



Education support for pupils with ME

Updated: March 2025

Contents

How to work with your child's school	1
What are care plans and when/why are they needed?	2
Information on IHCPs	2
Example of IHCP for a pupil with ME	
Information on EHCPs	8
16 and over	
How symptoms affect your child	9

How to work with your child's school

Simple physical or mental activities, or combinations of activities, can leave people with ME feeling utterly debilitated. They can also experience an increase in other symptoms.

Be proactive. As soon as your child becomes unwell, especially when ME is diagnosed or suspected, it is essential that you keep the school informed. Email or write a letter (keeping a copy) detailing all symptoms, appointments with doctors etc. so that they have information from the outset.

Absence. Schools have targets demanded of them regarding attendance. They can and should authorise absences in the case of ill health. It is only through a lack of understanding or poor communication that absence can become an issue regarding ME.

The Health Conditions in School Alliance (see useful contacts on p 12) has a [factsheet](#) with more information on this.

Educate the educators. Direct the school to the [Action for ME website](#) (see useful contacts on p 12) where there is information to help them understand the reality of ME and why it is impacting on attendance/engagement with learning.

Communicate. Provide the school with all the information and evidence you have to help them understand the situation you and your child are in. Keep the lines of communication open, even if for periods of time there is no new news.

Meet with the school. You have the right to request a meeting with anyone at the school involved in your child's education. When attending meetings, consider:

- **“What do I need to get out of this meeting?”** If you go in with that clear aim in mind it will help you keep focused.
- **Write notes** to take with you – bullet points are best. This will make sure you ask the questions you need answered and share the important information.
- **Take someone with you.** Meetings can feel intimidating and even if you feel completely comfortable, it's useful to have someone else to take notes.
- **Don't be rushed.** You are entitled to the school's time, and it is important that you feel heard.

- **Keep calm and positive.** You may encounter some challenges in working with the school, but it is essential to do everything possible to keep looking at the potential solutions. Always keep in mind that things can and will get better.

What are care plans and when/why are they needed?

There are two types of care (support) plans:

- Individual Health and Care Plan (IHCP)
- Education, Health and Care Plan (EHCP).

When/why depends on a number of factors: how your child is managing day to day, the age of your child (i.e. are they in their final year of school before moving school/college), how supportive the school/college is being etc.

To simplify matters:

- If you feel your child is receiving their education in a way that is accessible, as far as their symptoms allow with the school understanding and supporting their needs, then a formalised plan may not be necessary.
- 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 a care plan would be a positive move forward.

For reference, you can [find detailed statutory guidance](#) for governing bodies of maintained schools and proprietors of academies in England, updated August 2017, by the Department for Education, on the Government website:

Information on IHCPs

An IHCP should be compiled in collaboration with you, your child, school and those involved in medical care and treatment.

Your child can use this to explain to teachers and support staff the impact of ME on their daily living, how it affects them, and what may help them access lessons and stay in school.

IHCPs can be incredibly important in helping the school to demonstrate how they are supporting children with medical conditions, look at ways to make support practical and develop a positive dialogue with parents/carers, and medical and education professionals.

An IHCP must include certain information such as what the medical condition is, arrangements for specialist training, the impact of the medical condition on the young person, access to educational visits off-site, and support within school.

An IHCP should be personalised and relate to the individual needs of the child.

Below are some ideas that can help prompt conversation around what might be helpful. This is not an exhaustive list, and everyone involved should be invited to put forward suggestions.

Below are some ideas that can help prompt conversation around what might be helpful. This is not an exhaustive list, and everyone involved should be invited to put forward suggestions.

- Specific training on ME for key personnel; please contact Action for ME (see useful contacts on p 12) about this.
- Developing and sharing with key staff an IHCP which details level of support and how ME affects students individually.
- Staggered start times, later than their peers; many children with ME experience more severe symptoms in the morning hours and struggle to get to school on time.
- Reduced school timetable which is based around essential subjects or at a time when a pupil's energy levels allow for attendance.
- Reduction of subjects being taught, particularly at GCSE level.
- Staggered start and end times to avoid crowded public transport or longer car journeys caused by rush hour traffic.
- Access to virtual learning environments for pupils to access education from home.
- IT solutions such as Skype, Zoom and tele-presence robots to minimise travelling time to school/college.
- Being open to combination of school and home tutoring.
- Review of movement between classes; allow use of lift and review timetable to minimise movement or schedule opportunities to leave class earlier to avoid busy times in the school day.

