# Management of chronic fatigue syndrome in children

# Barry Wright, Ian Partridge & Christine Williams

Certain areas of child and adolescent mental health generate a degree of polarised debate, both within and outside the profession. Media attention, the development of self-help groups and the Internet lead to the publishing of papers and opinion, which exist alongside peer-reviewed research and evidence-based medicine. Parents reading such material may find it hard to know what advice is best. One area that falls into this category is chronic fatigue syndrome (CFS).

Previous studies have reviewed epidemiology, aetiology and prognosis both in adults and in children and adolescents (Wright & Cottrell, 1997). This paper therefore touches only briefly on these issues as its focus is upon the clinical management of cases of CFS in children and adolescents and is based on the model outlined in Fig. 1. The model explains the ways in which physiological and psychological factors interact to produce numerous vicious cycles that act together to maintain many of the symptoms of CFS. Each of these vicious cycles is considered in terms of active management through a joint approach with the young person, the family, child health and mental health professionals.

When management is discussed with families, it is important to be able to define what it is that one is treating. Three years ago, a joint report was published by the Royal College of Physicians, Royal College of Psychiatrists and Royal College of General Practitioners (Royal College of Physicians *et al*, 1996), clarifying the diagnosis. The absence of any inflammatory processes in the meninges or brain made the term myalgic encephalomyelitis (ME) inappropriate, and the term 'CFS' was endorsed although, despite this report, older names persist in some literature. One of our patients was recently

told by a member of a self-help group that ME was a sub-category of CFS. Several groups have attempted to establish clear criteria and the three Colleges' report adopted criteria established by Sharpe *et al* (1992) with slight alterations (see Box 1).

It is notable that attributions and responses within the family may have quite an impact upon both the development of the illness and recovery from it (Carter *et al*, 1995), and yet these factors, like many of the other maintaining factors considered below, are not included in any of the definitions.

A brief summary of epidemiology (Wright & Cottrell, 1997) is outlined in Box 2.

# **Aetiology**

# Viral infection

Acute illness, often viral infection, appears to precede the syndrome in two-thirds of affected children (Marshall *et al*, 1991; Feder *et al*, 1994). This acute illness with its powerful fatiguing component often leads to initial malaise, withdrawal, rest and inactivity. It is clear that a specific virus does not perpetuate the illness (Royal College of Physicians *et al*, 1996), and specific viruses when systematically searched for are often not found (Marshall *et al*, 1991; Carter *et al*, 1995). Indeed, tests rarely reveal a specific cause. A small proportion of children may have had recent Epstein–Barr infection, but chronic active Epstein–Barr virus infection (Ishihara *et al*, 1995) is rarely present and, if it is, it is not given the name CFS.

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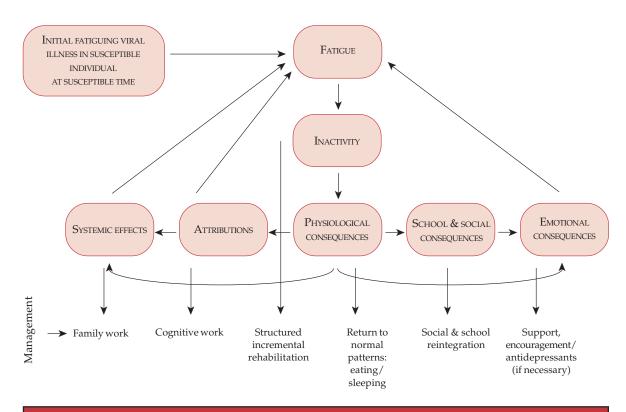


Fig. 1. Aetiology, maintaining factors and management in chronic fatigue syndrome

## Inactivity

It is known that beliefs and attributions about any illness drive behaviours and treatment approaches.

Box 1. Criteria for diagnosis of CFS in children (Royal College of Physicians *et al*, 1996)

CFS is defined as a syndrome that:

- is severe, disabling fatigue
- is not lifelong
- affects mental and physical functioning
- is present for 50% of the time for a minimum of three months
- may include myalgia, mood disturbance and/or sleep disturbance

An alternative diagnosis should be made for:

- medical conditions with severe fatigue (for example, anaemia)
- serious psychiatric illness (although it is recognised that anxiety or low mood may be present as part of CFS)

These may be helpful and adaptive, but they may on occasion be damaging to health and confidence. For example, it is now known that excessive rest and inactivity over a period of time can be hugely damaging to the developing child. There is abundant research demonstrating these damaging effects and this has been summarised in other work (Greenleaf, 1984; Wright & Cottrell, 1997).

