

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

This brief guide has been developed to support teachers to begin to understand the serious neurological condition Myalgic Encephalomyelitis (ME), sometimes diagnosed as chronic fatigue syndrome (CFS or ME/CFS). It offers practical advice and adjustments that can be incorporated into your student's educational programme.

The best way to support your student 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. Some young people are too ill to be in school, no matter how well they are supported.

This brief guide is just that – for more detailed support and information, for you and/or your student with ME, please visit www.actionforme.org.uk/supporting-you/me-for-professionals/

Key information about ME

The symptoms of ME and level of severity can fluctuate and form different patterns for each person living with ME. Children and young people already have significant changes in hormones and growth so their bodily systems can be more affected.

ME is not just 'feeling tired', a key symptom is **post-exertional malaise** (PEM). This is the delayed response to 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. It is not significantly improved by resting. Symptoms vary and this is not an exhaustive list; for more details, visit www.actionforme.org.uk/supporting-you/managing-symptoms/

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 to bright lights, noise, odours, some foods (for example dairy or wheat), some medications, alcohol.

Diagnosis

There is currently no test to detect ME, diagnosis is made after other possible known causes for symptoms have been excluded. The earlier the illness is recognised; the sooner symptom management and support can begin. Adjustments are necessary to stabilise health, and this is a priority over education.

Pacing to balance energy and rest

The most common form of management is pacing. This is all about balancing a safe level of activity and rest so that people do not push themselves beyond the limits of their body. This takes time to learn. For children and young people balance in activities and interests is needed. They need support for their all-round development and enough enjoyment to motivate and sustain them, as they have less experience in managing themselves and being resilient.

Risk

If children or young people with ME overexert themselves at the beginning of their illness it makes it more likely that they will be unwell for longer and maybe more severely or permanently affected. This means careful management of activities, and rest periods tailored to each child's situation and resources to get the best outcome for their future.

What helped Zoe?

Zoe Galbraith, 20, is a music student at the Royal Conservatoire of Scotland, a world-leading performance arts school in Glasgow.

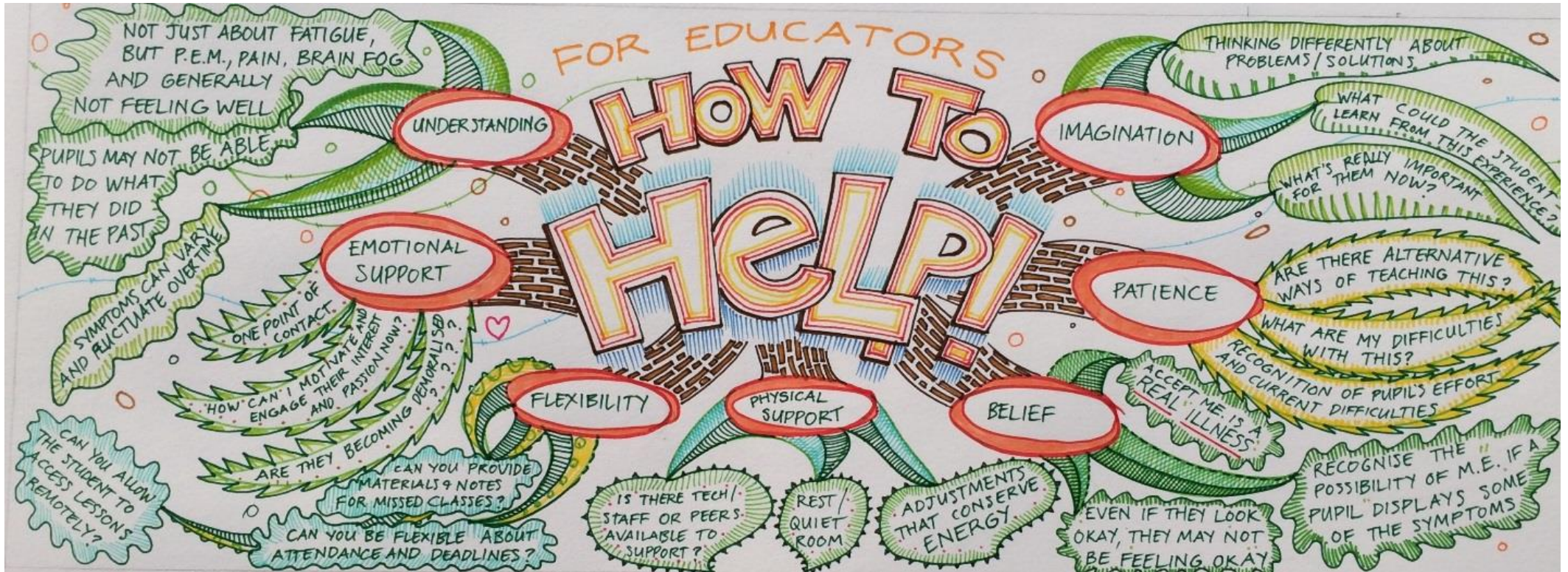
Zoe developed ME at 16, just as she was preparing for crucial exams, and starting to work towards her dream of becoming a music teacher. The knowledge, understanding and support of some of her teachers enabled Zoe to continue her education, and make her dream a reality.

