

Statistics for Recovery in Children

Margaret Williams 7th August 2007

In determining how many children and young people recover from ME, one needs to be careful. For a start, who diagnosed them with ME, and did they all have ME in the first place? How many had true ME, and how many in fact had chronic fatigue arising from another cause?

There is a general feeling amongst paediatricians that young people recover from ME better than adults, but this cannot be taken as fact. As Jane Colby points out, paediatricians stop seeing young people once they reach the age of 16, and many adolescents have relapses about the time they start college / university.

Crucially, improvement is not recovery.

Byron Hyde does not give figures for childhood recovery.

The 2002 CMO's Report does mention the figure of 70% + recovery in Annex 1 **BUT** these figures come from a study of only 25 children by Rangel et al *who used the Oxford criteria*, so technically none of the children in the study had true ME. One of the co-authors was Elena Garralda (whose published articles on ME have caused concern within the ME community) JRSM 2000;93:129-134.

In the actual CMO's report itself at section 4.2.1.4 it says:

"In children, the prognosis appears to be worse for more severe cases. Overall, the duration of disease appears shorter in younger people than adults, and a high proportion of children appear to recover". This statement does not appear to be supported by evidenced references. The Report's authors then seem to contradict themselves by stating: "Recovery may rarely be complete and some children will relapse in adult life" (Chapter 1, section 1.4.3).

Prof Jason's 2006 Paediatric Case Definition says a persistently disabled group tends to have symptoms that are worse from onset and result in severe activity limitation ie. that there is a subgroup of children whose illness persists for an extended period of time.

The RCPCH Guidelines of 2004 say "There are no population-based studies to provide evidence of prognosis. Information on prognosis comes from longitudinal follow-up of case series. Most studies involve few cases, with variable duration of follow-up. Studies with extended F/U show 60-80% partial or complete recovery with about 20% of cases remaining incapacitated. Smaller studies, with variable F/U times, identified groups of young people remaining seriously impaired, ranging from 5% - 47% of patients". Note that 47% of young people remaining seriously impaired is not far off 50% (ie. almost HALF of young people do NOT recover).

Those RCPCH Guidelines mention Wessely's "Systematic Review" of prognosis in QJMed from 1997, which found that up to 94% of young people made a full recovery. In the abstract, Wessely actually states: "Of 26 studies identified, four studied FATIGUE in children (so did they have true ME?) and found that 54-94% of children recovered over the periods of follow-up".

Note that in all four of these children studies, one used a self-rating of clinical condition, one used telephone contact by a doctor up to 72 (seventy two) months later, one used telephone contact with the family up to 40 months later, and the last one used a structured telephone interview with the parents up to 32 months later. How scientific is *that*? The RCPCH seems unaware of the intense criticism of Wessely's paper, which has been stringently criticised in the medical literature. For example:

- the authors use mixed terminology interchangeably, mixing up chronic fatigue / tiredness with CFS, but these are not interchangeable and to treat them as such misleads physicians
- the authors summarised a wide variety of studies encompassing persons with mild tiredness to classic ME/CFS so the authors' analysis was useless as it was based on confounded measurements and inconsistent patient populations
- even in 1997, the evidence for psychological factors playing a role in the perpetuation of disability had been contradicted
- correlation is not the same thing as causation
- Wessely was accused of actually doing harm by what was referred to as "the tragedy of poorly summarised research for CFS (which) is costing patients enormously"
- the authors state that they relied upon "assumption" (again, how scientific is that?)

I looked at the Canadian criteria but they don't seem to give any stats for recovery in children.

In summary, the recovery stats all come down to what case definition is used, and one needs to do some diligent homework before attempting to give information that purports to provide factual information.

Hope this is helpful.