Children & Young People with ME & CFS:
a report for the Welsh Assembly Government
by
WAMES (Welsh Association of ME & CFS Support)

1. Introduction

Children and young people with ME and CFS have specific needs which are not being catered for by the Welsh Assembly Government and others. This report aims to set out the main problems that young people and their parents/carers experience when attempting to access services from the health, education and social services departments in Wales, and suggest areas in which improvements can be made. Consideration also has to be given to the transition from children's to adult services in all service areas including benefits. Although benefits are not the responsibility of the Welsh Assembly Government they do impact on the young person's ability to live independently.

ME (or CFS, the preferred term of the medical profession) is a neurological disorder classified by the World Health Organisation under ICD10 G93.3. (1) It is characterised by a wide range of symptoms including post-exertional fatigue, muscle pain and aches, sore throat, headaches and in children, stomach ache. Stomach ache seems to be a more prominent symptom in children than in adults, although all other symptoms can similarly be present in both adults and children. Children as young as 3 can be affected and as in adults, the level of severity can range from mild to severe with some patients remaining housebound or bed-bound for many years.

It is felt that the prognosis for children is better than that for adults if appropriate management is put in place early on in the illness. There has been little research carried out into the causes of and treatments for ME in children and young people. It has previously been assumed that the same treatments given to adults are equally appropriate for children and young people. There has been a desire on the part of some medical professionals to blame the parent for their child's illness due to the controversy surrounding ME. (2)

It has to be noted that the majority of the documents listed in the References wrongly assume ME to be a psychological disorder.

2. Health

2.1 Lack of knowledge about ME

At present health provision for children and young people with ME and CFS in Wales is patchy or virtually non-existent throughout the whole of Wales. It can be difficult to get a diagnosis as few GPs and paediatricians have sufficient knowledge of the illness. Most of the professional literature on childhood ME and CFS that is written by and for Welsh doctors, suggests that ME and CFS is a somatic syndrome and doesn't recognise the existence of the illness described by the WHO as neurological.
(3) (4)

2.2. Lack of specialist service provision

There are no specialist paediatric services since the closure of the *Chronic Fatigue Service for Children* clinic at the University Hospital of Wales in 2003. This was not a diagnostic clinic and the only management tool offered was graded exercise therapy and/or cognitive behavioural therapy. Some children who attended this clinic although not severely affected before, relapsed during attendance and remain severely affected to this day, needing 24 hour care and support.

Throughout Wales there is no specialist unit, nor are there any paediatricians who specialise or take an interest in ME and CFS, and treat the illness as a neurological condition. Children and young people are dispersed throughout the system but still, to our knowledge, all that is offered is graded exercise and/or cognitive behavioural therapy.

2.3 Disbelief from health professionals

It is not unusual for parents and their children to be disbelieved by GPs and paediatricians when they present with the symptoms of ME. Even when parents provide their GP with a diagnosis from private practitioners they are met with scepticism. Parents and children/young people have been laughed at and ridiculed by GPs and paediatricians. Children have been refused equipment such as wheelchairs when their mobility is affected by their ME. Children's inability to be fully mobile has been attributed by some doctors to family pets, their illness has similarly been attributed to the death of a parent or sibling.

2.4 ‘Consent to treatment’ rights ignored

Because the literature describes ME as a somatic syndrome or a mental health disorder, doctors will often refer a child with ME to a psychiatrist or psychologist. There have been instances where doctors have ignored the guidelines about ‘consent to treatment’ (5) and have gone against the child’s and parents’ wishes and coerced parents into accepting treatment on their behalf. This treatment is usually Graded Exercise Therapy, a preferred treatment of psychiatrists. This contravenes the child’s right to decide his/her own treatment when competent to do so. This is against the child’s rights to decide their own treatment.

2.5 UN Convention on the Rights of the Child ignored

The UN document *Convention on the rights of the child* has been adopted by the Welsh Assembly Government. (6) In article 3 of the convention it is said *“In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.”* If children and parents decide, after giving the matter serious consideration, that a particular treatment is unsuitable for the child, then it cannot be said to be in the “best interests” of the child if doctors force a treatment on them This is in contravention of the child’s rights.