#### Physiological consequences of inactivity

Muscle volume, muscle strength, muscle protein synthesis, muscle energy-producing capacity,

#### Box 2. Epidemiology

Prevalence in people under the age of 18 is around 0.05%

Mean age of onset in clinic samples is between 11 and 15 years (perhaps lower in community samples)

Gender ratio in clinic samples: higher proportion of girls

Social class in clinic samples: more from higher socio-economic groups

mitochondrial function, muscle adenosine triphosphate (ATP) activity and muscle electromyographic activity are all adversely affected by rest. There is also an increase in muscle connective tissue. Not only is the muscle affected, but basal metabolic rate reduces significantly, and other bodily functions such as white cell function, cardiovascular function, sleep patterns, appetite and bone mineral density are also affected. It is important in CFS research that there are rested controls to ascertain that reported changes are not as a result of inactivity. More importantly, however, all of these changes result in further symptoms of exhaustion after exercise and confirm the belief in illness for both parent and child. What start as beliefs about the need to rest, inadvertently generate further confirmatory beliefs about how ill the child is and how much more they need to rest. A powerful and destructive vicious cycle may establish itself. Adult research shows that inactivity is associated with increased risk of depression (Taylor et al, 1985). Another vicious cycle may establish itself around mood and motivation. These cycles are powerful and a range of factors can maintain or reinforce them, including beliefs and attributions, the dynamic emotional situation and further social and systemic effects that set up their own contributory effects (see Fig. 1).

#### **Attributions**

Attributions, or the meanings that one gives to events, may shape potential responses, which in turn have effects on further events and responses. As an example from a separate problem, if we attribute a child's tummy ache to what they have eaten, that will affect how we deal with the child and what action we take. For example, it may make us give advice about what to eat at the next meal. Similarly, our responses will be shaped if we attribute the ache to appendicitis, because we will rush the child to hospital. If the child's pain is caused by a fear of school leading to autonomically generated discomfort, then we will attempt to tackle the reasons for the fear, talk to the teachers and child, and encourage and support the child as he or she learns new ways of dealing with his or her fears and conquering them. If, on the other hand, we do not recognise this cause and instead attribute the symptoms to serious gastro-intestinal pathology, then the child may have several admissions to hospital and numerous tests, and the cause of his or her pain is not addressed. The child stays off school which he or she may be relieved about – and a maintaining factor comes into play. Clearly, this is a separate problem from CFS, but demonstrates how attributional effects may operate.

Previous research suggests that the beliefs of individuals about their symptoms or their illness can substantially drive their behaviour and impact upon their prognosis (Wilson et al, 1994). In children and young people, the beliefs of their parents/ carers are also be important – there is an interplay between the beliefs of child and parent. It is becoming increasingly clear that the beliefs of clinicians can be very important (Cope et al, 1994), and particularly whether they collude with patients' inaccurate biomedical models for their illness, whether they give alienating, rejecting explanations or whether they give common-sense, understandable explanations that empower positive change. Patients' or parents' beliefs may impact upon the doctor's response (Salmon & May, 1995). The family may seek out clinicians with a point of view that matches their own, or they may merely fall prey to the beliefs held in their local area. Local general practitioners (GPs), paediatricians and child mental health workers, and distant experts, may all have different views. Beliefs about CFS drive treatment options. It is clear that some clinicians take a very hands-off approach, while others actively manage CFS in young people. Some clinicians admit to a therapeutic nihilism that involves recommending that children avoid generic services, but offer few alternatives, with only occasional appointments, little advice about what to do other than to rest, avoid stress and wait (perhaps years) for the symptoms to subside. We can only guess what a profound effect this may have on the family, but it cannot be an empowering message, and leads to more vicious cycles since it invariably leads to potential avoidance of school, exercise, positive experiences and social contact.