The mind-map on page 3 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 4) 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.

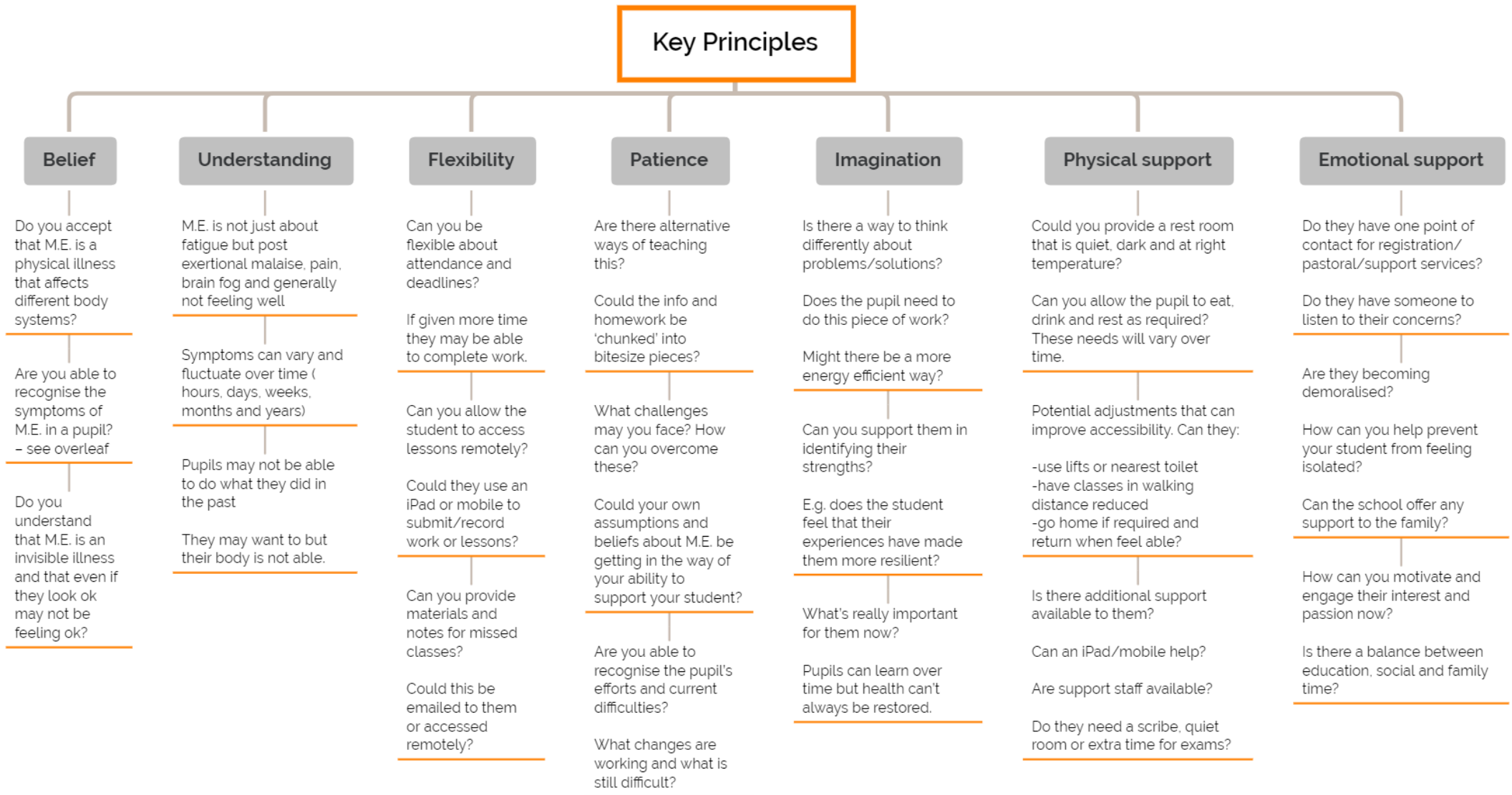
Educator's mind map

This was coproduced with student Zoe (see page 2), capturing what helped her manage her education and her ME.



Key principles in supporting a student with ME

This was coproduced with student Zoe (see page 2) based on her experiences with ME, education and the teachers who supported her.



