

Chronic Fatigue Syndrome (CFS)

29

helping your child to get better

Factsheet for parents and teachers

What is CFS?

The main symptom is extreme tiredness, which is not caused by any other physical illness, and which can dominate your life. The cause is unknown. Often there is an acute viral type of illness which, instead of settling completely develops into a chronic low-grade state of debility. The relationship with "glandular fever" (infectious mononucleosis) is not clear, a number of young people who have glandular fever experience a protracted (up to 18/24 months) convalescence with symptoms of debility in common with CFS, but only a minority of these with CFS have laboratory test evidence of recent Epstein Barr (glandular fever) virus infection.

Common symptoms include:

- headaches
- aching muscles
- swollen glands.

Like other severe physical illnesses, CFS has some important emotional and psychological effects (see Factsheet 27 on chronic physical illnesses). This does not mean that it is 'all in the mind', but that the whole person is affected. It can be a long road to recovery.

<http://www.trippin.co.nz>

What are the psychological effects of CFS?

Generally, the child or young person may have the following symptoms:

- feeling depressed
- feeling irritable
- feeling anxious
- having difficulty sleeping
- losing interest in food
- finding it difficult to concentrate or remember things
- feeling extremely tired
- getting headaches.

The disorder can seriously disrupt normal life. Your child may be unable to:

- carry out their usual activities
- go out and see friends
- carry on with their hobbies.

School can be very difficult to cope with. Young people with CFS may quickly become very unfit from staying in bed, or just doing not very much for a long time. This causes rapid muscle loss – even in healthy people. All these complications make recovery more difficult.

Everyone in the family can feel the strain. You may have to give up work to nurse your sick child. Brothers and sisters may feel that they are being neglected. Parents may disagree about whether the child is really sick, or is just attention-seeking.

How can I get help?

The diagnosis of CFS can be difficult. In the early stages of the illness, it may seem that no one knows what the problem is and how to solve it. This can upset the child, who may feel that no one believes that they are ill or understands. Relationships can become difficult at home and at school.

Your general practitioner or public health nurse will be able to refer your child to a paediatrician or child psychiatrist for treatment. The school, including the school nurse and school guidance counsellor or resource teacher for learning & behaviour, will be able to help with problems at school. The support and encouragement of family and friends are very important for good recovery.

Treatment

The aim is to help the child or young person with CFS to gradually resume normal activities. A programme of gradually increasing gentle activity will help to rebuild your child's muscles and fitness.

Family or individual counselling can help in overcoming depression, anxiety, lack of confidence, poor motivation, or family and relationship problems. It can be important to look at ways of getting your child's education back on track by talking with your child's teachers.

Carers can also feel stressed. You have to be very patient, but also determined and optimistic, even when things seem bleak and uncertain.

Often it is hard to know when to encourage your child, when to comfort them or when to put pressure on them. You may also find some expert advice helpful.

It can be helpful for everyone involved in helping a child with CFS to meet and talk about progress from time to time. This allows everyone to share ideas about the best ways forward – physical, psychological and educational. Working as a team is important and a regular review of progress is essential.

In a large proportion there is eventual recovery, but the duration may be months or longer (hence "chronic"). At present there is no reliable body of data on which to base estimates of likely duration.

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