

## Combating ill feelings

When children suffer from long-term illness it is important for their peers to be sympathetic and supportive. Márianna Csóti recommends using a story to promote understanding of glandular fever and ME.

During winter months, when viruses abound, it is common to have a child affected by glandular fever. In a few unlucky children this may be a route into a more lasting condition commonly known as ME (myalgic encephalomyelitis) but called chronic fatigue syndrome (CFS) by doctors. Children and young adults can be severely affected by these conditions. So it is useful for class mates to understand how isolating these illnesses make their friends feel and for teachers to understand how hard it is for these young people to carry on with schooling. Many do not manage it.

Read the story below with the class and use the discussion questions – adapting them to suit age and ability - to raise empathy for fatigued children and to help peers become informed about glandular fever, ME/CFS and depression – which often results from feeling ill for a long time. Part of developing positive relationships with others in and out of school is about being supportive of vulnerable peers.

### I'm so Tired

Tim stared uncaringly out of the sitting room window on to the street. Another day ahead. Another day exactly the same as the day before and the day before that. In fact, he was likely to have the same day for a long time to come. Who knew when it would change?

Tim's head rested on the chair back and a padded footstool supported his feet. He'd never known anyone could be so tired for so long, without a break. He'd only eaten breakfast, got washed and dressed and he felt worse than he'd had after a full day in school and partying on a Friday night.

His glandular fever had been bad enough. Because the tiredness had crept up on him so gradually, he thought he was only run down. Vitamins and early nights was what he needed. But the walk to school became more and more like climbing a steep mountain. And when he arrived, he had to sit down with his head in his hands. The headaches worried him but it wasn't until he kept feeling prickly hot for no reason and his throat became dreadfully sore that he told his mum. She took him to the doctor who took a swab from the back of his throat and blood from his arm. He was too tired to even think of leaving the house while he waited for the test results.

Even then, he hadn't understood what was wrong with him. He'd heard of glandular fever and it was something to be dreaded but he hadn't understood why until then. His friends weren't allowed to visit. Their parents were too worried that their children would catch it. He felt as though someone had marked a cross on his door like they did in the days of the plague. He had chatted to friends over the phone but it soon became obvious that their worlds were moving apart. He hadn't anything to say and his friends were coping fine without him. Even his best friend Jack had deserted him, becoming friendlier with other boys.

Tim had heard that the others who had glandular fever were back to normal in half the time he was. He was off school for three months before going back. But then he realised he hadn't got back to normal at all. Each day was harder to cope with. He couldn't wait to get to bed after his evening meal and could not do his homework.

Tim recalled his last day in school. He felt dizzy and ready to throw up after he got there. And then he had to go to assembly. There was a bottleneck in the corridor and there was a crowd of them waiting to get out of the classroom. Tim felt weak and strange and suddenly he was on the floor. When they tried to get him up he couldn't move. He was too tired to do anything.

That had been seven months ago. Tim wondered what his friends were doing now. They had visited at first, when they were told he wasn't infectious. But gradually they stopped coming altogether. They were embarrassed about being with him. There were too many awkward silences. As soon as they started to talk about parties and discos their voices trailed away, realising they'd been tactless.

Jack had a girlfriend now. Tim's mum had seen them together at the shops.

Tim closed his eyes, exhausted by the morning's efforts. What was the point in life if all he had to look forward to was Mum looking after him like a baby or a sick old man? His life had hardly started but he felt as though it were at an end. He could cope so much better if only he didn't feel so bloody alone. No one understood. And only Mum cared, but it was too much for her on top of everything else she'd got to do. And he didn't want to be dependent on Mum – he wanted his own life back.

### Discussion questions

The story is about medical conditions that make children feel extremely tired. First of all, Tim had glandular fever. Do you know what it is?

Glandular fever is a viral illness with an incubation period of up to six weeks before symptoms of a sore throat, tiredness, poor appetite, fever, headache and swollen glands appear. These symptoms can last up to two weeks but the person may not feel well until several weeks or even months later, feeling tired and depressed. Some children are lucky and don't have bad symptoms and may not even realise they have glandular fever.

Tim was later diagnosed with an illness often known as ME or chronic fatigue syndrome. Do you know what it is?

ME/CFS is a neurological illness - an illness that involves the brain and nerves. It is often triggered by a viral illness such as glandular fever but often the exact cause is not known. Diagnosis is given after all other explanations have been ruled out – there isn't a particular (diagnostic) test like there is for most other medical conditions.

Extreme fatigue is always present in ME/CFS but there are many other symptoms that may or may not be present which include:

- Cold hands and feet.
- Sensitivity to medicines, noise, light, smells, hot and cold weather or room temperatures.
- Fainting and feeling faint.
- Headaches.
- Insomnia.
- Muscular and joint pain.
- Feeling sick.
- Poor short-term memory and concentration.

Young people suffering from ME/CFS can be totally unable to care for themselves. Some, however, are able to attend school if they have considerable help.

What are the differences between ME/CFS and glandular fever?

- Glandular fever is an infection due to the Epstein-Barr virus and is transmitted through saliva. There is no single cause for ME/CFS and it is not infectious. It often develops following an infection where the person has not fully recovered but this is not so in all cases.
- Glandular fever occurs in adolescents and young adults, its incidence peaking between ages fifteen and seventeen. ME/CFS peaks in adults at age thirty to forty (although many children and younger adults do get it).
- The symptoms of glandular fever are not as severe or as long lasting as those of ME/CFS. It can take people a long time to recover from glandular fever but this often improves over a period of several months. According to the new NICE (National Institute for Health and Clinical Excellence) guidelines given in August 2007, for ME/CFS to be diagnosed in a child or young person symptoms need to have been present for at least three months.

