



Education support for children & young people with ME in England

Updated: December 2025

This guide applies to legislation in England, but the process and principles for securing support in Scotland, Wales, and Northern Ireland is very similar. If you live there and need support, please contact us for more information and signposting.



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1. What is your child legally entitled to?

If your child or young person is absent from school for more than **15 days** due to illness and/or their disability, the school must legally notify and work with your local authority as they (the local authority) should arrange alternative education for children aged five to 16 who are at home sick for more than 15 school days (consecutively or not).

This should be either full time or as much as the child or young person can manage. It can be provided in several different ways, including:

- A home tutor
- Online learning
- A small unit for children with medical needs

To manage this, the local authority should:

- have a written policy explaining how they'll meet their responsibilities to arrange suitable education for children who otherwise wouldn't receive one
- have a named officer who is responsible for the education of children with health needs
- make sure your child is not without access to education for more than 15 school days
- arrange education as soon as it's clear the child will be absent for more than 15 days.

There's more information on this in the resources list on page 12.

Getting a support plan in place is crucial, to have one place that all care and support for your child is recorded, reviewed and updated, and then communicated with all support staff that provide an education for your child.

2. What are support plans?

There are two types of support plans:

Individual Health and Care Plan (IHCP)

- A support plan that all children and young people can benefit from when they have a health condition and/or disability.
- The focus of this support plan is to identify the individuals' symptoms, the barriers they face, and the solutions for the school/college to implement
- Not a legally binding document
- They do not need a formal diagnosis to have an IHCP, just be working towards one
- **More detailed info on page 4**

Education Health and Care Plan (EHCP)

- A support plan for children and young people aged 0-25 who have special educational needs (SEN) and/or disabilities that mean they need special educational provision
- This support plan is to bring in additional funding as the school/college cannot provide the necessary adaptations and provisions for your child to have a needs appropriate education
- Is a legally binding document

If you feel your child's needs are not being met and they are not able to access their education or you don't believe the school/college is understanding of those needs, then applying for an EHCP could be a positive move forward.

An ICHP is the first step, through this it will identify if there are adaptations and provisions that the school cannot provide without additional funding, which should kick start the need for an EHCP assessment to bring in additional funding to support your child receive a needs appropriate education, that is in line with their peers.

3. How to work with your child's school

You and your child know their health and limitations more than anyone else, and pushing through their symptoms to fit in with an education system that isn't designed for them, could be detrimental to their physical and mental wellbeing. This resource is designed to empower you and your child to ask for a need's appropriate education, that suits them, now and for the future.

Sometimes, just a greater understanding of ME and its impact from the school/college, and a few adaptations and provisions, can make all the difference.

Be proactive in working with your child's school.

- Email/write a letter – to the SENCO & headteacher detailing: your child's health conditions, a diagnosis letter if you have one, and all evidence from GP's, paediatricians, and any other medical information that is relevant to the support of your child.
- Ask for a meeting to discuss the impact on your child's education and the support plan (Individual Health Care Plan – IHCP) to be put in place (see meeting with school below for more information).

Educate the educators.

- Alongside your letter/email you can send school our info sheet for teachers:
<https://www.actionforme.org.uk/wp-content/uploads/2025/05/ME-for-teachers-how-can-I-help.pdf>
- and our website page with all resources and comprehensive info:
<https://www.actionforme.org.uk/supporting-you/supporting-yp-with-me/>

Communicate effectively

- Ask for one contact at the school who can help you on this journey moving forward – preferably the SENCO, deputy head, head of year or pastoral teacher, for continuity and ease.
- Ask for their IHCP to be on the students database page, so all teachers have access
- Keep an open dialogue going – even if things do not change, regular updates on the condition and overall wellbeing of your child keeps the school informed
- Communications with the school should be in writing (over emails) for continuity
- Ask for dates when your child's support plan will be updated. This will be documented on the support plan and be sure as well as in your diary.

Keep calm and stay positive.

- Often, schools can bring in adaptations and provisions without any extra funding, and they most likely do not understand ME or the severity and complexity of the difficulties your child faces. Educating them on the condition and asking for a collaborative route forward usually opens the dialogue.

