

ain
COIN
ST
a
t
a
s
i
b
u
e



The Diagnosis and Management of Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/ME) - Child Protection Guidance

For professionals working in health, Social Services and education



Supported by

1. Management and treatment	pg 5
2. Misplaced allegations	pg 5
3. Why have parents been accused?	pg 5
4. Guidance and information	pg 6
5. Guidance for professionals	pg 7
6. Case studies	pg 9
7. Essential points for consideration before proceeding down child protection route	pg 10
8. Recognise the adversarial nature of the legal process	pg 10
9. First step	pg 11
10. Risks	pg 12
11. Signs and symptoms	pg 13
12. Useful reading	pg 15
13. Useful contacts	pg 16
14. Working group	pg 17

The Diagnosis and Management of Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/ME) - Child Protection Guidance

For professionals working in health, Social Services and education

This guidance leaflet has been written as a result of the ongoing reporting by families and health care professionals of cases where child protection action has been taken or threatened alongside a diagnosis of CFS/ME, or in the early stages of the condition prior to diagnosis. This is an often misunderstood, misdiagnosed condition, leaving professionals in health, education and Social Services with a confusing care pathway, often full of misinformation and suspicion.

The working group, from a range of professional backgrounds, has tried to dispel the myths and give you the information you need to make professional and informed decisions when child protection concerns are raised in a case of CFS/ME and has sign-posted you to further resources and organisations that can offer support. It is hoped the result will be a reduction in the number of families, children and young people placed in this stressful and avoidable position.

1. Management and treatment

“CFS/ME is an extremely unpredictable condition and patients vary with respect to severity and duration of illness although there is some evidence that young people are far more likely to make a full recovery.” (RCPCH Evidence Based Guidelines page 41)

Experience suggests that early diagnosis of the condition has a positive impact on prognosis. Therefore medical personnel should maintain a positive attitude about diagnosis. Research does not support any particular management programme as being the most effective treatment, although a multi-disciplinary approach – where the professionals have received training in the diagnosis and management of CFS/ME has proved to be both popular and successful for many children and young people.

2. Misplaced allegations

Sadly, there is a history of parents of children with CFS/ME being falsely accused of Fabricated or Induced Illness (FI), formerly known as Munchausen’s Syndrome by Proxy. This is a genuine but very rare condition where a parent induces or falsely reports symptoms of an illness in their child. The number of reported misplaced allegations against parents of children with CFS/ME has been small, but their impact is devastating. In addition, a larger number of parents report “feelings of not being believed” and of “being under threat of action” if they don’t comply with the advice given by professionals in education, health and Social Services (reported by numerous CFS/ME parents at workshops, conferences and on the Association of Young People with ME (AYME) telephone helpline).

3. Why have parents been accused?

In general, it seems that misplaced allegations have arisen from a lack of understanding and knowledge amongst professionals in health, education and Social Services about CFS/ME. In particular, it seems to focus around lack of clear diagnosis and disagreement between parents and professionals over preferred treatments.

Some child protection cases have been brought to enforce management programmes which were at variance with the wishes of the families or carers, child or young person, and without reference to Fabricated or Induced Illness. In other instances, cases have been brought by professionals who “did not believe” in CFS/ME, or have come across a severely affected child for the first time and did not recognise the disorder or were made very anxious by the severity of the symptoms. Although schools are obliged to

refer concerns over attendance to the Education Welfare Service and Social Services, consideration needs to be given to medical advice and reports provided by Consultants and General Practitioners.

Training and information for Education Welfare Officers, Special Education Needs Coordinators, District Nurses and other professionals can be requested through AYME.