2.6 Wrongful accusations of abuse & neglect

Sometimes if a child does not make the expected progress through their illness, or a particular health professional does not believe in ME, this can trigger an inappropriate referral to Social Services for neglect, or on the suspicion that the parents are causing or prolonging the child’s illness. The child can be labelled with Munchausen’s Syndrome by Proxy (MSbP) or Fabricated or Induced Illness (FII). Such referrals cause considerable distress to both the child concerned and their family, as such referrals involve all siblings of the referred child. The knowledge that a professional feels you are abusing your child is a huge burden for any parent to carry, especially if it is not true.

We do not dispute that there are some parents who do abuse or neglect their children, they, however, are a small minority of parents and not the norm. We also do not dispute that some parents attempt to fabricate or exacerbate their child’s illness, but again they are a very small minority of parents. MSbP or FII (2) is a controversial medical condition and there is no evidence to suggest that all children with ME are either being neglected or abused by their parents or that they are fabricating their illness, in fact it is very rare. ME is a very misunderstood condition amongst all professionals but research has produced clear evidence of physical dysfunction and to ignore this could open professionals to litigation.

When there is a problem with school attendance a child’s doctor (GP, paediatrician, school medical officer or community paediatrician) can be alerted by the school or other professionals. This can sometimes trigger suspicions that the child is being kept from attending school illegally, which can then lead to inappropriate referral to Social Services under suspicion of non-school attendance and neglect or abuse by the parents/carers. Families in this situation can also find themselves the subject of School Attendance Orders filed under Section 437 of the Education Act 1996. (7)

2.7 Failure to find evidence of harm

It is important that accusations of neglect & abuse are based on more than assumptions about the lack of physical illness. According to the English CMO’s report on CFS/ME, when doctors are faced with a child with unexplained symptoms they must have clear evidence of a suggestion of harm before making any referral to Social Services. (8)

2.8 Difference between treatment of children and adults

If a young person at 21 is affected by this illness it is unlikely that their parents will be blamed for their condition, unlike the parents of a 13 year old for example. This is one of the ways in which adults and children with the same medical condition and who share several of the same symptoms, are treated differently by the medical profession.

2.9 Housebound children and young people overlooked

House bound and bed-bound children find it particularly hard to get medical help and the seriousness of their condition is sometimes overlooked. It is not uncommon for the more severely affected child or young person to be confined to their bedroom unable to tolerate any noise or light. They spend their days and nights in a darkened room wearing earmuffs to protect them from sound and dark glasses and drawn curtains to protect their eyes from any light. GPs however are often reluctant to make home visits so the need for a referral to a hospital consultant is not identified. Parents are also often not informed that is it is possible for paediatricians to make domiciliary visits, if requested to do so by a GP. Children and young people with ME have become the 'forgotten people', too ill to visit the GP, too ill to visit a hospital clinic, too ill for an education.

It is important that the severely affected person with ME can access the same services as everybody else. Information about domiciliary dental and optical services throughout Wales however, is even harder to find. It would appear that unless the parent/carer of the child or young person approaches either their dentist or optician directly, they are not informed about the domiciliary services available to them.

2.10 Variable domiciliary dental services

Thus far, investigations into the availability of domiciliary dental services have found that:
(a) Domiciliary dental services are available on request from the NHS dental surgeon. They are able to provide basic treatments within the home and they can also refer on to the Community Dental Service team.
(b) Alternatively it is possible to receive dental treatment from the Community Dental Service who is able to perform certain treatments in a patient's home; this is governed by Health & Safety Regulations. If it is not possible to treat the patient in their own home then it is possible for arrangements to be made to treat the patient in a suitable centre. This service is good in some parts of Wales and in others it can be patchy and less effective.