4. Meeting with your child's school

- Ask to meet with the right people: the SEN support, pastoral support, deputy head, headteacher and head of year. You want 'decision makers' there to be able to implement the IHCP as soon as possible.
- Ask to see their 'supporting pupils with medical needs policy' before the meeting so you can read through to this what their duties are, what they are currently offering, and what they could/should be offering your child.
- Prior to the meeting, you can fill out an IHCP with your child, to explore what adaptations and provisions would create their 'ideal learning situation' you can use the list of symptoms/barriers/solutions (page 8) as a 'shopping list'.
- Know that a lot of provisions that the school can provide they do not need funding for – reduced timetable, delayed starts, quiet room, hall pass, etc.

Aims for the meeting can be:

- Heightened understanding about ME overall, but specifically the impact it has on your child's health and education
- IHCP to be put in place ASAP and to be used as a tool for ongoing support
- Non-attendance to be signed off as authorised as it is a disability (and fed back to the attendance officer) – it's not appropriate that attendance officers are at the meeting, since this is not an attendance issue but an issue relating to the needs that arise from your child's disability
- Exploring an EHCP – if your child could benefit from home tuition, online learning platforms and other adaptations to carry through to age 25
- Establishing one contact at the school to liaise with along with journey, eg. SENCO, Deputy Head, Head of Year.

Take with you:

- If appropriate, the filled in IHCP (see page 6 for full guidance on IHCPs)
- A paragraph of your child's 'ideal learning situation' – if possible, written in their words – use the list on page 7 as a foundation to work from.
- Info sheet for teachers if not already sent via email
- All the evidence you have – medical letters, diagnostic letters, and remember! You can ask your GP for a recommendation letter showing a needs appropriate education that is delivered in a way that suits their current symptoms and needs (part time timetable, later starts, quiet room, hall pass etc)
- An open and positive mindset. Most of the time, schools are underfunded, and their awareness of ME is limited. Once they have the right information and resources, they can often be very willing to work with you and your child

5. HCP information

We believe every child with a medical condition should have an Individual Healthcare Plan (IHCP) – this is a formal agreement, support plan, and a working document between parents/carers, the child/young person, the school and health care professionals (GP or paediatrician) and it is the responsibility of the head teachers, school governors and responsible bodies to ensure that the IHCP is implemented, and reviewed.

An IHCP is a very useful tool for both families and schools to use, to keep the child/young person's support plan in one document. It is recommended that the IHCP achieves the following:

- Describes the needs that arise from your child's disability - showing individual symptoms and the impact this has on their daily living.
- Identifies the barriers they face in accessing their education in a need's appropriate way.
- Describes how their needs will be met at school relevant to each symptom and/or barrier (in person and at home/hospital education/alternative provision).
- Be reviewed every 6 months, or when the medical condition changes/fluctuates – to be agreed upon when creating 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.
- Identifies training needs for teachers and support staff specific to ME and its impact on children and young people.

An IHCP in practise

Below is a table of:

- symptoms people with ME can experience
- the barriers it can create in accessing education
- the possible solutions that you and the school can implement

Having your child's voice heard is our collective objective here, and here are some simple suggested steps to ensure that this happens in the process of creating your child's IHCP. Working with your child (as much as their energy allows):

1. Get your IHCP template ready, you can print this out or edit it from your computer
2. Take your time to work through this table and document the relevant symptoms your child has due to their ME
3. Work through the solutions that you feel would create an ideal learning situation for your child – however it is now up to the school (they can use this table, and your suggestions) to document the relevant solutions into the IHCP
4. You can then meet with the school to ensure you are all happy with the suggestions and the IHCP can be agreed and finalised

(A note - the table is not exhaustive, and to be used as a foundation and edited according to the individual symptoms of your child)

6. Symptoms, barriers and possible solutions

This table below can be used as suggestions for both filling out an IHCP and EHCP. The list is not exhaustive and is to be used as a foundation for writing you/your child's own individual symptoms, barriers and the possible solution that is needs appropriate to you/them.

