

Under strict embargo until 23:30 hours (BST) Wednesday 20 September 2017

Study investigating effectiveness of The Lightning Process® programme to treat children with mild or moderate CFS or ME finds symptoms improve

[Science Media Centre briefing – Wednesday 20 September: see notes to editors]

The first trial to investigate The Lightning Process® (LP) is published today [Thursday 21 September] in the *Archives of Disease in Childhood*. In this trial, the effectiveness of LP in addition to specialist medical care was compared to specialist medical care alone in children with mild or moderate chronic fatigue syndrome (also known as myalgic encephalomyelitis (CFS/ME)).

CFS or ME affects at least <u>one per cent of secondary school children in the UK</u> and is very disabling. Despite the number of young people affected by this debilitating condition there is limited evidence for how we should treat this condition in children. The National Institute for Health and Care Excellence (NICE) recommends three treatment approaches: cognitive behavioural therapy (CBT), graded exercise therapy (GET) or activity management, however, even with treatment, only about two thirds of children can be expected to recover at six months.

Around 250 children with CFS/ME use LP each year. The programme, developed from osteopathy, life coaching and neuro-linguistic programming, teaches techniques for using the brain to make changes to the body's level of health and cost £620 when the study was carried out. However, there have been no reported studies investigating its effectiveness, cost-effectiveness or possible side effects.

The randomized controlled <u>SMILE</u> (Specialist Medical Intervention and Lightning Evaluation) trial, led by researchers at the <u>Bristol Medical School – Population Health</u> <u>Sciences</u>, is the first study to investigate the effectiveness and cost-effectiveness of LP in addition to specialist medical care compared with specialist medical care alone.

The trial recruited 100 eligible participants aged 12-to 18-years with a diagnosis of mild or moderate CFS/ME. Patients were allocated at random to either specialist medical care, or specialist medical care plus LP and were asked to read information about LP, attend three group sessions and receive follow-up phone calls with an LP practitioner. All participants were asked to complete questionnaires at regular intervals on levels of physical function, fatigue, pain, anxiety and school attendance.

After carrying out statistical and cost analyses, the team report that participants in the group allocated with LP in addition to specialist medical care had improved physical function at six months which improved further at 12 months. Fatigue and anxiety were reduced at six and 12 months when depression was also reduced. School attendance had also improved at 12 months.

The study's findings indicate that LP offered in addition to specialist medical care is effective and probably cost effective for children and young people who have been diagnosed with mild/moderate CFS/ME.

Professor Esther Crawley, Professor of Child Health in the University's <u>Centre for Child and Adolescent Health</u> and Consultant Paediatrician at the <u>Royal United Hospital</u>, said: "I was surprised that the LP provided additional benefit to specialist medical care. This is an important study as it provides another treatment approach that some children may find helpful. Ultimately, our aim is to find the most effective treatments that can help improve the debilitating symptoms of CFS or ME in children.

"However, while these results are promising, further research is needed to establish which aspects of the LP are helpful and whether it is an effective treatment on its own and whether it could be used to help more severely affected patients. Many children and families in our service did not want to have LP and therefore, this approach is not for everybody so we must continue to investigate other treatment approaches."

Paper: 'Clinical and cost-effectiveness of the Lightning Process in addition to Specialist Medical Care for pediatric Chronic Fatigue Syndrome: randomized controlled trial' by Esther Crawley et al in *Archives of Disease in Childhood*.

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Notes to editors:

The **Science Media Centre briefing** will be held at **10.30 am** on **Wednesday 20 September** at the Wellcome Collection, 183 Euston Road, London, NW1 2BE (next door to the Wellcome Trust).

The <u>SMILE</u> (Specialist Medical Intervention and Lightning Evaluation) study was funded by <u>Linbury Trust</u> and the <u>Ashden Trust</u>. No member of the LP team had any involvement in the analyses or in the paper though provided advice and information in relation to costs.

About Chronic Fatigue Syndrome (CFS) and Myalgic Encephalomyelitis (ME), also known as Myalgic Encephalomyelopathy

CFS/ME is a debilitating disease which has a major impact on the lives of those affected, causing persistent exhaustion that doesn't go away with rest or sleep. Patients with CFS/ME have fatigue that lasts longer than four months (adults) and three months in children. There are different definitions but patients with CFS/ME have disabling fatigue and other symptoms. In children common symptoms in addition to fatigue, are unrefreshing sleep, problems with concentration, muscle aches and pains, headaches, nausea, dizziness, sore throats and so on. The symptoms fluctuate and the fatigue typically occurs after doing too much. In adults, this is typically delayed by a day or so.

Paediatric CFS/ME is important because it is relatively common and very disabling. Children miss, on average, a year of school. Most children accessing specialist services are only attending two days a week or less of school. Families suffer as mothers usually reduce or stop work and CFS/ME has a negative impact on siblings. Paediatric CFS/ME is important to society because children cannot access education, their mothers reduce work and children with CFS/ME use considerable health care use.

The National Institute for Health and Care Excellence (NICE) guidance stipulates that children with CFS/ME should be offered referral to specialist services immediately if their condition is severe, or within three months if they are moderately affected, and within six months if mildly so. However, only an estimated ten per cent of UK children have access to a local NHS specialist service, which means they cannot access treatment without travelling long distances.

The specialist Paediatric CFS/ME service at the Royal United Hospital is the largest paediatric CFS/ME clinical service in the UK, and also provides services nationally. The team currently provides assessment and treatment for over 400 children from across the UK and Western Europe each year. Approximately fifteen per cent of the children referred into the service are severely affected and rarely able to leave the house. The Specialist Service offers all treatment approaches currently recommended by NICE. This includes cognitive behavioural therapy (CBT), graded exercise therapy (GET) and activity management.

The Lightning Process® is an intervention that is used for a variety of conditions including CFS/ME and has been developed from osteopathy, coaching and neuro-linguistic programming. It is a three-day training programme run by registered practitioners and designed to teach individuals a new set of techniques for improving life and health, through consciously switching on health promoting neurological pathways.

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