

Contribution of Sarah Found on behalf of the M.E Self Help (MESH) Nottingham Group to be submitted to the Nottingham City Health Scrutiny Panel for consideration at the meeting on 25th March 2015

Summary

For the purpose of simplicity, I will be referring to and Myalgic Encephalomyelitis and Chronic Fatigue Syndrome as the same illness (ME/CFS). There is a lot of medical conflict over whether they are exactly the same; however that is how the National Institute of Clinical Excellence (NICE) Guidelines currently define them, so using this is the best way forward.

M.E. Self Help Nottingham has had extensive contact with NHS services since June 2011, in an attempt to improve ME/CFS services in Nottingham City. Unfortunately MESH Nottingham are still currently (March 2015) no further with obtaining an integrated service for people with ME and have therefore asked Health Scrutiny to engage to try and get a service commissioned.

MESH Nottingham believes that an integrated service for ME/CFS should at least include the following:

- Clear information, guidance and advice to GPs in referral pathways for testing and diagnosis of ME/CFS.
- Re-training for all GPs in Nottingham City about the condition to ensure that they are all following the NICE Guidelines on ME/CFS. If it turns out after this that there are GPs still refusing to deal with the illness appropriately, sanctions should be applied.
- A community service for patients with severe ME/CFS which might include (depending on suitability for the patient) support through personal assistants provided via a personal budget.
- Individually tailored activity management programmes which might draw on CBT.
- Home visits from a GP when patients are too ill to attend their doctor's surgery or health centre.

Further points of concern raised by MESH are listed below and will be further explored within the Health Scrutiny Panel:

- Lack of clarity on what consultation has taken place with GPs on the options available to support people with severe ME/CFS and any outcomes from this.
- Concern that some GPs refuse to acknowledge ME/CFS as health conditions which need treatment/ support.

- Concern that some GPs don't make referrals to test for ME/CFS, which results in diagnoses not being made and, therefore, people are not able to access appropriate support.
- Concern about lack of service provision for people severely affected by ME/CFS.
- The need for clarity regarding the commissioning process for integrated community services for ME/CFS.
- The allocation of services on supply and demand basis.
- Collaborative working to develop appropriate services.