SYMPTOM	BARRIERS	SOLUTION
Fatigue and Post exertional malaise	<ul style="list-style-type: none"> Physically getting into school to study can be a real issue, causes school absences Not being able to concentrate for long periods of time Feeling overwhelmed by coming into school 	<ul style="list-style-type: none"> Access to a designated quiet area for rest periods if in school Flexible arrangements: online provision/work sent home/home tuition 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 1 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
Feeling generally unwell: this may be a recurrent sore throat or flu-like illness.	<ul style="list-style-type: none"> Difficulties accessing education when feeling unwell 	<ul style="list-style-type: none"> 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.	<ul style="list-style-type: none"> Difficulty navigating between different lessons Difficulties dressing/travelling in to school 	<ul style="list-style-type: none"> 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.	<ul style="list-style-type: none"> • Being overly fatigued in the mornings and often early starts are very difficult 	<ul style="list-style-type: none"> • Delayed starts to their days • Flexible arrangements: online provision/work sent home
Problems with concentration, thinking and memory ('brain fog').	<ul style="list-style-type: none"> • Difficulties concentrating for longer periods of time • Lack of understanding of topics taught – which might cause embarrassment and anxiety • The pace of the lesson can be too quick 	<ul style="list-style-type: none"> • 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 1 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
Problems with the nervous system: very sensitive to light, sound, odours and foods and can have dizziness and headaches	<ul style="list-style-type: none"> • Lighting in school can be overwhelming • Busy classrooms can be too noisy 	<ul style="list-style-type: none"> • 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
Poor temperature control and circulation.	<ul style="list-style-type: none"> • It can be too cold/warm in the classroom 	<ul style="list-style-type: none"> • Allow the student to wear their own clothes and take breaks if needed
Digestive problems: nausea, loss of appetite, IBS like symptoms, indigestion.	<ul style="list-style-type: none"> • 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 	<ul style="list-style-type: none"> • Toilet/hall pass • Authorised absence from school • Flexible provision: online learning, work sent home • Authorised snacks/drinks so they can manage their energy levels better
Mental health issues	<ul style="list-style-type: none"> • As ME is a very difficult illness to manage, and there is a lack of understanding of ME it can cause the young person to lose trust with the people that are supporting them as they 	<ul style="list-style-type: none"> • Regular wellbeing check ins by 1 contact • Pastoral support • Being told by the teachers/support staff that the YP is believed, and understood, and seen – empathic understanding is a powerful tool

are not believed or supported in the right way

- This can cause anxiety and in some cases feelings of depression. This is because of the illness's impact on their lives, not the cause of the illness.

7. EHCP information

While the name sounds similar to the Individual Healthcare Plan, they are different documents, and there are a few key differences:

- an EHCP is a legally binding agreement, that supports the individual up to the age of 25.
- an EHCP is for children and young people who need more support than currently available through the school/college's general support system – meaning the school/college need additional funding to bring in this support.

The impact of ME can be such that it causes special educational needs for pupils who previously would not have been considered as having them. That is, if symptoms prevent a pupil from learning in the way they usually would then adaptations are required. EHCPs identify educational, health and social needs and set out the additional support required to meet those needs.

Schools or parents/carers can apply directly to their local authority to assess the needs of a young person with a view to creating an EHCP. Ideally the school will make this application but if the parent/carer is doing so, there is support available and should be accessed as this process can be challenging.

Having an EHCP in place protects your child's rights long term and as it can be reviewed any time (outside of the formal annual review), it can adapt as your child's health/situation changes.

Top tips:

- Filling out the forms, and going along the EHCP journey is long journey, that can be a very difficult and emotional one. You are relaying very sensitive and difficult information, so take the time to look after yourself, and do something nice as a family.
- Celebrate the small wins! Whether that is a family outing, or your child simply reading a page of a book or drawing a picture – to counter the difficult process of applying for an EHCP.