Have you had glandular fever or ME/CFS or do you know anyone with ME/CFS? Have you had a bad flu virus and been off school feeling very tired and unwell for several days? If so can you imagine how it might feel to feel like that every day for months?

(Personal responses required.)

What sort of help do you think someone with ME/CFS who was able to attend school would need from the school?

The school may need to:

- allow the person to attend on a part-time basis.
- arrange for the person to have lifts to and from school.
- excuse the person from games/PE lessons.
- understand the person's needs and understand that these may vary from day to day and week to week. People suffering from ME/CFS do not have consistent energy levels – they often have good and bad days.
- inform all the teachers about the person's needs.
- be flexible about deadlines.
- be patient with the person and recognise when that person's limits are being pushed too hard.

- provide a rest area so that the person can lie down if necessary.
- be understanding of repeated absences and part day attendance.
- have certain lessons timetabled on the ground floor if the stairs are too much for the person to cope with.

If your friend had ME/CFS, what could you do to help?

- Help them to remember commitments.
- Offer to carry their school bag.
- Offer to fetch things that they need.
- Be understanding.
- Be a good friend and understand if they are too tired to talk, but don't let them become socially isolated. Be near.

Tim is not very happy. Why is this?

- He is lonely – he spends all day everyday at home with his mother. He needs friends of his own age.
- He is frustrated that he is physically unable to do much each day and sees his life wasting away before him, all his dreams and hopes for himself and his future melting away.
- He feels unwell. It makes him feel vulnerable. No one feels happy or able to face hardships in life if they are feeling bad – and bad for so long. They find problems harder to cope with and they have more impact than they would on someone who was feeling mentally very positive.
- He knows his friends are carrying on with their lives and moving on without him. He feels unloved and unimportant. Now he is a nobody.
- He feels socially isolated.

What does it mean to feel socially isolated?

- It is more than being lonely. Tim meets no one at all apart from his family. When people go to school or work they interact with many people which gives interest to the day and allows many small rewarding conversations to take place.
- It is possible to feel lonely and socially isolated even when there are many people around you as you can mentally and emotionally cut yourself off from others making it impossible for them to 'reach' you. Then you don't experience other's feelings of care for you or your feelings for them.
- When people feel socially isolated they lose their sense of worth and importance in the world and can very easily become depressed.

Many people who are sick for a long time suffer from depression. What is this?

Depression is a feeling of deep unhappiness that doesn't leave you. You may feel so low that you do not want to get out of bed at all, lose all interest in yourself and do not eat properly or wash. The intensity of your unhappiness is so great that you cannot 'snap out of it', but many people may tell you to, thinking that you only need a strong talking to.

Other symptoms of depression include tiredness, pessimism, feelings of hopelessness and sometimes anxiety, loss of appetite and weight, and insomnia. It is common to have suicidal feelings and there is a high risk of suicide in the depressed – that is why it is essential to seek medical help.

What can be done to help a depressed person?

- They could be offered counselling.
- They could be given medication called an anti-depressant. There are many different types working in slightly different ways so that usually one can be found to suit.
- It is helpful to get out and meet people and go out with friends if they can or have friends visit them.

### Getting the right balance

According to Home Education Special, an organisation that helps parents home educate children with SEN, 25,000 young people in the UK are affected by ME/CFS.

Children with either glandular fever or ME/CFS cannot be pushed to recover. They can only be taught to manage their illness and be patient. Since symptoms fluctuate daily or even from hour to hour with ME/CFS, it is easy for a child to overdo things and then be made worse. It is important that friends and teachers understand that what they may see a child coping with one day may not be something that can be repeated the next day – or even the next week.

Access to Education for Children and Young People with Medical Needs states that pupils should not be at home without access to education for more than 15 working days and the education should be of similar quality to that available in school, including a broad and balanced curriculum. Pupils educated at home should receive a minimum entitlement of 5 hours teaching per week. The right balance must be struck between encouraging pupils to study and recognising when they are not well enough to benefit from teaching.

The education must also be suitable - to the age, ability, and aptitude and to any special educational needs the young person may have - and be flexible and responsive to the demands of what can be a changing medical status. All schools need to have a written policy and procedures for dealing with the education of pupils with medical needs, which may stand alone or be incorporated into the schools' SEN policy.

### Further information

NICE

Web: [www.nice.org.uk](http://www.nice.org.uk)

Home Education Special

Web: [www.he-special.org.uk](http://www.he-special.org.uk)

Access to Education

[www.dfes.gov.uk/sickchildren/Pdfs/AccessstoEducation.pdf](http://www.dfes.gov.uk/sickchildren/Pdfs/AccessstoEducation.pdf)

Action for ME: Third Floor, Canningford House, 38 Victoria Street, Bristol BS1 6BY

Tel: 0845 123 2380 / 0117 9279551 Web: [www.afme.org.uk](http://www.afme.org.uk) and [www.a4me.org.uk](http://www.a4me.org.uk) (a site specifically for young people with ME/CFS)

The ME Association: 4 Top Angel, Buckingham MK18 1TH

Tel: 0870 444 1836 Web: [www.meassociation.org.uk](http://www.meassociation.org.uk)

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