



Support plans for pupils with M.E.

January 2021

This Action for M.E. factsheet is aimed at children and young people with M.E., their parents, teachers, and other professionals supporting them.

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Individual Healthcare Plans

If a child/young person has a long-term medical condition such as M.E. it is a statutory requirement for the school to have in place an Individual Healthcare Plan (IHCP) compiled in collaboration with the young person, school, parents/carers and those involved in medical care and treatment.

The child/young person can use this to explain to teachers and support staff the impact of M.E. on their daily living, how it affects them, and what may help them access lessons and stay in school.

IHCPs are incredibly important and can help the school 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.

A well-written IHCP can help the school carry out their statutory responsibilities, as detailed in the Department for Education resource, *Managing Medical Conditions in School* (see useful contacts on p 16).

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.

Examples of an IHCPs for a pupil with M.E. can be found on p 4.

Examples of others IHCPs can be found on the Medical Conditions in School Alliance website (see useful contacts on p 16).

Some ideas that may help to make reasonable adjustments and write an IHCP

In order to help meet responsibilities under The Equality Act 2010 and the *Managing Medical Conditions in School* guidance, it is important to have open dialogue between the young person with M.E., where practicable, the family, and health and education professionals about what may benefit the young person and provide them with the best support.

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 M.E. for key personnel; please contact Action for M.E. about this.
- Developing and sharing with key staff an IHCP which details level of support and how M.E. affects students individually.
- Staggered start times, later than their peers; many children with M.E. 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 student'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 PE, which can be very physically demanding for children with M.E.
- 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 school books 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 an Individual Healthcare Plan for a pupil with M.E./CFS

Individual Healthcare Plans can help to ensure that schools effectively support pupils with the medical condition M.E./CFS, so that they are enabled to attend school for as much as their medical condition allows. This is a plan individually compiled by school professionals, in consultation with health professionals, parents/carers and the child/young person.

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>a) allowance for homework deadlines / suspension of homework</p> <p>b) reduced timetable</p> <p>c) 'time out' card to enable child to leave the classroom without unnecessary attention....</p> <p>d) facilitating communication outside of class, for example, via email</p>
<p>Excessive fatigue</p>	<p>a) has access to a designated quiet area for rest periods,</p> <p>b) exclusion from physical exercise</p> <p>c) allowance for time required between lessons and/or provide buddy to accompany and carry books</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>a) delayed start of exam</p> <p>b) extra time</p> <p>c) rest breaks</p> <p>d) use of a laptop</p> <p>e) scribe</p> <p>f) alternative accommodation</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, 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>
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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 M.E.
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)			

Education Health and Care Plans

For young people up to age 25, an **Education, Health and Care Plan (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 an institution's general support system. For those identified as having special educational needs, EHCPs identify educational, health and social needs and set out the additional support required to meet those needs.

Parents can ask their local authority to assess the needs of a young person with special educational needs or a disability, taking into account their individual needs. See our exemplar letter on p 9, and "M.E. and how it affects me" on p 14.

This information is then brought together in an EHCP which identifies and sets out support to meet those needs. All local council websites will show their "local offer," a list of education, health and social care services in their local area provided for children, young people and families who have special education needs or disabilities.

The Department for Education resource, *Supporting pupils at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England*, may be useful (see useful contacts on p 16).

Many parents/carers find that they need additional legal/professional help with this process, as it can take months and can be very challenging. Not all requests for an EHCP are successful and therefore getting extra support, if affordable, may be worthwhile.

There may be organisations in your local area to help with this process. Independent Parental Special Education Advice (see useful contacts on p 16) is a useful organisation, offering online training, seminars and impartial advice.

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 to school/college. 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.

Requesting an Education Health Care Needs Assessment: exemplar letter for M.E.

For the attention of Director of Children's Services
[Name of child and their DOB]

Re: Request for Education Health Care Needs Assessment

Dear Director of Children's Services

I am writing as the parent of the above child to request an assessment of their Education, Health and Social Care needs under section 36(1) of the Children and Families Act 2014.

[Name of child] currently attends **[name of school/institution]**.

I understand that the test that the LA must apply in considering this request is contained in section 36(8) of the Children and Families Act 2014 and has two parts.

Part one of the test is that the child or young person has or may have special educational needs.

