

The quality of life of children with ME/CFS

In Western societies, ME/CFS is thought to affect 50 to 70 children per 100,000. Most eventually improve in health, but some remain ill or even get worse over time. A report to the Chief

Medical Officer of England concluded that ME/CFS represents “a substantial problem in the young”, while the Royal College of Paediatrics and Child Health has produced evidence-based guidelines on how best to diagnose and manage the illness in children.

Dr Gwen Kennedy and her colleagues in the Vascular and Inflammatory Diseases Research Unit, in the University of Dundee, have recently completed one of the first ever biomedical research projects in children with ME/CFS. Her work was supported by ME Research UK, Tenovus Scotland, The Young ME Sufferers (Tymes) Trust (see the box opposite for more information) and Search ME.

Dr Kennedy’s group has previously reported a whole raft of abnormalities in adults with ME/CFS, mainly involving the immune and cardiovascular systems. These findings have included an increase in the programmed death (apoptosis) of white blood cells, raised levels of oxidative stress which can damage blood vessels and other organs, increased markers of inflammation, and abnormalities in blood vessel function. All of these are potentially associated with a future risk for cardiovascular problems such as heart disease and stroke.

These studies have all been in adults with ME/CFS, but for her latest work Dr Kennedy decided to focus on children with the disease. One aspect was to investigate whether the abnormalities found in adult patients are also present in children with ME/CFS. These results have yet to be published, but another important aim of the research was to investigate objectively the quality of life of children with ME/CFS, and these results were published recently in *Pediatrics*.