2.11 Variable domiciliary optical services

Similarly with dental services if the patient or their parent/carer firstly approaches their NHS Optician it is possible that they provide a domiciliary optical service. It is not known if all Opticians offer a domiciliary service. This can only be ascertained by making enquiries of them. The treatment that a visiting Optician can provide is governed by Health & Safety Regulations. We have not been able to discover if all opticians offer a domiciliary service nor how many opticians are aware of the literature about eye problems in ME patients, such as the paper by Lesley Vedelago. (9) It is important that children and young people receive regular eye tests especially if they are light sensitive.

2.12 Poor transition from children's to adult services

At present throughout Wales there seems to be little provision for transition from paediatric to adult specialist. Due to the shortage of specialist adult services for ME/CFS there is little or no scope for children to be transferred to a specialist.

3. Education

3.1. Failure to provide 'suitable education'

There is a legal requirement to educate children up to the age of 16, which should be a partnership between parents, the LEA and the child's school as all are equally legally responsible for providing a child with a 'suitable education'. (10) There is a particular requirement to make sure that children who are sick are provided with an education appropriate to their health needs (11) and (12). All too often children and young people with ME fail to receive what could be legally construed as a 'suitable education'.

3.2 Unnecessary pressure to return to school

Young people and their parents are often put under pressure by the school and doctors to return to school before they are ready, this can then lead to relapse and a further lengthy absence from school. Research carried out in the '90s showed that ME was the biggest cause of long-term absence from school and that inappropriate educational provision contributed to this. (13)

3.3 Misunderstandings about ME & PE

Many teachers know little about ME and its fluctuating nature or the seriousness of the illness. They can be unsympathetic to the young person and dismissive of any advice from parents regarding the way the condition affects the young person and their ability to learn. Teachers can sometimes disregard medical advice provided by the young person's GP with regard to Physical Education. They can sometimes mistakenly actively encourage the young person to take part in PE lessons when it might be more appropriate either to provide a quiet room for the young person to rest in or to allow the young person to sit in on another lesson. Many teachers, in some cases unknowingly, put the young person under immense stress due to their ignorance and cause their condition to relapse.

3.4 Inappropriate guidance from the medical profession

School medical officers and other paediatricians due to their lack of knowledge fail to provide appropriate guidance to schools or sometimes provide an incorrect diagnosis of a psychological illness. Sometimes there is a dispute between the young person's paediatrician and the SMO with regard to the diagnosis. This can lead to conflict and a further delay in providing correct guidance to schools. Advice and information leaflets from charities advising the best management of the young person are poorly received by schools and are often ignored in favour of a local doctor's advice that can sometimes be conflicting.

3.5 Misunderstandings about ME & learning

Schools sometimes do not understand the limitations that the young person's neurological disabilities place on their ability to learn. They are reluctant to allow a student to study part time or follow a reduced curriculum as reduced timetables in school or at home can impact on the placing of the school in exam timetables. Pupils can have difficulties with concentration, short and long term memory, fluorescent lighting, normal classroom noise, mobility and allergies. This can make it difficult to cope with many subjects in the national curriculum e.g. PE, music, science. Noise in the communal areas can also impact on the pupil's ability to socialise. When a child is ill for any length of time it may be necessary for the school and others to accept that the classroom is not the best place for them to be educated, if at all.

A child's motivation can be called into question when teachers see their grades dropping or homework not handed in on time. There is little understanding about the cognitive impairments that children and young people with ME suffer from. Some professionals wrongly interpret dropping grades and frequent absences from school as a sign of school phobia and set a chain of events in motion which are totally inappropriate for a young person with ME.