4. Guidance and information

There are several key documents on the management of CFS/ME addressing the issues that have led to false accusations and which emphasise the partnership needed between the child and their family and the professional team:

The Chief Medical Officer's Working Group Report on CFS/ME (2002)

"The working group notes that neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choices about treatment or education for such a patient by parents/carers and/or young person constitutes evidence of abuse" (page 64)

The Royal College of Paediatrics and Child-Health-Evidence Based Guideline for the Management of CFS/ME (2004)

"Developing a rapport with the family and establishing a cooperative and empathetic relationship using a sensitive and flexible approach is essential to the success of the management plan" (page 43)

"As the differential diagnosis of FII [Fabricated or Induced Illness] can be very difficult, great care must be taken and the paediatrician should review the Department of Health guidelines and the RCPCH guidelines on FII....A referral is likely to be destructive if based on flimsy or ill-reasoned evidence" (page 72)

"Refusal to follow a treatment programme is unlikely to be regarded by a Court as sufficient reason on its own to make an order under the Children Act, especially where it may hear conflicting expert evidence as to the efficacy or otherwise of the proposed treatment." (page 72)

This is endorsed by the report of the CMO which states:

"Neither the fact of a child or young person having unexplained symptoms nor the exercising of selective choice about treatment or education for such a patient by the parents/carers and or young person constitutes evidence of abuse.... It is important to listen to the child, as well as to family members to respect their experiences and give

due weight to their views, especially the child's. The young person should be given the opportunity to speak to the clinician, with or without their parents/carers."

(CMO page 64)

Therefore, provided that the medical professionals are satisfied that the child/young person is receiving regular medical checks from the primary care team, the management programme must be the child and family's choice.

The guidance contained in the above reports is clear. When followed, it should help to end the stress and difficulties that families face due to suspicion and misplaced allegations of abuse. Health professionals in contact with children and young people with CFS/ME need to be aware of this guidance, and ensure it is followed in their management of the disorder.

5. Guidance for professionals

A typical pattern of events is outlined below:

- Concerns are raised about a child by a member of the professional team or a family member about frequent absence from school, the child/young person being withdrawn from social activities, the child/young person being unable to make contact visits with an estranged parent or other family members
- There is no firm diagnosis
- The GP is unable or unwilling to make a diagnosis and/or refer for an expert assessment
- The parents/carers don't agree with the diagnosis given
- Parents may be frightened, angry, defensive, inarticulate or nervous
- Communication breaks down between the family and professionals

If parents suspect that their child has CFS/ME, all professionals involved with the family must listen carefully to their history and consider this in the context of what they observe. "Social Services should be made aware that medical opinion in this area is divided, and consideration should be given to obtaining a further opinion from an expert medical practitioner with a specialist knowledge of CFS/ME." (CMO page 64)

Fatigue in CFS/ME is post-exertion (post-exertional malaise) and often has a delayed onset. This means that the child/young person may present as being well and happy at school and during visits to friends and family, but may relapse significantly days after activity. Accordingly, if the parents report that the child is shattered the next day or even a few days later, this should be believed unless there is direct evidence that this is not

the case. (RCPCH Guidance page 26)

Parents need support in obtaining a clear diagnosis of their child's illness because this removes a lot of the worry for the child and family.

It is essential for all professionals involved to remain open-minded because CFS/ME is often misdiagnosed and misunderstood, even within the medical profession.

If the child's GP is unable to support the family for any reason, please contact Action for ME (AfME) or the Association of Young People with ME (AYME) who can signpost the professional and/or family to the nearest paediatric CFS/ME specialist service in England.

Sometimes the child has a confirmed diagnosis and the family wishes to manage the condition by pacing the child/young person's activity at home, rather than the clinician's preferred management programme. There is no research evidence to prove that any particular management programme is more effective and the CMO and RCPCH both support patient choice. (RCPCH page 43, 56-59, 87, 92, 93)

Education Welfare Officers, Special Educational Needs Coordinators, District Nurses and other professionals involved should ask for a letter from the consultant paediatrician, GP or other medical professional responsible for the care of the child asking for guidance about the level of activity it is reasonable to expect from the child. Following this, the level of input and support needed by the child should be agreed with the family.

If parents report that the child/young person is too poorly to see a consultant or other health care professional, it is important not to immediately jump to conclusions. Visits from friends and family can be exhausting enough; professional visits are even more tiring. It is better to begin by offering support and liaison with parents/carers and make an open offer to see the child/young person when they are ready and able. It is unhelpful to put pressure on the family, child or young person; they are already under enough pressure coping with their illness.

Within social care and education, if there is someone within the team who has knowledge and experience of working with CFS/ME, the case should be allocated to them, with a reminder that this illness is a very individual condition and few cases are identical, especially when it comes to severely and very severely affected patients.

