

Understanding ME in Secondary School Pupils

Richmond & Kingston



M.E. Group

Understanding ME (Myalgic Encephalomyelitis)

“The medical establishment’s use of the term Chronic Fatigue Syndrome (CFS) in place of ME has been a disaster for children. People think it is just tiredness, so when they are absent from school the parents are blamed or the child is labelled with a psychiatric condition. This is causing untold misery for families”

Common Misconceptions:

- That ME is a mental health issue
- That treatments recommended by NICE can always be expected to 'cure' or substantially to improve the condition.
- That the illness is neither long lasting (chronic), relapsing nor severe.

Severity and Duration of ME (1)

“The physical symptoms can be as disabling as multiple sclerosis, systemic lupus erythematosus, rheumatoid arthritis, congestive heart failure and other chronic conditions.”

National Institute for Health and Clinical Excellence [NICE]
Guidelines 2007

Severity and Duration of ME (2)

“S. contracted ME at 15. She had to give up her education (which was her being) all her friendships and activities. She has no experience of working life and never goes out (theatre, concerts, pubs, libraries, parks, ..anywhere, in fact, other than compulsory visits to doctor or to work assessment panel!)” Father of S.

ME and Education

- ME has a devastating effect on education causing more long term sickness absence than any other illness.
- Educational demands often turn a mild case into a severe one.
- Paradoxically and counter intuitively putting education second to health actually achieves the best educational results in this illness.
- Remember it is not the child's fault they are ill. It can be very damaging if the LA and school impose inflexible rules

Rest is the cornerstone to stabilising the condition and any chance of improvement.

ME and School Attendance

- Fluctuating symptoms and the delayed effect of activity mean that you may not witness the extreme pain and exhaustion of the illness in school.
- A child with ME may look and seem well and be able to concentrate for 10 minutes or half an hour but then need to spend the rest of the day in bed.
- Children with ME may cope with a few hours in school by doing even less than usual in the preceding days and then spending days afterwards recovering. This tends to give a false idea of energy levels and abilities as a whole.

Case Study

- Anna was 9 when first diagnosed.
- Serious relapse at 11 and diagnosis confirmed.
- Diagnosis questioned at initial school meeting
- Constant pressure for return to school attendance and inflexible home tutoring led to severe relapse
- Anna is now 16 and has severe ME and is unable to read, study or cognitively process information
- Nevertheless Anna longs to be in school and dreams most nights of being there.

How you can help

- Look out for early signs of condition. Refer to school nurse and work with us.
- 'Pacing' is essential to recover and avoid relapse. Children need support to avoid 'boom and bust'.
- Treat each child as an individual. Be flexible. Rate and timing of re-integration to school needs to reflect child's energy levels.
- If child relapses, work with family not against them. Support and believe the family.
- **Rest is the cornerstone to stabilising the condition and any chance of improvement.**

Richmond and Kingston ME Group

To find out more about Richmond and Kingston ME Group,
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