

■ The Chief Medical Officer's Working Group Report on CFS/M.E.

Children and Young People's Guide

Wise up about the Chief Medical Officer's (CMO) new report on Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/M.E.) – it's a crucial step forward because at last CFS/M.E. has been recognised as a serious and widespread illness that has a major impact on the person who has it and their family and friends.



Between 1998 and 2002 a large group of people met to think about how the National Health Service could provide better care for people who have CFS/M.E. and to publish a report of their findings. This Working Group consisted of people who have CFS/M.E., a range of different doctors, CFS/M.E. charities and people who work for the Government at the Department of Education and Skills (DfES)

The report is an official document that reviews how CFS/M.E. is managed and sets out guidance to improve the quality of care for people with CFS/M.E.

The Working Group was set up by the Government's main medical adviser – the Chief Medical Officer (CMO). His job includes developing new ideas and plans that will try to improve and protect everyone's health. The current CMO is Professor Liam Donaldson. He said at the launch of the report on 11 January 2002,

'Until now sufferers were ignored or not taken seriously, labelled as hypochondriacs, or urged to pull themselves together and get better on their own. From today that changes.'

Action for M.E. has written a guide summarising the report and explaining what it means for people who have CFS/M.E. If you would like a free copy contact our Wells office on 01749 670799 or email sally@afme.org.uk.

If you would like to read the whole report (150 pages divided into six chapters and seven annexes) then contact the Department of Health Public Enquiry Office on 020 7210 4850, or check out their website on www.doh.gov.uk. You can also write to: Department of Health, Richmond House, 79 Whitehall, London, SW1A 2NS.

This document is a special summary of the chapter in the CMO's report which relates to young people. It is fairly detailed, so take your time reading it and don't feel that you have to read it all at once. If you or your parents would like further information about diagnosis, treatment and management, education etc, please contact Action for M.E.

Here are some quotes from the report that you can think about...

It is important to believe the child and listen to their views [p.57](#)

Children's rights are safeguarded by UN convention and need to be respected at all times by professionals and parents/carers. The rights to be heard, to have their views taken into account, to access quality medical treatment, and to be protected from abuse both by individuals and by systems need particular attention [p.57](#)

An educational plan is not an optional extra but an integral part of therapy [p.63](#)

Key points of the report are in the boxes:

CFS/M.E. is a serious illness that young people get, however even after a long time many get better.

CFS/M.E. can be isolating, particularly as the condition is not well known or understood and can be met with disbelief. This can make the situation even more difficult for young people who have learning difficulties or are from ethnic minority groups.

How widespread is CFS/M.E.? (Epidemiology)

During the last ten years more and more young people (particularly 14–15 year olds but some even as young as 5 years old) have been diagnosed with CFS/M.E. No one is certain exactly how many young people in the UK have CFS/M.E.

There are differences between the way CFS/M.E. is experienced by both adults and young people both in the nature of the disease and the way it affects their lives.

There is no more known about CFS/M.E. in young people than adults and the report recommends that the Royal Colleges do more work and research with young people, parents, voluntary organisations, paediatricians and child psychiatrists. The Royal College aims to advance the art and science of paediatrics, improve standards of medical care for children, and to educate and examine doctors in paediatrics. Additionally, the College has a function in providing information and education of the public in child health matters.

So what are the symptoms of CFS/M.E.? (Clinical Profile)

Whilst most of the symptoms are the same as adults, young people can be prone to more pains in the stomach area, feeling sick and changes in appetite which may lead to the young person putting on or losing weight. It appears that young people can take longer to recover after having done some exercise or activity.

For many young people, even if their CFS/M.E. is mild, it can be much more difficult to do physical activity and may mean you cannot go to college or school. The CFS/M.E. symptoms come and go and this can depend on different circumstances like how healthy you were before you got poorly and how your body responds to the illness.

It seems that young people are more vulnerable to being told 'it's all in your mind'. But it's really hard when as a young person you sometimes do not want to admit it to yourself or your friends that you have CFS/M.E. For really small children it can be frustrating because you don't understand why some days you feel good and some days you feel bad. How long you will have CFS/M.E. is unique to you, but many young people/children recover even after being poorly for ages.

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How can CFS/M.E. affect your everyday life? (Social Impact and Management)

Some young people are so poorly that they have to stay in bed and often their symptoms are similar to someone who has problems with their nervous system (neurological condition). The report acknowledges that CFS/M.E. can have a serious affect on family life:

- It can increase stress levels in your family
- It can put a stop to or reduce the amount of usual family activities
- Some people in the family may not be able to accept your CFS/M.E.
- Some parents or carers may have to give up their jobs to look after you or your brother or sister

The report also acknowledges how CFS/M.E. affects young people

- It can take longer to move towards increasing your independence
- It can make you more dependent on your parents or carers just at the time when all your friends are becoming less dependant
- It may, over time, mean you lose contact with your friends
- Sometimes your only close friends may be your brother or sister
- Sometimes your brother or sister may feel left out because of the attention you are getting due to your illness

Health and Social care professionals can help you and your family:

- By working with you to help you learn how to cope and manage CFS/M.E. Disability Social Work Teams can help your family get the support you may be entitled to get from other services
- Many young people, children and their families have spoken very warmly of the support they have had from child services

As little is understood about CFS/M.E. your doctor and other medical staff can find it difficult to decide that your illness is CFS/M.E. and agree how to manage it.