For the more severely affected patients, offer to organise a Team Around the Child meeting to see what additional help and support can be identified. Agree any notes that are

made at the meeting (Every Child Matters) and provide the family and the child/young person, should they wish, with a copy within an agreed timeframe to cultivate trust and good relations.

Where there is a confirmed diagnosis, it is essential that all professionals working with the child respect and show trust in the diagnosis. It is surprising that even where there is a diagnosis, some teachers, social workers and health care professionals still find it difficult to accept. This leaves families repeatedly having to justify and explain the symptoms and difficulties they are experiencing.

6. Case studies

Case study one - David, aged 13

David was given a diagnosis of CFS/ME when aged 9 and was seen by a general paediatrician. His GP was very understanding and visited every three months but felt able to offer little intervention, only pain relief. By the age of 14 David had become severely affected, was bed bound and his parents were very worried about his weight. The paediatrician requested that the local medical team fit a nasogastric feeding tube at home. The GP was happy to support this. However, on arrival at the home, the District Nurse, having never seen a case of CFS/ME before, especially a severe case, left without fitting the tube and called for a child protection case conference to be held. Ignoring the input of two specialist paediatricians, David was admitted to hospital as a ward of court, against both his and his parents wishes. The hospital lacked any training or understanding of CFS/ME and David was eventually discharged 12 months later, on instructions from the court. He was in a much worse condition both physically and psychologically, now fed directly into his stomach via a PEG (percutaneous endoscopic gastroscopy) through his abdominal wall and catheterised. The family was so traumatised that on returning home they refused input from all health care practitioners and all care was and is still being provided by parents. This court case cost the family in excess of £60,000 and nothing was gained.

Case study two – Susan, aged 14

Susan had no diagnosis and was only attending school on average two half days a week. Whilst at school she appeared to cope fairly well with classes but struggled walking between classes. Her parents believed Susan had CFS/ME but they were unable to get a diagnosis, although they noted that Susan did meet the relevant diagnostic criteria. After half a term the Education Welfare Officer asked the parents for a letter confirming the diagnosis or she would have to call a child protection case conference. Up to this point the family had received no advice, input or support from health, Social Services or

education, although they had repeatedly requested a referral to a specialist clinic and begged for help. They contacted AYME who were able to organise a referral to a specialist clinic. The parents immediately notified the Education Welfare Officer giving the date, time and name of the paediatrician Susan was due to see. Unfortunately before they could attend the appointment they were informed during a visit from a social worker and the Education Welfare Officer that a child protection case conference had been held and attended by 11 professionals from the police, health, education and Social Services and Susan was more than likely going to be placed on the At Risk Register.

Following this visit Susan and her family were extremely distressed and alarmed. The following week Susan saw the specialist paediatrician who gave a definite diagnosis of CFS/ME. The paediatrician attended a professionals meeting, following which Susan's parents were told the "issue had gone away". This process caused so much stress for Susan and her family that it resulted in her being removed from the school register and tutored at home.

7. Essential points for consideration before proceeding down child protection route

- CP should only be considered as in any other diagnosis.
- If the professionals involved are unfamiliar with CFS/ME, advice from an experienced specialist should be sought before considering any action.
- What evidence is there to support Fabricated Induced Illness (FII)?
- What evidence is there that significant harm is being caused and its linkage to the actions or non-actions of parents?
- There needs to be sound evidence of harm before considering Section 47.
- Consider the risk of leaving FII unmanaged versus the risks of (child protection) intervention and the fact that there are risks to both.
- Could this be addressed in other ways?
- In weighing up relative harm, due consideration needs to be given to the loss of opportunity for therapeutic working.
- Once a case is in the court arena there is potential for an extended period with little or no physical or psychological progress being made. Is this really in the child/young person's best interest?

8. Recognise the adversarial nature of the legal process

The law is essentially a binary system i.e. a person is or is not competent, is guilty or not

guilty. In contrast, most paediatricians are used to biological phenomena in which there is usually a “normal” distribution of a characteristic about a mean value for the population. Thus, there is a mean age at which boys will enter puberty but there is also a “normal” range statistically defined. Paediatricians are used to developmental constructs in which children gradually acquire skills or characteristics but show variation at the rate at which they do so. When these parameters are applied to CFS/ME and considerations of FII and significant harm, it is unsurprising that there are difficulties and disputes.

