team at Action for ME with any questions about your student’s education and support. We will be happy to help you.
Our details are on the resources page.

10. Useful resources

- Statutory guidance for supporting pupils with medical needs
- Department of Education - Full guide for schools, governors and local authority
- Statutory guidance - Education for children with health needs who cannot attend school
- Legal support and info for Supporting children with medical needs in schools
- Statutory guidance for LA on notional SEN budget
- AV Robot info
- Statutory Templates for IHCP's
- Statutory flow chart procedure for schools to follow for IHCPs
- Medical School Alliance resources
- IPSEA – experts on special educational needs and disabilities (SEND)
- Explaining PEM video
- AFME Explaining ME/CFS
- AFME Education support for CYP resource
- AFME IHCP Template
- AFME Information and Support team
- AFME Explaining Pacing