# Systemic effects

Family factors become relevant with children because of the impact that relatives may have on attributions and expectations. Parents may become more caring, more child-centred and less confrontational. Interactions may centre around illness. Role changes occur within the family system and these may inadvertently contribute to maintenance of illness. There seems to be a point at the beginning of illness when parents search for information, but there comes a time when they choose a path and a set of beliefs. Many parents we have met choose a rehabilitative path and go on a journey (which can at times be a struggle) to health. Other parents choose to remove their children from therapeutic involvement, as well as removing them from school. There are no definitive studies, but there is growing evidence that these choices have a large impact on prognosis. Despite the fact that there is substantial evidence that physical illnesses have psychological consequences (Hill, 1994), and psychological illnesses have physical consequences (Dinan, 1999), many people seek to polarise their views and seek an exclusively physical explanation. Families who adopt this approach about the illness may resent child mental health involvement, believing it to be an untreatable physical condition or believing that rehabilitation should be avoided. Other members of the family may have CFS (Feder et al, 1994) and this may shape their views. In one series of 32 children, 50% had adult family members with the condition (Levine et al, 1989). Hence, attributional and systemic effects may interact. There is growing evidence that children who come from families with these approaches may have the worst prognosis (Khawaja & Van Boxel, 1998). There is an interesting adult study (Chalder et al, 1996) that shows that those who attributed their illness to ME were less likely to get better in 18 months than those who attributed fatigue to social reasons, even when controlling for duration and level of fatigue. Research needs to be done on this in children.

#### School and social consequences

Children with CFS miss a great deal of school (Wright & Cottrell, 1997). Despite the fact that about a third of such children have home tutors (Marshall *et al*, 1991), they usually only cover limited amounts of time and curriculum. Children may continue to miss out educationally. More importantly, however, they are missing out on the developmental tasks of childhood and adolescence, and they are missing out on social experiences and development. The more they miss, the more frightened they become, and the more frightened they become, the more they want to miss. We have seen numerous children who were confident, outgoing gregarious young people at the outset of illness, who became terrified of mixing with their friends a year after onset of the illness. This is a further vicious cycle. The fact that there continues to be a persistent tendency to miss school even after recovery from CFS supports this (Carter et al, 1995).

Some children may be trying to maintain very high educational or sporting standards (Lidstone *et al*, 1991) and this makes return to school more difficult. Occasionally, there may be learning difficulties, teasing, bullying or other anxieties. School anxiety and physical symptoms can coexist, as our autonomic nervous systems are good at linking physiological phenomena to emotions. The symptoms of the illness, such as poor concentration and problems

with low mood and social withdrawal (Carter *et al*, 1995), also conspire in a vicious cycle to prevent return to school. We should anticipate these difficulties and plan for them.

#### Emotional consequences

Children may have been or may become anxious, depressed or angry. This may be in response to illness but may pre-date illness. Significant life events such as loss and bereavement have been reported in some young people prior to the development of CFS (Pipe & Wait, 1995). In comparison with controls, children with chronic fatigue are more likely to have problems with low mood, social withdrawal and isolation (Carter et al, 1995). Other studies confirm this, with marked mood disturbance reported in 35–80% of referred patients (Bell, 1995; Wright & Cottrell, 1997). It would be surprising if children with CFS were not affected in this way as they struggle to understand what is happening to them. Indeed, young people with CFS have more mood disturbance than child cancer sufferers (Pelcovitz et al, 1995) or healthy controls (Carter et

Discussing whether the illness is physical or psychological is narrow-minded and misses the point. All serious physical illnesses have psychological consequences and vice versa. Chronic fatigue syndrome has numerous physiological, emotional and social consequences and correlates that interweave. As soon as we sidetrack down one and ignore the others, we miss avenues of holistic management, and we do not pursue optimum progress.

# Summary of aetiology and maintaining factors

A sensible hypothesis about generation of the illness is that individual susceptibilities interact with viral aggression to kick-start an illness that leads to fatigue. Subsequent attributional, systemic, emotional and social factors set up vicious cycles that act as interweaving perpetuating factors. These factors trap the child in a state that renders them exhausted, physiologically weak and vulnerable, inactive, avoidant, demotivated, demoralised, anxious and 'stuck'. The saddest part about it is that, sometimes, beliefs about treatment can be one of the factors pinning them down. Thankfully, most families are happy to discuss the illness and its mechanisms, and come to common-sense, pragmatic decisions about rehabilitation (see below), where professionals may support them and their child on the road to recovery.

# Management

#### Assessment and investigation

A good history is crucial, taking into account the development of the illness, past personal history, premorbid personality and a good family history. It is prudent to see the child on his or her own and the parents/carers, both on their own and in the family context. Investigations include discussions with the school, and a range of tests needs to be done, usually by the paediatrician. These depend on the presentation, and there needs to be a clear rationale for each test to avoid 'fishing expeditions'. It is important to exclude common causes of prolonged fatigue (Wessely, 1995). Numerous tests are possible, but specialist clinics show very few positive findings when employing a wide range of tests in fatigued children (Feder et al, 1994; Carter et al, 1995).

