

PACING HELPS ME 2010

Brighton & Sussex Medical School and the Sussex & Kent ME/CFS Society 1st January 2010

Working with the Brighton & Sussex Medical School the Sussex & Kent ME/CFS Society recently ran a survey about the experiences over two years of those affected by the Chronic Fatigue Syndrome – ME across their region. This is the first professionally run comprehensive study of its type and the findings are being seriously viewed by service providers and users alike.

The project looked at which NHS and other services people are using and how helpful these services are to patients. The questionnaire that was sent to over 900 people also enquired about which treatment approaches are being tried and how helpful those are. After analysing nearly 460 completed questionnaires findings show that a number of treatments and approaches are helping a lot of people affected by the debilitating illness and that most doctors in the area are seen by ME/CFS patients as being helpful as is the Burgess Hill and Maidstone specialist NHS centres.

The majority, 54% of those that completed the questionnaire were moderately affected and unable to work and a further 16% virtually housebound and a few confined to the bedroom. Of those that have practiced the management approach of Pacing a massive 94% found it of some help or very helpful. Treatments such as specialist Cognitive Behavioural Therapy has helped 74% of those that have tried it and specialist pain medications have helped the majority prescribed them as have low doses of antidepressants such as Lustral and Amitriptyline that can help some with sleep, mood and pain. Lifestyle courses run by the NHS centres and the Expert Patient Programmes are helping a lot of people and alternative approaches such as Yoga, Nutrition, Acupuncture and Homeopathy along with the Lightning Process are rated highly by patients who have benefited from them.

Colin Barton of the Sussex & Kent Society said “Although ME/CFS can be a long term seriously disabling illness for many people there is much that can be done to help lots of patients make significant improvements as our survey clearly shows.”

Dr Michael Broughton who is the lead clinician at the NHS Sussex-wide CFS/ME Service says “The preliminary results of this comprehensive survey support the view that a wide variety of approaches can be very helpful in managing CFS/ME. It is particularly pleasing to see how the concept of Pacing seems to help such a large number of patients. The NHS Sussex CFS/ME Team supports an evidence-based, holistic approach in managing this illness and we are pleased that the survey reveals a good level of patient satisfaction with our service. We are constantly striving to improve results and reduce waiting times for treatment and there has been major progress since April 2005 when we first opened and were inundated with referrals.

Retrieved from Brighton & Sussex Medical School the Sussex & Kent ME/CFS Society Jan 2010

Approaches	Very helpful	Reasonably helpful	Not at all helpful
The Lightning Process	44%	36%	20%
Pacing	38%	56%	6%
NHS Sussex CFS/ME Service	28%	48%	24%
Hospital consultant	26%	45%	29%
Special Pain Med	26%	39%	35%
Specialist CBT	24%	50%	26%
GP	23%	53%	24%
Nutrition	23%	59%	18%
NHS Kent CFS/ME Service	21%	54%	25%
Amitriptyline etc (Tricyclics)	20%	46%	34%
Yoga	20%	59%	21%
Lifestyle courses (EPP & NHS)	16%	64%	20%
Sertraline etc(SSRIs)	15%	52%	33%
Acupuncture	14%	43%	43%
Homeopathy	13%	44%	43%
Specialist GET	12%	51%	37%

N=457

Male: 23% Female:77% Mild:29% Moderate: 54% Severe: 16% Very severe: 1%

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