

# Follow Up Survey on People with M.E.

**A follow up survey was conducted of ME/CFS/MCS patients who had previously completed detailed research questionnaires.**

A one-page Follow-up Questionnaire was sent to 378 subjects in late January/early February 2001, requesting responses to three main questions:

Q.1 Patients current state of health, compared to that over the past 2-3 years, or at the time of completion of the original questionnaire.

Q.2 What treatment methods, therapies or management strategies were adopted by them in that period and how these affected their health.

Q.3 How severely affected these patients are now by their illness.

Additional details related to present age, any new or additional diagnosis and provision for any other information. – By late March 2001, 174 completed questionnaires were received (46%); 32 letters were returned (8%), as addressees had gone away or died.

## The Study Groups

Responses came from 3 groups for the following periods:

79 MSc study subjects – for over 10 years

51 Patients with Chemical Sensitivities – for up to 3 years.

44 Co-TMZ/TMP (Septrin) \* - ME/CFS cases – for up to 5 years.

The male : female ratio was approximately 1 : 6

\*NOTE Co-TMZ/TMP = Co-Trimoxazole {UK:Septrin/US:Bactrim} /Trimethoprim. Some cases of ME appear to have been caused by this drug.

## Results

Responses to Q.1 showed that

31% had improved

25% deteriorated

13% returned to normal or had almost fully recovered

The rest had remained relatively stable or experienced fluctuating periods of health.

### **Responses to Q.2 revealed that the most helpful strategies were**

Pacing activity with rest,  
Adjusting diet  
Alternative treatments.

Most unhelpful strategies were  
orthodox medical treatments  
Graded exercises  
Cognitive Behavioural Therapy (CBT).

### **Responses to Q.3 indicated that now**

35% were mildly affected  
30% moderately  
18% severely  
4% very severely  
13% had regained normal or near normal health.

Further analysis of details on patients who made a full or almost full recovery showed that the vast majority had achieved this by opting for a variety of Alternative treatments, notably homeopathy and acupuncture, but frequently also by using supplements (vitamins + minerals {e.g. zinc, magnesium, selenium}, EFAs and fish oils), and making dietary adjustments.

45% of respondents reported further diagnoses or additional health problems, gastrointestinal disorders and other health problems.

Additional analysis on osteoporosis and bone disorder cases indicates that these may be related to undetected and untreated hypothyroidism.

Results of this Follow-up Survey were made available to Key Group members of the CMO's Working Group on CFS/ME in April 2001.