Diagnosis must be quick, careful and exact and be from someone who is a health professional. If there is any doubt you must get a second opinion. Unfortunately there is no test that can be done that will tell you whether you have CFS/M.E. or not. The best doctors can do at the moment is put together all the positive clues from your symptoms and history and a medical examination. It is important that doctors are sympathetic to parents/carers as CFS/M.E. can be such an uncertain illness.

Health, Social Care and Education services for young people with CFS/M.E. need to take into account that they are also growing up and their needs will change. It is especially important to plan a smooth transition from children's services to adult services. These professionals also need to support and help minimise the impact that CFS/M.E. can have on emotional, physical, sexual and social development.

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It is really important that CFS/M.E. is promptly diagnosed by a health professional as the cause of your illness. The possibility that your symptoms might be due to another illness that could cause other complications should not be ruled out by your GP.

CFS/M.E. may produce different symptoms if the young person has other disabilities – which can make it even harder to detect. Just to make things even trickier, other conditions can mimic or complicate CFS/M.E. such as physical illnesses eg. Heart disorders, mental/social conditions, depression or eating disorders.

Because we do not know as much about CFS/M.E. as we do with other similar illnesses (for example what causes it, or how best to treat it) there have been instances where professionals, parents and young people have disagreed about what is best for the child involved. The Working Group which published this report made it clear that parents have the right to reject a certain type of treatment without being accused of putting their child at risk.

However we cannot ignore that a few children with CFS/M.E. suffer harm and it is vital that this is considered during the early stages. In all cases it is vital that the child is listened to, as well as the family and parents/carers to understand the situation.

All these need to be considered early on in the illness and either ruled out or treated. Also excess tiredness or 'fatigue' might not show itself as an initial problem in young people.

Any management of your illness should be focused on your needs and regularly reviewed by a locally organised group of different health professionals. Most young people (especially those who have been off school for more than 15 days) should be seen by Community Paediatric services (these are people who specialise in health and social care for young people).

It is:

- Vital that your treatment meets your needs – 'patient-centred'
- Important that CFS/M.E. is recognised early by your doctor and confirmed by a child health specialist, if appropriate
- Really important that an appropriate treatment plan is developed with you and your family (depending on how poorly you are) and that the plan is regularly revised according to your feedback

Doctors can give valuable support to help you and your family to:

- Work alongside the community Paediatrician (child health specialist) to co-ordinate your care needs and keep in touch with your education needs
- Keep a diary of how your CFS/M.E. affects you
- Manage the energy you have each day
- Develop a suitable approach to doing activities
- Develop a timetable to help you focus on what you want to achieve – this does not mean you will be in trouble if you cannot reach them it just gives you some goals
- Develop a new plan as you start to get better to help you to get back to school and go out with your family and friends

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Where the doctor is unsure about anything they should seek advice from a specialist. However you decide to manage your CFS/M.E. it is vital that all the services -health, education and social services – work together with you and your family/carers to ensure you are having the best possible advice and support – this is sometimes called 'Integrated Multidisciplinary Support'.

It is important that a health or social care professional takes the lead in co-ordinating this support.

The medical person who works with you to manage your CFS/M.E. needs to focus on your education needs and the impact that your illness is going to have on you and your family.

Your care should be written into a clear, detailed treatment plan. The plan should be designed and agreed by you and your health and social care professionals, to meet your needs. The plan needs to be regularly reviewed.

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To ensure your education needs are met it will be important to draw up an individual education plan (IEP) and work together with the Education Welfare Service (EWS). The EWS is a support service for pupils, parents and schools working in the area of school attendance. Nearly all young people who are severely ill and many who are moderately ill will require home tuition and/or distance learning. Some young people are too poorly to study at all for quite a long period after they become ill.

However once you begin to feel more able, your IEP can start. This should not be forced, but can be used to encourage a suitable pace of work and provide a starting point to review progress. With the right support you can start back at school for short sessions. You can work in a separate quiet area, take rests and have a chance to chat with your friends.

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Your ongoing CFS/M.E. management plan should include:

- Information about your medicines
- Help on dealing with your personal thoughts about the illness
- Your education plan
- Your range of activities agreed to try to keep your body alert

There may be a range of people who support you with this plan such as home tutors, physiotherapists, occupational therapists, nutritional experts and specialist nurses. It is important that they have a common approach to working with you and your family/carers.

Who are CAMHS and how can they help?

- The staff that work for the Child and Adolescent Mental Health Service (CAMHS) can play an important role in the assessment and management of CFS/M.E.
- Psychiatric opinion can try and work out whether a young person is depressed about something and has symptoms that make it look like they might have CFS/M.E., or whether the young person is feeling depressed due to CFS/M.E. It is important to know and understand the difference. CAMHS will be able to offer you advice
- CAMHS can work closely with education and other services
- It is important that professionals understand that any referral to the CAMHS needs to be sensitive to the beliefs and fears of the young person and their family/carers

Follow-up to any treatment needs to focus on the progress made towards your agreed goals and to highlight any potential complications.

Helping family/carers to help you manage your CFS/M.E.

Sometimes, because of all the uncertainty, some parents can blame themselves and feel guilty. It is important to help prevent this happening by giving parents/carers the information they will need and a management plan. The parents/carers need support as well, or they risk they same problems as the young person eg. not seeing their friends, difficulties with work etc. Good ways of helping equip parents and young people to improve their situations can be worked through with the health staff.


New Health, Social and Education services need to be developed around you and your family's needs

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