If your child has already been identified as having a SEN then you can list the SEN identified by the school/college and attach supporting evidence and use the wording below. Delete the paragraphs below which is not applicable:

1.a. **[Name of child]** has already been identified as having special educational needs by **[name of school / college]**. They identified them as **[List the SEN already identified by school/college and provide any supporting evidence – for example reports from school/college or professionals. You can also add any other needs that you think your child has which have not yet been identified by your school/college.]**

OR

1.b. **[Name of child]** requires an assessment due to the barriers caused to accessing education as a result of special educational needs because they have a diagnosis of [add any diagnosis/es your child has and dates of diagnosis].

This affects them in the following ways: **[list all the symptoms your child has and the severity, for example, extreme fatigue, sleeping issues, muscle/joint pain, headaches, sore throat, cognitive dysfunction, dizziness, palpitation]**.

[Include information about M.E. from our website and refer to a copy of the Functional Ability Scale].

The impact on him/her is **[refer to the impact on skills/abilities here, making it clear that M.E. results in a SEN – see table on p 10]**.

S/he has difficulty with **[academic/emotional/social skills - reading, writing, numbers, talking, listening and understanding, friendships, physical skills, concentration, emotions, behaviour, mental health]**.

Therefore her/his needs education to be delivered [request for specific delivery of education that is accessible].

You **must** include evidence from education and health professionals – this needs to be a school report or letter, evidence of exclusions, and a letter from a Specialist Consultant showing evidence of the young person’s physical, emotional and social development and their health needs. You can also ask their GP for a more up-to-date description of their condition, how it impacts them and how the difficulties affect their educational needs.

Examples of how the impact of M.E. relates to education and SEN:

Symptoms according to criteria of SEN (examples)	SEN impact (examples)	How it affects the delivery of education (examples)
<p>Communication, interaction, cognition and learning</p> <ul style="list-style-type: none"> • Variable and unpredictable levels of fatigue can limit the amount of communication and the level, type and amount of interaction my child is capable of. • Difficulty with processing speech, understand and hold it in mind to formulate a response. • Ability to listen is impaired. Speech can be delayed, vague, slurred and confused. • Memory is affected. • Meeting the challenges of a medical condition and balancing that with the demands of communication and interaction can be difficult. • Can struggle to read or understand what has been read. • Sleep deprivation – day/night reversal. • Headaches/dizziness/ heart palpitations. 	<ul style="list-style-type: none"> • Difficulty remembering things, getting stuck on their words. • Poor focus, reduced attention span and concentration. • Can only absorb small amounts of information at a time. • Not making academic progress on par with ability, does not have access to suitable education. • Excessive fatigue resulting in not being able to wake up in the morning and having days when s/he is asleep and cannot get up and therefore cannot study. 	<ul style="list-style-type: none"> • <i>Difficulty with reading and writing. Can focus for short amounts of time, e.g. 10 minutes of education, then needs change of activity or rest.</i> • <i>After exertion of studying for 10 minutes, s/he needs to rest for 1 hour to recover from onset of symptoms.</i> • <i>Needs reinforcement of education through repetition and explanation, with 1:1 tutor due to poor s/t memory and need for tasks to be simplified and broken down.</i> • <i>Needs a scribe and lessons to be explained afterwards.</i> • <i>Learning needs to be efficiently presented and flexible to the needs of a changing health status and requires personalised input to access the basis of a lesson.</i> • <i>Requires flexible learning at variable times, such as on-line learning.</i>

Symptoms according to criteria of SEN (examples)	SEN impact (examples)	How it affects the delivery of education (examples)
<p>Sensory</p> <ul style="list-style-type: none"> • Sensitivity to environment, including noise and light 	<ul style="list-style-type: none"> • Difficulty with noisy bright environments can bring on symptoms, e.g. headaches, nausea, dizziness and fatigue. • Over-sensitivity to environment can use more energy quickly which results in increase of symptoms and fatigue. 	<ul style="list-style-type: none"> • <i>Needs minimum distraction, noise and low light level.</i> • <i>Needs home tutors due to severity of fatigue and symptoms after travel or lessons at school.</i> • <i>Needs a quiet space for rest.</i> • <i>Avoid noisy times in transitions.</i> • <i>Normal classroom/ canteen too noisy and bright. Lessons and breaktimes need to be provided in area with reduced noise and bright lights, in a dedicated area, away from noise of main school, such as learning support area.</i>
<p>Physical</p> <ul style="list-style-type: none"> • Difficulty walking. • Any physical exertion increases fatigue, pain and other symptoms. • Cannot write due to poor motor skills. • Chronic pain in joints/muscles. 	<ul style="list-style-type: none"> • Cannot walk for long periods. • Cannot walk at any time. • Unable to do written assignments. 	<ul style="list-style-type: none"> • <i>Assistance for travel with a companion.</i> • <i>Need to use lift.</i> • <i>Need wheelchair access.</i> • <i>Cannot do PE.</i> • <i>Requires home learning.</i> • <i>Requires regular rest breaks.</i> • <i>Requires a scribe.</i>
<p>Social, emotional and mental health</p> <ul style="list-style-type: none"> • Concerns about health needs not being met or pressure to do too much, increases anxiety. 	<ul style="list-style-type: none"> • Anxiety increases symptoms. • Worry about coming into school affects attendance. 	<ul style="list-style-type: none"> • <i>Re-integration requires careful management.</i> • <i>Staff need to be trained in medical condition to support emotional well-being and prevent harm to health.</i>

