

Burstow replies to Parliamentary Questions

16 May 2012

Minister for social care Paul Burstow has replied to four written Parliamentary Questions tabled by Ian Swales MP, Vice Chair of the All Party Parliamentary Group on M.E. based the Action for M.E. report, *Ignorance, injustice and neglect*.

The [full report](#) and the [executive summary](#) are both available to download

Mr Swales' first three questions were: "To ask the Secretary of State for Health (Andrew Lansley):

- with reference to the report by Action for M.E., *Ignorance, injustice and neglect*, for what reason more than a quarter of patient care trusts in England do not commission specialist secondary care for myalgic encephalomyelitis/chronic fatigue syndrome;
- for what reason 37 out of 151 patient care trusts in England provide domiciliary care for people with myalgic encephalomyelitis/chronic fatigue syndrome;
- with reference to the recommendation by the National Institute for Health and Clinical Excellence that patient care trusts (PCTs) should provide a designated myalgic encephalomyelitis/chronic fatigue syndrome pathway, for what reason fewer than a third of PCTs in England provide such a pathway."

Paul Burstow replied to these three questions with one answer, saying: "In 2007, the National Institute for Health and Clinical Excellence (NICE) issued a clinical guideline on the management of chronic fatigue syndrome/myalgic encephalomyelitis (CFS/M.E.).

"The guideline recommends the use of cognitive behaviour therapy and graded exercise in patients mildly or moderately affected by CFS/M.E. on the basis that these were the interventions for which there was the clearest research evidence of benefit. A number of other treatments, including particular drugs, vitamin supplements and complementary therapies, were not recommended because there was not enough evidence to suggest that they were effective. The guideline acknowledges that there is no one form of treatment to suit every patient, and that treatment and care should take into account the personal needs and preferences of the patient.

"It is important to emphasise that NICE clinical guidelines are just that - guidelines for health care professionals - Government policy is for the National Health Service locally to set its own priorities in response to local need and local circumstances and commission services accordingly.

"Improving quality and delivering better health outcomes for patients is the primary purpose of the NHS. Accountability throughout the system needs to be focused on the outcomes of care, rather than the processes. This focus on outcomes will start at a national level with the 2012-13 NHS Outcomes Framework, which defines and will enable measurement of the key outcomes that matter to patients.

"All five domains within the NHS Outcomes Framework have relevance for people living with CFS/M.E. and other neurological conditions.

"Domain two - enhancing the quality of life for people with long-term conditions as a whole - is the most immediately relevant. This reflects the fact that increasing numbers of people have multiple long-term conditions, and it is not always helpful to see their care from the perspective of a single clinical pathway.

"Domain two seeks to capture how successfully the NHS is supporting people with long-term conditions to live as normal a life as possible and will be measured using three outcomes:

- (i) feeling supported to manage their condition - this measures how, well the NHS as a whole is doing in supporting people to look after themselves and handle the consequences of their conditions;
- (ii) functional ability - this measures how well the person is able to live as normal a life as possible, and by looking at employment ties in well with the Department for Work and Pensions and the Government's wider policies about getting people back to work;
- (iii) reduced time spent in hospital—this measures how successfully the NHS manages the condition(s) by looking at unnecessary hospital admissions and excessive length of stay.

"It will be the responsibility of the NHS Commissioning Board to determine how to deliver the outcomes in the NHS Outcomes Framework. The board will use the Outcomes Framework and NICE Quality Standards to develop a Commissioning Outcomes Framework and together these will be the basis for clinical commissioning groups to be held to account. The board will also support commissioning by developing detailed commissioning guidance and tools such as standard contracts and tariffs."

Ian Swales's fourth question was:

- "To ask the Secretary of State for Health with reference to the report by Action for ME, *Ignorance, Injustice and Neglect*, for what reason 53 out of 151 patient care trusts in England were able to provide full or partial information about their funding of services for people with myalgic encephalomyelitis/chronic fatigue syndrome."

Paul Burstow replied: "Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/M.E.) is a complex long-term neurological condition with a range of symptoms, with each sufferer experiencing their own personal combination. Physical and/or mental fatigue is the most well-known symptom, but others include pain, disturbed sleep, and gastrointestinal problems. Information about actual numbers of people with CFS/M.E. - and the funding spent on services locally - is difficult to obtain because of the problems with producing a precise definition of the illness.

"The World Health Organisation classes benign myalgic encephalomyelitis and post viral fatigue syndrome under the same classification G93.3 'diseases of the nervous system'—subheading 'other disorders of the brain'. The Chief Medical Officer's Independent Working Group on CFS/M.E., which reported in 2002, recognised that there were widely different views on how symptoms are described, defined and classified, and called for a consensus to be reached on terminology and definition. While awaiting this, the group recommended that the composite term CFS/M.E. should be used. While this will help with gathering information from the National Health

Service, there is still only partial information available and some local variations.

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