- Flexible approach towards physical education, which can be very physically demanding for children with ME.
- Making arrangements for work to be sent home and marked if a child is absent.
- Scheduling regular rest periods in a designated area such as the medical room.
- Providing a named adult for support within the school, so the pupil knows who to go to if they need to.
- Opportunities to 'catch up' with missed work.
- Extensions for homework assignments.
- A designated place (locker, classroom) to leave schoolbooks or heavy items.
- A buddy to carry bags/books and/or to push their wheelchair (with appropriate training).
- Additional copies of school resources, one to at home and one to keep at school.
- Providing a "Time Out" card so that the young person can let staff know they need an unscheduled break.
- Allowing drinks and snacks in class to help with energy levels.

Example of IHCP for a pupil with ME

CHILD/YOUNG PERSON'S INFORMATION	
Name:	
Date of birth:	
Year group:	
School/College:	
Address:	
Town:	
Postcode:	
Date:	
Frequency of review:	
Next review date:	
MEDICAL CONDITON	
Condition Give a brief description of the medical condition and symptoms	<i>Add a list of signs and symptoms, for example: extreme fatigue, sleeping issues, muscle/joint pain, headaches, sore throat, cognitive dysfunction, dizziness, palpitations.....</i>
Medication Does the young person take medication? If yes, does this require administering during the school day? Name of medication/s:	Yes/No Yes/No
Allergies/Intolerances:	

FAMILY/CARER CONTACT INFORMATION - first contact	
Name and relationship:	
Home / Mobile phone number:	
Work phone number:	
Email:	

FAMILY/CARER CONTACT INFORMATION - second contact	
Name and relationship:	
Home / Mobile phone number:	
Work phone number:	
Email:	

RELEVANT KEY PROFESSIONALS		
	NAME	CONTACT DETAILS
Consultant Paediatrician or named NHS Contact: (if applicable)		
GP		
Class Teacher		
School Nurse		
SEN Co-ordinator		
Head Teacher:		
OT/Physio, etc		
Named liaison for School		
Any other professional/s involved, e.g. Specialist Nurse, Key Worker (Nursery), other related teaching or non-teaching staff		

Examples when completing the Daily Care Requirements	
<p>Impact on child's learning - examples:</p> <p>Cognitive impairment</p>	<p><i>For example:</i></p> <p><i>a) allowance for homework deadlines / suspension of homework</i></p> <p><i>b) reduced timetable</i></p> <p><i>c) 'time out' card to enable child to leave the classroom without unnecessary attention....</i></p> <p><i>d) facilitating communication outside of class, for example, via email</i></p>
Excessive fatigue	<p><i>a) has access to a designated quiet area for rest periods,</i></p> <p><i>b) exclusion from physical exercise</i></p> <p><i>c) allowance for time required between lessons and/or provide buddy to accompany and carry books</i></p>
<p>Exam provisions</p> <p>Special arrangements can be organised through the medical examination officer. This might include:</p>	<p><i>Examples below, further arrangement may be available.</i></p> <p><i>a) delayed start of exam</i></p> <p><i>b) extra time</i></p> <p><i>c) rest breaks</i></p> <p><i>d) use of a laptop</i></p> <p><i>e) scribe</i></p> <p><i>f) alternative accommodation</i></p>
Absence from school	<p><i>a) guidance from GP, paediatrician/specialist regarding ability to attend school & medical report...</i></p> <p><i>b) alternative arrangements - home tuition, virtual learning,</i></p>

	<p><i>pupil referral unit...</i></p> <p><i>c) regular meetings with parents, teachers, health professionals to update progress</i></p> <p><i>d) agreed plan/timetable for school attendance</i></p> <p><i>e) copies of notes/PowerPoint from lessons to be made available</i></p> <p><i>f) communication from school sent home</i></p>
--	--

DAILY CARE REQUIREMENTS (See examples above)	
Impact On Child's Learning:	Actions:
Application for an EHCP to be considered	
Curriculum meets individual needs	For example, core subjects are not mandatory, considering brain fog. Consider young person's preferred subjects
Special considerations	For example, access around school premises and the use of a lift
Trips and activities away from school	
Staff training	Support available from Action for ME
Emotional and social needs	For example, sessions with the School Counsellor and/or a quiet place to meet 1-3 friends in break times
[Add more as needed]	

Additional information (Add here any information from parent/carer that you feel will enable your child to reach his/her current potential)
<i>Any comments from the young person:</i>

SIGNED BY	Name:	Signatures:	Date:
Young Person			
Parent/Carer			
School representative			
School nurse			
Health professional (by post/email)			

Information on EHCPs

For young people up to age 25, an EHCP can be put in place. A similar document used to be called a Statement of Special Educational Needs.