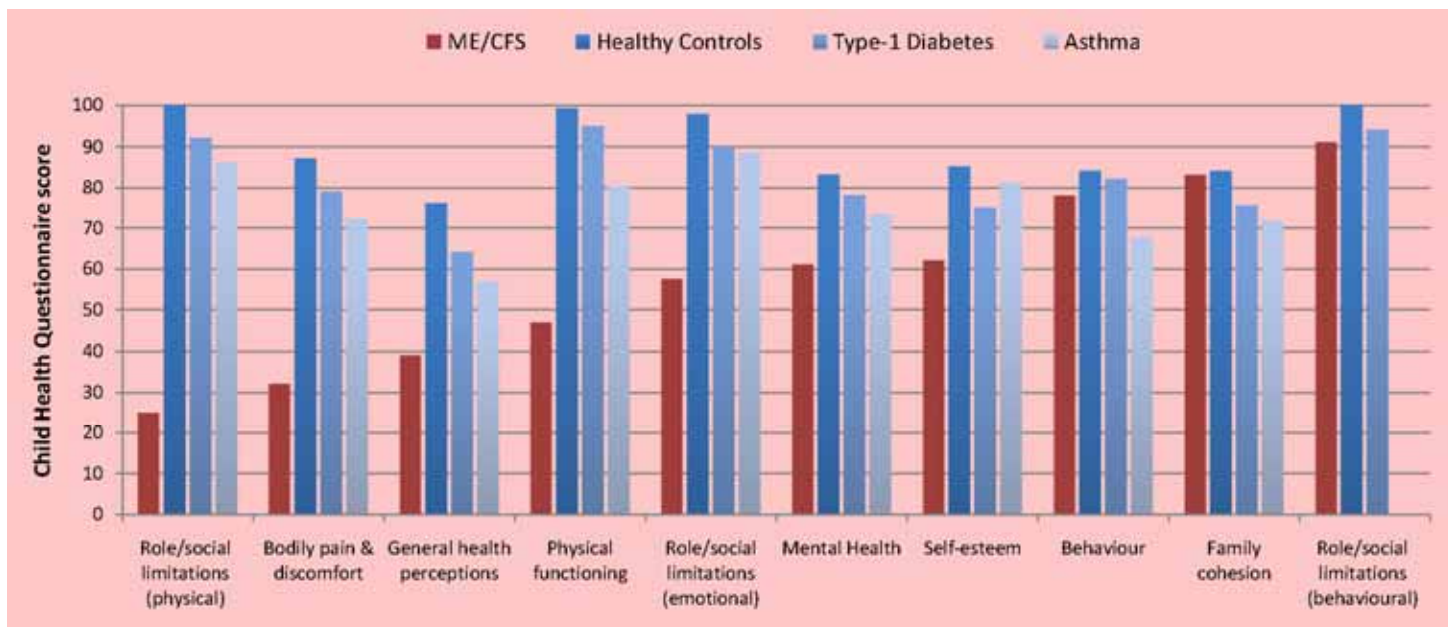
Dr Gwen Kennedy

Twenty-five children with ME/CFS and 23 healthy children were recruited from throughout the UK. All were between the ages of 10 and 18 years, and the healthy children were matched to the patients for age, gender and stage of puberty. This meant that a comparison between the two groups was as valid as possible.

The initial diagnosis of ME/CFS had been made by the children’s local consultant paediatrician or general practitioner according to a revised version of the CDC-1994 case definition, but it was also confirmed by the researchers from a clinical examination.

Each child was asked to complete the Child Form of the Child Health Questionnaire, while their parents were asked to





complete the Parent Form. This questionnaire collects information on a number of different areas related to the quality of life of an individual. These include their physical abilities, their social limitations, how they perceive their general health, whether they experience any pain or discomfort, and how they are able to interact with their family. The questionnaire also covers emotional and mental health, including self-esteem, behaviour and their effect on the parents. The responses were converted into scores for each area, which were then summed to produce a total score out of 100, with higher scores indicating a better health status.

The children were asked about their situation when they became unwell, factors which may have contributed to the illness, and whether they thought they were currently improving, worsening or unchanged. They were also asked what impact the CDC-1994 minor criteria symptoms (short term memory loss, sore throat, tender lymph nodes, muscle pain, multi-joint pain, headaches, un-refreshing sleep and post exertional malaise) had on their lives.

The main finding of the study was that children with ME/CFS scored significantly lower than the healthy children in 10 out of 14 areas covered by the Child Health Questionnaire (illustrated in the chart above). They had particularly low scores for global health (21.4 compared with 84.1 in the healthy children) and for social limitations due to physical health (24.9 compared with 100). Self-esteem, mental health, body pain and discomfort, and the

effect of the child's health on family activities were also significantly worse for children with ME/CFS. However, there were no differences between children with ME/CFS and healthy children in how well the family got along, or in the children's perception of their own behaviour.

It is important to note that the quality of life reported by these children with ME/CFS was not only worse than that of healthy children of a similar age, but also worse than that of children with type 1 diabetes or those with asthma (as reported in previous studies, and illustrated in the chart above). Furthermore, the physical symptoms of ME/CFS can be at least as disabling as those of multiple sclerosis and other chronic conditions.

Importantly, the illness had started with an infection in 88% of the children, while only one child (out of 25) was able to attend school full-time. Fortunately, just over half of the children who participated felt that their symptoms were improving, and the prognosis for children with ME/CFS is generally better than for adults, although no long-term studies have been conducted. However, Dr Kennedy's findings confirm that ME/CFS does have a serious impact on children's quality of life, and she comments:

"This experience of illness occurs at a particularly vulnerable time of life when disruption to education and family has the severest consequences... it is important that the condition be recognised and diagnosed so that the consequences on quality of life can be attenuated." ●

The Tymes Trust

The Young ME Sufferers (Tymes) Trust, one of the major co-founders of the study at the University of Dundee, is the longest established national UK service for children and young people with ME and their families.



A well-respected national charity, its entire professional team give their time free of charge. It runs an Advice Line, provides access to ME experts for doctors, teachers and social workers, and produces a magazine for children, families and professionals. The Trust played a major role in producing the children's section of the Department of Health Report on CFS/ME (2002). It promotes interactive virtual education for children with ME, and provides the Tymes Trustcard — a pass card for children in school, endorsed by the Association of School and College Leaders.

More information can be obtained from 08450 039002 or at its website www.tymestrust.org.