Medical leaders sign joint statement in response to NICE guidance on ME/CFS

Details
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Medical leaders have signed a joint statement in response to the National Institute for Health and Care Excellence (NICE) guidance on the treatment and diagnosis of Myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS).

We are pleased that NICE have now published their guidance for the management of ME/CFS which is a chronic, poorly understood condition and can be highly disabling and distressing. It is important that all patients with this condition have free access to the specialist services and treatments available.

The published guideline contains some positive changes, but there are areas of concern and further clarification is needed. We remain concerned that the guideline does not fully address the important issue of the potential for treatments such as Cognitive Behavioural Therapy (CBT) and graded exercise therapy to alleviate symptoms.

As in many chronic conditions, people's mental and physical health are intrinsically linked. This guidance risks undermining the importance of these links by dismissing the potential of treatments such as CBT as of less value than pharmacological interventions.

There is considerable disquiet in the medical profession and some patient groups about the way the data and evidence have been assessed but the important thing now is that services are commissioned in a safe and effective way that does not disadvantage any patients being treated now or in the future.

We would like to see that:

Specialist rehabilitation medicine services and exercise medicine services regularly look after patients with ME/CFS (and also provide complex care and long-term support for very severe ME/CFS) but are not specifically recommended in the guidance. There are very few dedicated ME/CFS specialist services either in the community or hospital setting and thus if commissioners do not use specialist rehabilitation medicine services, these patients will lose out.

Commissioners must also take action to ensure training and support is available for the full range of specialist ME/CFS roles needed and are easily accessible for GPs and other clinicians across the NHS, so that this guidance can effectively be put into practice.

Many patients with ME/CFS have other conditions including chronic pain and fibromyalgia which are improved with exercise as recommended in other NICE guidance. It is important that a holistic approach is taken to ensure that other conditions do not deteriorate.

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