Practitioners are strongly urged to use “Working Together” procedures (safeguarding children in whom illness is fabricated or induced, DoH, Home Office, DfES, Welsh Office 2002) and are encouraged to seek advice from a range of professionals, to include a specialist in CFS/ME and a designated child protection doctor.

Professionals should consider appropriate use of Section 27: Child in Need of Services versus Section 47: Child in Need of Protection (Children Act 1989).

Parents need to be supported by professionals when they request a second opinion from a CFS/ME specialist if there is a breakdown in relationships. Professionals should not take this personally, it is about patient choice.

“A breakdown in the therapeutic relationship can occur if the doctor and family have irreconcilable views on how the illness should be managed... The paediatrician should behave no differently from when this happens in other illnesses... it is not in a young person’s interest to be in the middle of a parent/doctor feud..... the paediatrician should facilitate referral to a colleague, either directly or through the young person’s general practitioner. Ideally such a second opinion should be from a clinician with a sufficiently different approach or temperament for the chances of engagement to be reasonable... breakdown of relationship on its own is not a reason for referral to Social Services. The parental and family choice should be taken into account with regards of which colleague to refer to.” (RCPCH Guideline page 70)

An independent mediator acceptable to both the family and professionals can be helpful in ensuring that dialogue is maintained. AYME can support families and professionals in identifying a mediator where it would be helpful.

9. First step

The first step should be a planning meeting. One outcome might be to identify an appropriate person to undertake a CAF assessment (Common Assessment Framework section 17 Child in Need).

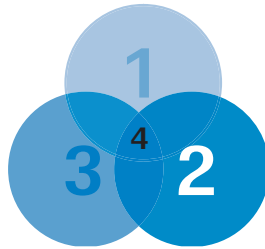
Social Services should be encouraged to follow the Team Around the Child model of practice, ensuring that the best interests of the child and their individual needs and wishes remain at the centre of the process.

10. Risks

Risks of invoking CP procedures	Risks of not invoking CP procedures
Loss of any therapeutic relationship with the family for duration of proceedings, which may be up to three years	Failure to protect young person from significant harm
Increased isolation of young person	Loss of opportunity that might arise from invoking procedures to move the family forward
Young person develops long-term suspicion of, or resistance to, all services	Inability to reduce professionals' feelings of vulnerability/failure in a situation that is proving difficult to resolve
Young person may be an adult before legal proceedings are completed	Extra threat may force parents to address issues in themselves that are relevant to concerns
Lack of sufficient evidence will make the child more vulnerable after failed proceedings	
When parents are defensive it may be more difficult to identify triggering issues in a young person	

In order to balance these issues, procedures in Working Together allow for confidential meetings of professionals to plan any investigation that might be needed under the heading of Fabricated and Induced Illness. Such discussions should include named or designated professionals able to help the team consider the appropriate balance in relation to the above issues, building in to the process a review of the level of risk.

Once completed, there may be a need to proceed to Section 47 only if all areas overlap in 4 (see chart).

When to move or not, towards Section 47 investigations:

1. CFS/ME or uncertain clinical condition
2. Breakdown or failure of working relationship between professional and family
3. High suspicion of FII based on reasonable evidence

If evidence exists only in area 1, 2, or 3, there is a need to gather more information and consider Child in Need Section 17.

Only when all areas overlap in 4 with clear evidence for areas 1, 2, and 3, move to Section 47.

Section 47 in this context relates to children and young people with a primary diagnosis of CFS/ME in whom the other factors are also present.

11. Signs and symptoms

Symptoms of CFS/ME that children and young people may experience include:

Fatigue:

- Utter exhaustion, often to the point of collapse, totally different from the normal tiredness healthy people experience.
- Fatigue levels fluctuate over the day and are different from patient to patient. Pallor of the skin may be evident when fatigue is worst.
- If standing, some patients may need to sit or lie down quickly wherever they are.
- Many patients experience post-exertional malaise (the delayed onset of fatigue) after activity – sometimes up to a few days later.
- Persistent fatigue must be present for a diagnosis to be made but is not always the worst symptom.