3.6 UN Convention on the Rights of the Child ignored

Article 28 of the Convention commits signatories to "… recognize the right of the child to education and with a view to achieving this right progressively and on the basis of equal opportunity…" Children and young people with ME are denied an education suitable to their health needs therefore schools and LEAs act contrary to the Article 28 of the UN Convention. (6)

3.7 Human Rights Act on Education ignored

The Human Rights Act 1998 states (under Article 2) that "No person shall be denied the right to education…" Children and young people with ME are denied a 'suitable education' because schools and LEAs do not understand the limitations a child's or young person's health needs have on their ability to learn. This is therefore contrary to the child or young person's human rights. (14)

3.8 Home tuition difficulties

Although an LEA might offer home tuition in principle, this does not always materialise in practice. When it does, it is not always appropriate for the child. It can be difficult to negotiate a package of education suitable to the child's ability to learn. e.g. some children are too ill to concentrate for a full hour but home tutors and LEAs insist on this being a minimum requirement. Some children are too ill to be educated at all. Some children have problems in writing, due to the neurological symptoms they have. The contribution that home tuition makes to the education of a child or young person with ME cannot be undervalued but what suits one child does not necessarily suit another. The package put in by the LEA must be child or young person specific.

3.9 Inaccessibility to computer based education

There are computer based education programmes that follow the national curriculum and are suitable for young people. (15) They are not easily available however because they are seen by the LEA as unsuitable or too expensive. These computer courses can be more suitable for a child or young person with cognitive problems as lessons can be saved and gone back to as many times as they need. This is not an option with home tuition. The contribution that home tuition makes to the education of a child or young persons with ME cannot be undervalued, but what suits one child does not necessarily suit another and the package put in by the LEA must be child or young person specific.

3.10 Problems with exam concessions

Once a child is being educated outside of the school, either through the medium of home tuition provided by the LEA or through computer based learning packages it can be difficult to obtain examination or coursework concessions suitable to them or the relevant educational psychology assessment to apply for such concessions. There are various concessions available to people with ME such as reduced provision of coursework, extra time, rest breaks, amanuensis and the ability to sit exams at a time of day suitable to the child with the help of a home invigilator. (16) The child and their parents are rarely informed of the range of concessions available to them. This can also be the case if the child is still able to attend school on a part time basis.

3.11 Removing children from school

Many parents, due to the lack of compassion their children receive at the hands of schools because of their illness, remove their children from the school register and provide education for them at home, called home education. Such education can be more flexible for the child as it can be provided in an environment more suitable to the child and at times which are more suited to the child's health needs. Organisations like Education Otherwise provide valuable guidance for parents. (17)

3.12 Inappropriate Referrals

A lack of understanding on the part of school doctors, community paediatricians and teachers on the frequent school absences' of a child with ME can lead to inappropriate accusations of neglect and abuse and inappropriate referrals to Social Services.

3.13 Difficulties accessing education post 16

If a child misses a great deal of schooling due to illness, they need to 'catch up' when they feel well enough. This means that young people can be past compulsory school age before they are able to tackle some, or all, of the national curriculum. For some people this may be at a Further Education College either on a part time or full time basis. For others, who are still severely affected and housebound or bed-bound and whose health allows, it may mean that they are only able to study at home either through Correspondence Courses or computer based programmes. There are few suitable courses available and funding is problematic.

3.14 Difficulties accessing funding post 16

Students who are unable to attend an educational establishment for more than one quarter of a full time course are not eligible for any funding, bursaries or grants to help them with the cost of their education. Funding education can then become a heavy burden for the young person and their family, as it has to continue for far longer than a healthy student. The student is rarely able to juggle work and study to supplement the cost of their course even if they are well enough to be able to attend an educational establishment in the first place. (18)

3.15 Limitations of Welsh Assembly Learning Grant

The Assembly Learning Grant is a means tested grant which is paid to full and part time students in further or higher education and who meet the strict entry criteria. Unfortunately the ALG is not accessible to all students. Those students who suffer with ME and are housebound, or who cannot meet the set amount of hours needed to qualify in an educational establishment, are not able to claim the ALG. (19)

3.16 Limitations of Individual Learning Account

The Individual Learning Account is paid to people who have low or no qualifications, to contribute towards the cost of books and fees for their course. The ILA can be used for correspondence courses and is ideal for a person who wishes to study at home. (20) The ILA is set up in such a way that only specified educational establishments are used and this can be problematic for a housebound person with ME. If a student is granted the maximum £200 this only covers approximately ¾ of the cost of the course. The student has to pay for all examination fees and the rest of the cost of the course plus any books needed. The student also has to pay all examination fees, and if they have any special needs, the cost of the educational psychologist's report as well. For a student with ME who is housebound, the cost of paying for an EP's report, as well as the exams and also for the invigilator to visit their home to allow them to sit any exams, becomes prohibitive. Therefore it is becoming apparent that students with ME who are housebound need more financial help and assistance to enable them to obtain an education.