What adjustments could I make?

Potential adjustments may help reduce symptoms of ME or their impact on children or young people while in school. Here are some examples, continued on page 6.

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| Reduce hours at school | If a child can drop down the number of hours they attend school this can allow them to continue to learn while they work to stabilise their health. |
| Reduce the number of subjects studied | <p>Prioritising important subjects and those that they have an interest helps students whose health allows to continue education and increases future prospects.</p> <p>Although their condition may be a barrier in accessing education this doesn't mean that this will always be the case. It's important that students are supported in order to limit impact that their illness has on their education.</p> |
| Be flexible about attending classes and schedules | Symptoms and the impact of ME can vary minute to minute, hourly, weekly - as it's a fluctuating condition. This means that a child's ability to complete tasks may vary. If they are able to rest when it's needed, then they may be able to return when their health changes. If they are worried about not attending classes, this may affect their confidence if their health does allow them to return to education in the future. Sleep difficulties may also impact on how they are able to function. |
| Studying at home | Having a home tutor or being able to access teaching remotely may be a real benefit. Can they participate through an online platform or through a mobile? Can they get notes they missed or access them or lessons electronically? Can a laptop and software help them to capture lessons and respond in ways that suit their needs? |
| Re-integration – attending school | There may be points in their illness where it may not be appropriate for a child with ME to be physically in school. Health needs may need to be prioritized over education. This does not mean that they don't need education just that it may have to be delivered at home. Only if their health has stabilized and they are ready should they return into school. Return to school should be done slowly and appropriately. Can they have a phased return? Could their schedule be designed around their condition and health needs? |
| 'Chunking' of work | Can the work be broken down into 'chunks' that could be completed more easily by a child who has less energy available? Is there any way that the school can allow them more time on pieces of work and extensions on deadlines? |
| Time extension | ME can cause problems with memory and cognitive functioning so they may need longer to process information, think about it and respond. They may also need more support with recalling and retaining information. |
| Support staff | Can support staff offer help to the young person to manage their activities at school? Can you help them liaise with other people, design resources or highlight options that will help? Can they check that there is clear understanding on what is needed and what the child has to complete by themselves? Just listening and understanding can be a real help. |
| Refreshments | Can they eat or drink when they need to? It's very important for people with ME to drink enough water as this helps to regulate their body and stop dizziness. |

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| Reduce physical activity | Small activities such as walking to class, carrying textbooks or even talking to friends may use up lots of energy for someone with ME. Thinking of ways to reduce this allows them more room to manage what they can do at school. What mobility aids are available? Can they use a taxi to get to and from school? Knowing that you can get home when you need to may increase their confidence in attending school. |
| Accessibility | Can the young person access any resources such as a lift or a disabled toilet? Could they use a wheelchair while in school? Are there any other mobility aids available that could make lessons or school more accessible to them? Can they use a laptop, tablet, mobile or Dictaphone? |
| Sensory | Can lights be dimmed in the class or can the level of noise be reduced? Are there any strong odours that could impact on a child? They may also be sensitive or intolerant to certain food or drink. At times they may also be dizzy, have poor circulation or temperature control and so may need adjustments around this. |
| Rest room | Can they access a room where they can rest when they need to? Ideally this room would be quiet, dimly lit and feel like a safe space. Is there a comfortable resting place where they can lie down? |
| Medication | They may need support in taking medication to manage symptoms. |
| One point of contact | Could there be one point of contact for registration, pastoral and support services? If they are able to have a flexible schedule, then can they contact one person who will contact class teachers? Could support staff liaise on their behalf? |
| Deadlines | Can they have extended deadlines or deadlines for 'chunks' of work? |
| Exams | Could they have the support of a scribe or technology to sit exams? Could they have a longer time for completion? If the light and temperature of the room able to be adjusted. Is a quiet space available? |
| Inclusion | <p>It's important that they can take part in in school activities when their health allows. Can adjustments be made so that they can take part in school trips and other events? Can you support them in maintaining friendships and interests in school? By doing so this can help reduce exclusion.</p> <p>Their condition may make exams challenging, and in some cases your student's participation in exams may need to be delayed. Can you provide them with the tools to continue to study?</p> <p>One of the biggest aids for including people with ME is believing that they are ill and understanding their current experiences and hopes and dreams for the future. Given the right support pupils with ME can continue to learn and be part of education.</p> |

This guide has been developed as part of Educate ME, a project set up to develop and deliver awareness-raising sessions in secondary schools in Scotland, funded by the National Lottery Community Fund, and co-produced by people living with ME.

For more information and support, call Action for ME on 0117 927 9551.

www.actionforme.org.uk