Pain:

- Anywhere in the body but particularly headaches and intense muscle and joint pain, especially in the lower limbs which is usually difficult to relieve with standard painkillers.

- Skin sensations such as crawling and pins and needles may be felt.
- Pain can be felt both at rest and on exercise.

Cognitive impairment: these symptoms are commonly called “brain fog”.

- Poor short and medium-term memory, mental confusion and mental fatigue.
- Difficulty concentrating, word finding and thinking. Inability to plan.

Other symptoms:

- Body temperature disturbance.
- Dizziness.
- Vertigo.
- Postural hypotension.
- Sensitivity to light and noise (making school and hospital a very difficult environment to tolerate).
- Sleep disturbance.
- Nausea, loss of appetite, gastrointestinal disturbance.
- Acquired sensitivity to food, medication, alcohol and chemicals.
- Mood swings, panic and anxiety attacks and in some cases depression.

A minority of the most severely affected patients (see AYME Functional Ability Scale) may experience blackouts, temporary paralysis, loss of speech, loss of swallowing function. These symptoms are severely disabling.

12. Useful reading

A Report of the CFS/ME Working Group January 2002

www.doh.gov.uk search for CFS/ME on site, PDF file only

Royal College of Paediatrics and Child Health Evidence Based Guideline for the Management of CFS/ME December 2004

Tel: 0207 307 5600 | Fax: 0207 307 5601

www.rcpch.ac.uk/Publications/Publications-list-by-title

Royal College of Paediatrics and Child Health - Patient Leaflet - Young Persons Guide to CFS/ME

www.rcpch.ac.uk or **www.ayme.org.uk**

National Service Framework for Children NSF Exemplar CFS/ME

Tel: 08701 555 455 | Email: dh@prolog.uk.com | Order Number: 08701 267 836

www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/ChildrenServices/Childservicesinformation/index.htm

Access to Education for Children and Young People with Medical Needs

Tel: 0845 6022260 | Email: dfes@prolog.uk.com

Surviving Severe ME - Association of Young People with ME

Tel: 01908 379737 | www.ayme.org.uk

13. Useful contacts

Association of Young People with ME (AYME)

Bank House, 4 Bouverie Square, Upper Third St, Milton Keynes MK9 1EB

Tel: 08451 23 23 89 | www.ayme.org.uk

Action for ME (AfME)

Third Floor, Canningford House, 38 Victoria Street, Bristol BS1 6BY

Tel: 0845 123 2380 | www.afme.org.uk

National Union of Teachers

HQ Hamilton House, Mabledon Place, London WC1H 9BD

Tel: 020 7388 6191 | Fax: 020 7387 8458 | www.teachers.org.uk

National Association of Headteachers

1 Heath Square, Boltro Rd, Haywards Heath, West Sussex RH16 1BL

Tel: 01444 472472 | www.naht.org.uk

Royal College of Paediatrics and Child Health

50 Hallam Street, London W1W 6DE

Tel: 020 7307 5600 | Fax: 020 7307 5601 | www.rcpch.ac.uk

14. Working group

Tim Benson: Head teacher, National Association of Head Teachers Executive Committee

Caroline Dugdell: Parent and former police officer

Anna Gregorowski: Nurse Consultant Adolescent Health

Victor Larcher: Consultant Paediatrician

Kay Lawther: Action for ME

Trish Taylor: Chair of Trustees, Action for ME

Mike Tettenborn: Consultant Paediatrician

David Vickers: Consultant Paediatrician, Designated Doctor for child protection, Clinical Lead, children and young people's CFS/ME service.

Mary-Jane Willows: CEO Association of Young People with ME, Chair of Working Group

Shanne Woodhouse: Parent and Special Educational Needs Co-Coordinator (SENCO)

The working group wishes to express its thanks to Children in Need for funding the production of this leaflet.



Association of Young People with M.E.
www.ayme.org.uk

Action for M.E.
www.afme.org.uk

Children in Need
www.bbc.co.uk/pudsey