4. CAMHS

The Child and Adolescent Mental Health Service is in place to support children and young people up to the age of 18 who have, for varying reasons, either psychological problems or a mental health illness. ME is not, as is written in the document "Children in Mind", a mental health illness. (21) It is classified by the World Health Organisation under Neurological Disorders ICD10 G.93.3.

4.1 Inappropriate referral to the CAMHS team

Some children and young people with ME may need help in coming to terms with their illness and learning coping strategies, and as a result may develop some psychological problems. These however are secondary to their ME. Under these circumstances the involvement of the CAMHS team could be valuable. It is also true that some children and young people with a mental health problem go on to develop ME as a secondary condition and they should not be denied help when needed. However the involvement of the CAMHS team will not be appropriate from the beginning of all children's illness, nor should the CAMHS team be forcibly used because of the wrongful assumptions by the medical profession.

5. Social Care

5.1 Inexperience of Social Services

At present, provision of social care is patchy and contact with Social Services can prove to be an unnecessarily stressful situation for both the child and their parents, especially if an inappropriate referral has been made. Social workers can be poorly equipped to deal with a child/young person with ME. Sometimes they only learn about ME if they have to deal with a child with that condition and the information they receive on ME may not necessarily be about the neurological condition and thus may be inappropriate.

5.2 Legal requirements of Social Services and inappropriate use of the Children Act

When a child, his parents or another professional make a referral for assessment to Social Services, it is a legal requirement for social services to ascertain the child's needs. (22) Depending upon the nature of the initial referral (whether or not harm was suspected) a section 17 assessment should be carried out. (23) This assessment determines whether the child is 'in need' through illness or disability or whether there is sufficient evidence of harm to progress to a section 47 child protection investigation. (24) The section 47 investigation determines whether there is need for a 'case conference' and placement of the child on the 'child protection' register. Children with ME have been wrongly assumed to have been neglected by their parents and wrongly placed on the 'at risk register'. This is mainly because of incorrect medical evidence and advice. This can, and has, caused extreme stress to the child and their parents/carers.

5.3 Failure to follow social work guidelines

Before these steps are reached it is imperative that all social workers and other professionals strictly adhere to the "Framework for the Assessment of Children in Need and their Families" (25) and all professionals involved work rigidly to the 15 points contained within "Working Together to Safeguard Children". (26) At present adherence to these regulations is patchy and can cause the family immense problems.

5.4 Stressful home visits
When social workers, carers or any other professional visit a young person with ME in their home they might find it difficult to understand that the young person may be chemically sensitive and that by wearing deodorants, perfumes or even clothes worn in smoky atmospheres may impact on the young persons condition. Prolonging a visit may also cause deterioration in a young person's condition and their ability to cope with visitors for more than a few minutes at a time can be difficult or almost impossible.

5.5 Difficulties in accessing mobility aids and equipment
Children who are severely affected need to be assessed for mobility aids such as wheelchairs, stair lifts and other aids to help with day to day living, as well as blue badges for the car. The provision of these items can mean the difference between a child being confined to their bedroom indefinitely or being totally housebound. These aids can help with socialisation as they enable friends to visit and the young person to leave the home with support. Provision of mobility aids etc can be patchy and can be determined by which type of referral is made to Social Services. It can also be very hard to convince a social worker that the equipment is needed.