While the name sounds similar to the Individual Healthcare Plan, they are different documents, with a different purpose.

An EHCP is for those who need more support than currently available through the school/college's general support system. 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.

Do not let that put you off! Having an EHCP in place protects your child's rights long term and as it can be reviewed any time, it can adapt as your child's health/situation changes.

IPSEA (see useful contacts on p 12) has a template letter you can download to request an EHCP needs assessment at www.ipsea.org.uk/making-a-request-for-an-ehc-needs-assessment.

16 and over

Most young people with an EHCP plan complete their further education by the age of 19. However, some young people may take longer, as the time it takes for a young person to complete their further education will differ depending on individual circumstances and needs.

Therefore, the judgement to maintain or stop an EHCP is made on an individual basis.

If there is an EHCP in place this should outline how the student will be supported during transition to post-16 education.

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

- full- or part-time study in a school, college or with a training provider
- employment, self-employment or volunteering (20 hours or more) combined with part-time education or training
- an apprenticeship or traineeship
- 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.

How symptoms affect your child

The following table offers a simple way for your child to explain how their symptoms affect them, and the support that may help address this. It can be edited/added to as needed.

It can be used for the EHCP application process (it can help you complete the template letter), and also to explain to school/college about their support needs.

Symptom	How it affects me and my learning	Support needed
Cognitive dysfunction	<ul style="list-style-type: none"> • Difficulty processing information. • Struggling with formulating what I need to say and struggling with finding the words. This is heightened by anxiety. ☑ 	<ul style="list-style-type: none"> • Audible and written (more than one format is preferable). • Tutor to break things down and repeat as needed. • Regular rest breaks. • Having understanding tutors will help if they can recognise my symptoms and when I am struggling. • Having 1:1 support with someone who knows me well.
Poor short-term and long-term memory	Difficulty remembering information	<ul style="list-style-type: none"> • Regular rest breaks • Repetition of information • Different formats, some facilitated by a tutor to help me remember. • Review of lesson afterwards with a tutor.
Intense fatigue	<ul style="list-style-type: none"> • I struggle to concentrate • I work for way too long, and this can make my symptoms worse. 	<ul style="list-style-type: none"> • Regular rest breaks. • Having a schedule so I have to stop. • Online learning removes the physical exertion of moving and allows me to focus on cognitive work which wears me out. • Teaching staff to be aware and understand ME and how it affects me.
Dizziness when standing for too long or	Depends on activity, e.g. reading it can kick in quickly; art I can do for longer as this is less tiring	<ul style="list-style-type: none"> • Stopping and having a break, which is easier to do at home. • Unpredictable and requires

Symptom	How it affects me and my learning	Support needed
concentrating too much.	on my brain.	flexible learning as it depends how the day and on a bad day, it is quicker to kick in e.g. after 10 minutes.
Sound sensitivity	Affects my concentration. Can increase my anxiety which can make me tired, and symptoms worsen. Processing the noise takes more energy.	A quiet environment to study is helpful as if I was in a <u>noisy environments</u> I would need much more breaks.
Light sensitivity	Bright lights make me tired	Dimmed screens. I don't have lights on in the day and have low lighting at night.
Sleep dysfunction	<ul style="list-style-type: none"> • Feeling less alert • Makes other symptoms worse 	I would prefer to have the <u>majority</u> of my education in the morning/afternoon [delete as applicable]
Difficulty walking	I would struggle to walk around to different lessons and stairs are hard if there are lots of them.	Lessons close together distance wise but ideally online and home learning.



Useful contacts

Action for ME

Unit 2.2 Streamline, 436-441 Paintworks
Bristol, BS4 3AS
Tel: 0117 927 9551 (Mon to Fri 10am to 4pm)
Email: infosupport@actionforme.org.uk
www.actionforme.org.uk

SENDIASS

The Special Educational Needs and Disabilities Information Advice and Support Services
www.kids.org.uk/sendiaass

IPSEA

Independent Parental Special Education Advice.
Book a helpline appointment online at www.ipsea.org.uk

Medical Conditions in Schools Alliance

<http://medicalconditionsatschool.org.uk>

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

If you have found this resource useful, please consider making a donation to help us reach even more people affected by ME.

www.actionforme.org.uk/donate/

 [@actionform.e](https://www.instagram.com/actionform.e)  [@actionforme](https://www.facebook.com/actionforme)  [@actionforme](https://www.linkedin.com/company/actionforme)

Registered charity in England and Wales no. 1036419
Registered in Scotland no. SC040452
Company registered by guarantee in England no. 2906840