## Trust and rapport

Trying to make sense of the child's predicament alongside the family is a crucial part of management, as at this point a trusting therapeutic relationship may begin. Listening, clarifying and discussing aspects of the situation can lead to a point where the professional can reflect back a model for understanding the child's illness. Beliefs and attributions need to be taken into account, not dismissed. Involving the family is necessary, and preferably all of the family living in the house at the outset, although subsequently working with the parents/carers and child may be adequate. Every child is different and a good way to explain things to the family is a flow chart that demonstrates vicious cycles and interactional effects (Fig. 1). High attrition rates usually mean high rates of poor prognosis, so clinicians should not give in too easily.

# Family work

Once diagnosis is established, a management plan should be agreed with child and family. At this point, several authors have recommended that attention should be paid to emotional, social and family factors (Bell, 1995) and that co-working between appropriate professionals may be in the interests of the child and family. The optimum approach is to have child mental health professionals working in collaboration with paediatricians (Black *et al*, 1999; Williams *et al* 1999), but also in liaison with school

regarding the best way of re-integrating, the potential for a 'circle of friends' and so on.

As with all illnesses, the clinician and the family need to arrive at a common understanding of the illness, which integrates physiological, social and emotional aspects of the illness (Garralda, 1996), and which can then be used as a basis for planning interventions. In CFS, this may mean some work with the parents to explain that a purely physical understanding of the illness is not sufficient (Feder *et al*, 1994).

The clinician needs to pursue realistic optimism and challenge nihilism, and many good clinicians have numerous experiences of success that make him or her believe strongly in this approach and present it positively to the family. Children understand straightforward analogies to explain things such as muscle wasting during rest (for example, wasting after a broken leg is immobilised).

## Cognitive work

This approach fits very much with adult models of cognitive therapy. One randomised controlled study in adults has shown that cognitive-behavioural therapy improves outcome when added to medical care (Sharpe et al, 1996). The approach sought to change nihilistic or pessimistic beliefs about the illness; it explained some of the vicious cycles and negative social and emotional processes, and guided sufferers away from perfectionistic self-hopes. It gave people pragmatic treatment options with clear goals. In this way, cognitive therapy seeks to renegotiate beliefs that have resulted in detrimental coping strategies. Childhood studies have also sought to use this approach (Feder et al, 1994) with some success. Coming to understand the processes of the illness, the nature of the vicious cycles and realigning coping strategies all become important to return the child to a normal way of life.

# Structured incremental rehabilitation (STIR)

Some children and their families believe fervently that rest and avoidance of stress are the best treatments. Reports show that this belief has been fuelled by information from a variety of places including the Internet (Wright *et al*, 1999), some self-help groups (Wessely, 1995) and some clinicians (Richards & Smith, 1998).

A structured incremental approach to exercise can be tailored to the needs of the child, avoids large fluctuations in exercise and prepares the body physiologically for recovery in a gradual way. This

approach has been shown to be helpful in children in a number of studies (Vereker, 1992; Feder *et al*, 1994). Many children like organised treatment programmes and most will enthusiastically keep diaries, which can be helpful in plotting steady improvement and giving responsibilities to the child.

Large day-by-day changes in levels of activity may need to be avoided to prevent giving confused rehabilitative messages to the body. The notion of 'setbacks' should be encouraged to replace a belief in 'relapses', which can be avoided with appropriate management.

Some clinicians use incentives, goal-setting and rewards in their programmes, with, for example, holidays abroad only being physically possible when certain levels of fitness allow it. Some trusts have physiotherapists who have an interest in this area and may support a child in the early stages of rehabilitation, and such professionals need to be closely linked with the team with an understanding of the model of working and objectives.

# Return to normal patterns of eating and sleeping

Routines are easily lost in illness, with odd sleeping times and eating habits being common. Gradually returning to normal routines is the first part of treatment. It avoids a confused body with confused hormonal signals.

This includes avoiding naps during the day, not going to bed very late and getting up at a reasonable time. It means being dressed during the day and not staying in nightclothes. A healthy diet needs to be re-established. Diaries are helpful. Reintroducing routine to the day, with mealtimes, hobbies and times for learning, may help morale and give a normality to life, which children may initially resist but will come to value.

