

ME wreaks havoc for children

When ME (Chronic Fatigue Syndrome) hits a child or adolescent, the effect on their social development, education and family life can be devastating. MEG DAVIDSON reports.

It's 10.30am and Kate has finished her school day. The 20-minute trip to high school and the single period of French have left the Waikato 15-year-old exhausted, but she manages to do her French homework at the kitchen table before collapsing into bed.

An hour later, she drags herself up again and starts her Correspondence School lessons. "It's really hard to get up but I make myself. I want to go to law school and I need to get good grades," she explains. By mid-afternoon, Kate's bed has claimed her again. On average, she spends 14 hours out of 24 asleep and many more resting. At times, the exhaustion is so overwhelming she can't get up at all, even to feed herself. She's been like this since a bout of tonsillitis a year ago.

When all Kate's lab tests came back negative and she remained ill, she was diagnosed with ME (Myalgic Encephalomyelopathy) also known as Chronic Fatigue Syndrome (CFS), a baffling disorder characterised by fatigue and malaise which persists despite rest and gets worse with exertion. Other symptoms like joint and muscle pain and "brain fog" are often present.

While ME is now widely recognised in adults, the fact that children and adolescents can get it is less well known. The youngest known sufferer was 5. Auckland GP and ME expert Dr Ros Vallings makes no distinction between the incidence in adults and children, putting the overall figure at two per 1000 people. With no definitive diagnostic test and a wide range of possible symptoms, it is difficult to diagnose, especially in children.

"If a child is feeling tired, they just accept it. They don't know it's abnormal so they don't complain," Dr Vallings says. Symptoms like fatigue, headache and difficulty concentrating - all common in ME - are easy to pass off as depression, school phobia, attention deficit disorder or just plain laziness.

It gets worse. Parents who continue to maintain their child is physically ill against medical opinion can be labelled as interfering and even accused of causing the child's illness - Munchausen by Proxy Syndrome. A Dunedin family lived in dread after a health professional said he could no longer support their child's absence from school, giving the school no choice but to label the absences as truancy. To this family the message was clear: get that kid out of bed and on the school bus or Child Youth and Family will be called. The fear the child would be removed from their care was not completely fanciful; it has happened overseas.

Education is a massive problem for most children with ME. While the disease wreaks havoc in the lives of adults, it can completely derail the social development and learning of a young person who has barely begun to live.

The need for normality and continued social contact means fronting up at school, even for short periods as Kate does. This is usually seen as the best option. However, school is a far from ideal learning environment for most with ME - it's noisy, the lessons move too fast, school bags are heavy and precious energy is squandered just getting there.

Dr Vallings, who estimates 200 young ME sufferers have passed through her care, says a creative approach is needed. "Some I've known have made a good recovery only after they've finally left school."

Health schools, established in 2000 by the Ministry of Education, bridge the gap between home and school. Sadly, says Southern Regional Health School deputy principal Liana Johnston, some sick children still miss out because schools are not aware of their existence. Access to a referring specialist is difficult for some, especially in rural areas.

Under the health school system, the child remains on the mainstream school roll; health school teachers liaise with the family and the student's regular school to formulate a workable education plan. That may be anything from a full school day minus physical education to home lessons with a weekly trip to assembly.

The byword is flexibility, says Central Regional Health School teacher Cathie Trotter. "Once the pressure is lifted, children with ME often function better. If their energy is limited, we concentrate on basic literacy and numeracy."

Parents of ME sufferers can be vastly relieved to find an ally in a hospital school teacher, Mrs Trotter says. "I remember one mother just burst into tears. She said: 'At last, someone who will actually help us'."

Having a child with ME puts a tremendous strain on a family. Kate's mother Rachel, a sole parent of three children, has stretched the family budget to its limits in her quest for a cure. Juggling Kate's needs with those of her other children and her own formidable work commitments is a nightmare. She hates having to leave her sick daughter home alone while she works. Frightened by her continuing illness, Kate is desperate for reassurance and Rachel must keep her own fears to herself. "I cry in bed at night, wondering if she will ever marry, if she will ever be the lawyer she wants to be."

Chances are Rachel will see her daughter restored to the athletic, vibrant young woman she once was. It is true some people with ME never recover, but most do, and children bounce back more quickly than adults.

"The average course of the illness is three to five years. With efficient management, it can be a lot less than that," Dr Vallings says.

For some children, recovery takes longer. ME Support and Information Service (Otago-Southland) co-ordinator Heather Wilson has seen the devastating consequences when the problem was judged to be psychological because "they should be better by now".

There is ample scientific evidence that ME is a physical illness and Dr Vallings says better education for health professionals on its management is needed. Although it is diagnosed only when fatigue has lasted six months and other conditions have been excluded, she says GPs should consider ME when a child is still unwell three months after a viral illness (these being the most common triggers for the immune system overload thought to be responsible for the condition). In children, headaches and sleep and bowel disorders are common accompanying symptoms.

There is no magic bullet for ME and the emphasis is on managing individual symptoms like pain. Rest is vital, and ME sufferers must learn to pace themselves. "It's easier with younger children because they will lie down when they're tired," Dr Vallings says.

"Adolescents are different: they want to keep up with their peers. Ultra-high level sports training after a viral illness can lead into the condition. In the recovery phase, it's often parents who will pressure them back into sport or ballet before they're ready."

Kate's illness has made her grow up fast.

"My friends are still giggly and laughing. Me - I'm not so crazy anymore. I've learned a lot of things, like patience. I've had time to reflect." What she misses most is her freedom. She can't walk into town or along the river. In fact, she can't go anywhere without checking first that there's somewhere she can lie down: a consideration with big implications for this tramping, kayaking family's leisure activities.

But Kate still enjoys herself when she can. A recent highlight was a friend's birthday party. She paid the price and landed back in bed. "But it was worth it," she says with a smile. And she believes - some days with confidence, others with a greater measure of hope - that one day she will again be able to dance and then dance some more.