Symptoms according to criteria of SEN (examples)	SEN impact (examples)	How it affects the delivery of education (examples)
<ul style="list-style-type: none"> • Due to health needs and inability to attend school regularly, social interaction has been severely limited. 	<ul style="list-style-type: none"> • Delayed development socially and building and retaining friendships is hard. 	<ul style="list-style-type: none"> • <i>Careful reintegration required and introduction of social time at school a priority.</i> • <i>Education, with pupil's consent, about the condition for the pupil's peers so there is an awareness about why they have not been able to attend and their health needs eg. Not managing noisy/environments or talking to lots of people</i>

The views of the young person are important – **what help do they need to achieve their goals and aspirations?** Some further questions to consider - Does your child enjoy going to school? What do they like best? What would they like to achieve? What makes it hard for them to do this? What help does your child think they need? Link this to the need for delivery of education specific to their SEN.

Part two of the test is that it may be necessary for special educational provision to be made for the child/young person through the issuing of an EHC plan.

My reasons for believing that **[child / young person's name]** may need an EHC plan are:

- [List reasons why an EHCP Plan may be needed]
- [What the school has provided to meet their health needs, eg. provided reduced timetable and exit card]
- [How this impacted their rate of progress. S/he still cannot attend due to the above reasons]
- [What further support is needed which the school cannot provide without an EHCP, eg. 1:1 tutors, online learning etc. Link this to aspirations of young person.]

Please find enclosed evidence from **[child / young person's name]** school as follows.

- Rate of progress
- Attainment
- Evidence of action already taken by school, what has been done to meet their health needs, where any progress has been made it is a result of support above and beyond what is usually provided.
- Evidence that the yp is not making progress despite the school putting interventions in place.

The two-part test outlined above is the only test to be applied under the law. I understand

that it would be unlawful for a local authority to apply a higher threshold for accessing an EHC needs assessment. Furthermore, this legal test is different to that which must be applied in the decision about whether or not to issue an EHC plan.

[I / We] believe that the local authority should carry out an EHC needs assessment to determine the full extent of **[child / young person's name]**'s needs.

I understand that you are required by law to reply to this request within six weeks, and that if you refuse **[I / young person's name]** will be able to appeal to the First-tier Tribunal (Special Educational Needs and Disability).

Yours faithfully

[Your name]

[OR, if on behalf of a young person]

[Your name] on behalf of **[name of young person]**

M.E. and how it affects me

The following table offers a simple way in which the child or young person with M.E. can complete 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, 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 M.E. and how it affects me.
Dizziness when standing for too long or concentrating too much.	Depends on activity, eg: reading it can kick in quickly; art I can do for longer as this is less tiring on my brain.	<ul style="list-style-type: none"> • Stopping and having a break, which is easier to do at home. • Unpredictable and requires flexible learning as it depends

Symptom	How it affects me and my learning	Support needed
		how the day and on a bad day, it is quicker to kick in eg. after X mins.
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 noisy environments 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 majority 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 M.E.

42 Temple Street, Keynsham BS31 1EH

Information and Welfare Support: 0117 927 9551 (Mon to Fri 10am to 4pm)

Email: questions@actionforme.org.uk

www.actionforme.org.uk

@actionforme

Supporting pupils at school with medical conditions

Statutory guidance for governing bodies of maintained schools and proprietors of academies in England, published December 2015 by the Department for Education

www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions

Independent Parental Special Education Advice

Book a helpline appointment online

www.ipsea.org.uk

Medical Conditions in Schools Alliance

<http://medicalconditionsatschool.org.uk>



If you have found the information in this factsheet helpful, please consider making a donation to help us reach more children and families living with M.E.

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