5.6 Poor transition from children's to adult services
At present there appears to be little or no provision for transition from children's to adult social services, although there has been some improvement of late. Transition can mean having to explain again your needs and this can be difficult due to the nature of the illness. It can mean having to deal with a different social worker who may have different ideas about your illness. Therefore, unless the transition process is handled sensitively and efficiently it can lead to extra stress on a young person and their family.

6. Benefits

6.1 Lack of promotional material on benefits
At 16 or 19 when a young person seeks financial independence from their parents it can be very difficult for them to obtain benefits to which they may be entitled. There seems to be very little literature that informs the young person about their rights when they are too ill to work. It is being left to patient organisations to inform these young people or their parents/carers of what their entitlements are. It would be advantageous if there were a publicity campaign to inform this patient group of the entitlements that are available to them.

6.2 Difficulties in claiming benefits
Children or young people often have trouble claiming Disability Living Allowance. Allocation of this allowance by the Benefits Agency appears to be a lottery. Some severely affected children and young people have been turned down for this benefit, even though they are bed-bound or housebound and unable to self-care at all. This then necessitates an appeal, and more often than not, an appeal to a tribunal. Even going to these lengths they can still be turned down. All this adds extra stress to the family in which the parent may have had to give up work to care for their very poorly child.

6.3 Problems in re-claiming benefits
Some young people are left with no money whatsoever to live on if they have started work and had to give up through illness, due to the complexities of claiming the necessary benefits. There is very little information in the public domain that educates the general public who are ill about the benefits they are entitled to. This lack of information especially affects young people with ME, as they do not have the energy to search for information.

6.4 Help from the Welsh Assembly Government
Any representations the Welsh Assembly Government can make to the Benefits Agency on the matters of DLA, incapacity benefit and income support for people with ME would be appreciated although we appreciate it is not the responsibility of the Welsh Assembly Government.

7. Future Provision

Suggestions for improvement to services are as follows:

i) An **ongoing education programme** about the neurological illness of ME for all professionals who have any contact with a child or young person with ME or CFS. This education has to be based on the organic nature of this illness and not as is thus far in most of the literature being disseminated to professionals, as a somatic syndrome. This would include guidance on the differentiation between physical and somatic fatigue conditions, the importance of respecting and accepting the child's experience, and patient support organisations & literature. This would be aimed at all health professionals including doctors (GPs, hospital & community paediatricians), physiotherapists, occupational therapists, dieticians, psychiatrists, psychologists, CAMHS team, teachers, LEA's and social workers.

ii) A **full review of the literature**, especially that produced in Wales and affecting Welsh children and young people, and the correction of that literature which ignores the WHO classification of ME and CFS as a neurological condition.

iii) Supervision of healthcare development for neurological ME should come **under the control of paediatric services**, not psychiatry, with a clear system of referrals for young people aged 16-18 to adult neurological services, if necessary.

iv) Provision of **domiciliary or outreach services** for those children and young people who are too ill to attend a hospital, clinic or medical practice.

v) A **wider range of education options** and special exam arrangements more widely available throughout Wales, to enable moderately and severely ill pupils to be educated in the most appropriate manner i.e. through part time schooling, home tuition or open learning packages.

vi) Provision of **suitable funding and financial support** through grants and bursaries for severely affected housebound students aged 16 and over to enable them to gain the necessary qualifications to allow them to continue with their education in a way that is suitable for them.

vii) **Appropriate social care assessments** that acknowledge the existence of ME and do not consider it evidence of neglect or abuse.

viii) **Provision of appropriate aids, benefit advice and support mechanisms** from Social Services for *all* children and young people with ME and CFS, without families having to fight for them.

ix) A **benefits publicity campaign** to inform patients aged 16+ of the entitlements that are available to them.

8. Conclusion

This summary cannot be described as exhaustive but it outlines a starting point for improving the care and service provision for children and young people with ME and CFS and we would welcome the opportunity to discuss these concerns further at the earliest opportunity. Further information on children and young people with ME has been published by ME charities and references to these can be found in the WAMES report on ME & CFS. (27)

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