SEE RESOURCES PAGE FOR LINKS TO CHARITIES AND AGENCIES WHO CAN HELP YOU WITH THE EHCP PROCESS

8. 16 and over

The time it takes for a young person to complete their further education will differ depending on individual circumstances and needs – EHCP's support the young person up to age 25, which means that a young person with an EHCP could spread their GCSE's and A-levels over 3-4 years etc

If there is an EHCP in place this should outline how the student will be supported during transition to post-16 education - ensure that you work with your school early on to get this transition support brought in with plenty of time.

With or without an EHCP, the options for studying post-16 are:

1. full- or part-time study in a school, college or with a training provider
2. online college providers offer GCSE's, A-levels, and BTEC's (this can be funded by an EHCP or using PIP if appropriate)
3. employment, self-employment or volunteering (20 hours or more) combined with part-time education or training
4. an apprenticeship or traineeship
5. certificates, diplomas and degree at the Open University (this can be funded by an EHCP)

It's important to be realistic – if the student has had home teaching for GCSEs, think about the support needed to go on to further education. One consideration is continuing education at home; however, if there isn't an EHCP in place this is unlikely to be funded by the local authority.

In instances where an EHCP is in place, then it may be that Education Other Than at School (EOTAS) is named, but only if this is deemed most appropriate option by the local authority.

Your child is also entitled to Disabled Students' Allowance, this helps covers costs such as specialist equipment, travel and a person to provide support, such as a British Sign Language (BSL) interpreter, a specialist note-taker, or a study skills tutor. More details on the resources page.

For support and information on entitlements, and the responsibility of the 6th form, or college – there is a very useful resource on the below page – “Disabled students and the Equality Act 2010: What colleges need to know and do”

9. Useful resources and links

Organisation	Area	About	Link
IPSEA	EHCP	A template letter you can download to request an EHCP needs assessment	www.ipsea.org.uk/making-a-request-for-an-ehc-needs-assessment
Education Advocacy	EHCP	EHCP timeline and info	https://educationadvocacy.co.uk/what-is-a-ehcp/timeline/
Government	General education support	15 day rule info	https://www.gov.uk/illness-child-education
Government	General education support	This guidance outlines how local authorities and schools can best support children who cannot attend school because of physical or mental health needs.	https://assets.publishing.service.gov.uk/media/657995f0254aaa00d050bff/Arranging_education_for_children_who_cannot_attend_school_because_of_health_needs.pdf
Government	General education support	Statutory guidance for governing bodies of maintained schools and proprietors of academies in England	https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions
Disability Rights UK	School adaptations	List of adaptations for students with medical conditions - school and exams	https://www.disabilityrightsuk.org/resources/adjustments-disabled-students-and-apprentices#_Toc119421698
Citizens advice	Discrimination in education	Identifying discrimination and what to do next	https://www.citizensadvice.org.uk/family/education/overview-of-discrimination-in-education/
Child Law advice	Legal info and support	Resources and support	https://childlawadvice.org.uk/education/
Young Minds	Young People Mental Health	Helpline and webchat for parents concerned about the mental health of their CYP (up to 25)	https://www.youngminds.org.uk/parent/parents-helpline-and-webchat/
Care for Carers	Support groups for carers	Online meet ups for carers	Helpline and other support Carers UK
NICE guidelines	Education support	Recommended support for CYP with ME	https://www.nice.org.uk/guidance/ng206/chapter/recommendations#supporting-people-with-mecfs-in-work-education-and-training
AFME	CYP resource	Explaining ME – written by CYP for CYP	https://www.actionforme.org.uk/wp-content/uploads/2025/03/Explaining-ME.pdf
AFME	Going to school support for CYP	General info and support for CYP going to school	https://www.actionforme.org.uk/18-and-under/going-to-school/
Council for Disabled Children	CYP – 16 and over support in	Disabled students and the Equality Act 2010: What colleges need to know and do	https://councilfordisabledchildren.org.uk/sites/default/files/uploads/attachments/Disabled%20students%20and%20

	6 th form and college		20the%20Equality%20Act%202010.pdf
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Registered office:

Action for ME
Unit 2.2 Streamline
436-441 Paintworks
Bristol, BS4 3AS




Telephone: 0117 927 9551

Info & Support: infosupport@actionforme.org.uk

Fundraising: fundraising@actionforme.org.uk

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