

Brief Notes on Dr Charles Shepherd's Comments on the Draft Report Version
19 June 2001 by the 25%ME Group for the Severely Affected 4 July 2001

We are in strong agreement with much of what Dr Shepherd states and we support his overall objective.

There are, however, certain points on which we cannot agree, and we believe that these are matters of substantial importance.

[Page numbers refer to Dr Shepherd's Comments]

page 2 (re: chapter 1: paragraph 1.4.3): Dr Shepherd agrees with psychiatrist Peter White that more information should have been obtained from patients who have substantially improved or largely recovered from their illness. **Few patients “substantially improve” or “largely recover” from ME and this needs to be emphasised.** We do, however, agree with Shepherd's comments re paragraph 1.5.3 on prognosis, where he says that there should be a distinction between “improve” and “recover”.

page 4 (re: chapter 3: paragraph 3.2.4 Maintaining factors) Shepherd here states that “This is a useful section” but this section in the draft Report states that “*Disorders of mood occur in a large minority of CFS/ME sufferers*”; it links pervasive inactivity and deconditioning to the maintenance of the disorder and it states that “*illness beliefs*” act as an obstacle to recovery. **We strongly disagree that this is a “useful section” as far as ME is concerned.**

page 5 (re:chapter 3 paragraph 3.2.5 Possible pathophysiological mechanisms):
re: Immune system, Shepherd states “This is acceptable”. **We strongly disagree: it is unacceptable because it is scientifically incorrect.** p[lease refer to our submission dated 29 June 2001, which includes evidence which shows it is incorrect.

page 6 (re: chapter 3, paragraph 3.2.5 Possible pathophysiological mechanisms):
Shepherd here recommends *removing* from the Report the reference to dysfunction of the peripheral nervous system. Currently, the draft report includes reference to the fact that both *evidence* and *specific symptoms* implicate the PNS. It seems counter-productive to suggest that something so helpful should be removed.

page 7 (re: chapter 3, paragraph 3.3.3 Symptom profiles): Shepherd suggests replacing the current draft with a sentence which puts undue emphasis on postural hypotension and dizziness being secondary effects of inactivity; they can certainly be the result of inactivity **but they can also be unrelated to inactivity, and in ME they can occur as primary symptoms, but this point is not made.** It is an important point.

page 9 (re:chapter 4, paragraph 4.2.1.2 Criteria): **We strongly disagree that the Ramsay clinical description of ME should be relegated to an appendix. It is central to the disorder of true ME.**

page 9 (re: chapter 4: paragraph 4.2.2 Unnecessary and unproven tests): **We cannot agree with Shepherd on this important issue.**

page 11: (re: chapter 4, paragraph 4.3.3 Symptom control): Shepherd here states “ *I feel very strongly that there should be a much greater discussion of the pharmacological management of individual CFS/ME symptoms (as was contained in the earlier draft of this chapter)*”. As an active member of HealthWatch (which was set up to promote the interests of the pharmaceutical industry (*ref: Dirty Medicine. Martin J Walker, first edition 1993 page 340*), this is exactly what one would expect on this matter, **but it wholly ignores all the evidence that those with ME/core CFS whose immune system is disrupted cannot safely be given pharmaceutical interventions because they suffer adverse reactions. The literature is full of references to this. At the 1994 Dublin Conference, Professor Charles Poser of Harvard (a world authority on MS and on the similarities between MS and ME) said that such adverse reactions to medicinal drugs were virtually pathognomonic of ME (ie. it is a symptom which is unique to the disorder). As Medical Director of the ME Association, is it unethical for Shepherd to promote the use of drugs when there is such an enormous body of published evidence that sufferers react badly to them, including anaesthetics? This is a danger which Shepherd should be emphasising, not ignoring.**

4th July 2001