# School and social reintegration

By the time a child reaches a child mental health professional, he or she has often been off school for a considerable period of time. It is therefore unlikely that children in such a predicament who say that they have no problems with school and absolutely no anxieties about returning are being realistic (Walford *et al*, 1993). Where school absence and social isolation have arisen, a flexible approach to reintegrating the young person with peers and school activities should be taken, paying careful attention to the concerns of the child and parents (Dale & Straus, 1992), with return to school as early as practicable (Feder *et al*, 1994). This may need to

be done incrementally, with short periods of time at first just to get the child back and build his or her confidence again.

Home tuition may be helpful educationally, but maintains an isolation from peers and school. If used, it needs to be part of an integrated package of management with clear goals, and linked to a plan regarding return to school. We have seen home tutors who have supported the child's return to school in a very positive way.

There may be resistance to return, but it can be a powerful factor in children's improvement once they have been back to school (even in a limited way) for a while. They see their place in the community again. We need only to look at the unemployment research in adults to see what a profound effect taking this daily traction out of life can have on a person.

Planning school return should be done with parents, teachers and special-needs coordinators. Therapists may facilitate the process of cooperation and communication. The exact details should be judged against the situation but may start with small amounts of schooling such as an hour a day in ground-floor classrooms without any sport initially. This can be gradually built up while monitoring progress. Attention should also be paid to the social factors mentioned, such as what the teacher tells classmates, what the child tells friends, and how they answer questions about their illness. The child, family and teachers alike may all feel more confident when they have an idea what to expect and how to deal with potential difficulties.

# Emotional support

Emotional support is very important for the child, but also for the family. As treatment progresses, young people are often seen on their own, but alongside this, they may be seen with parents, and on occasion the parents on their own. They need frequent reassurance, and they all need to understand and own the process of change so that they can support each other.

#### Medication

There is no research evidence on antidepressants in children with CFS, but evidence in adults shows few long-term advantages, and what benefits do accrue tend to be specific to the depressive symptomatology (Wessely, 1995; Wearden *et al*, 1998). Prudence dictates that we use them only if very clearly indicated by severe depressive symptomatology, and even then a response may not be forthcoming in children (Smith *et al*, 1991).

Antiviral agents or immunoglobulins have no routine place in treatment (Wessely, 1995). Various sites on the Internet suggest a range of other treatments in children (details available from the first author upon request) but there is little research evidence to support them.

#### Outcome

Most children reaching paediatric wards or specialist infectious diseases clinics are at the severe end of the spectrum of CFS. General practitioners frequently tell us about children who improved with simple advice and reassurance. The research is not extensive, but different treatment approaches have been tried. In one study (Smith et al, 1991) a low-key approach to treatment with simple medical followup, encouragement and referral to a child psychiatric clinic if severe low mood was present resulted in half the children being well or markedly improved between one and three years later. More active treatment with a joint child health/child mental health approach shows improvement rates of about 75% at about two years (Marshall et al, 1991; Vereker, 1992; Carter et al, 1995), although some studies have done much better than this (Feder et al, 1994) with a similar approach to that described above.

### **Further work**

Chronic fatigue syndrome carries significant implications for child and family. Randomised research would be helpful, particularly looking at alternative treatment approaches. Despite being recommended by some, there are no research papers demonstrating that treatment based on inactivity and social avoidance is useful and so this approach should be used with caution. Research into the natural history of the illness, across a range of severities, in a community sample would also be helpful. Finally, more research into how the attributions of family, child and professionals impact upon the development and outcome of the illness would be fruitful.

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#### 2. Children with CFS:

- a have inflammation of the meninges
- b have more mood disturbance than cancer sufferers
- c have a specific virus that perpetuates the illness
- d usually feel anxious about return school
- e are likely to have an active social life.

#### 3. Management principles include:

- a long-term bed rest
- b gradual return to normal eating/sleeping patterns
- c avoidance of social contact
- d a structured incremental exercise program
- e assessment of the family's illness attributions.

# Multiple choice questions

- 1. CFS is defined as a syndrome:
  - a that is lifelong
  - b with severe disabling fatigue
  - c that does not affect mental functioning
  - d with profound fatigue associated with severe anaemia
  - e that may include myalgia, mood and sleep disturbance.

MCQ answers		
1	2	3
a F	a F	a F
b T	bТ	b T
c F	c F	c F
d F	d T	d T
e T	e F	e T