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| HEALTH SCRUTINY PANEL |
| 25 MARCH 2015 |
| ACCESS TO SERVICES FOR PEOPLE WITH ME (MYALGIC ENCEPHALOPATHY/ ENCEPHALOMYELITIS) |
| REPORT OF HEAD OF DEMOCRATIC SERVICES |

1. Purpose

- 1.1 To receive a briefing and a range of views on access to services for people with ME, to help identify whether further scrutiny is required

2. Action required

- 2.1 The Panel is asked to use the information provided to decide whether further scrutiny could add value and influence any of the issues raised.

3. Background information

- 3.1 The UK ME Association notes that there are a number of different names for what is an illness of uncertain cause affecting many thousands of people. The Association estimates that approximately 250,000 people in Britain are affected by this illness, which affects people at all ages. Severe and debilitating fatigue, painful muscles and joints, disordered sleep, gastric disturbances, poor memory and concentration are commonplace. In many cases, onset is linked to a viral infection. Other triggers may include an operation or an accident, although some people experience a slow, insidious onset. Diagnosis may include the following:

- Myalgic Encephalopathy or 'ME' (a term which The ME Association feels is more appropriate than the original, Myalgic Encephalomyelitis)
- Chronic Fatigue Syndrome or 'CFS'
- Post-Viral Fatigue Syndrome or 'PVFS'
- Chronic Fatigue Immune Dysfunction Syndrome or 'CFIDS'

- 3.2 According to the Association, effects range from minimal to lives which are changed drastically: in the young, schooling and higher education can be severely disrupted; in the working population, employment becomes impossible for many. For all, social life and family life become restricted and in some cases severely strained. People may be housebound or confined to bed for months or years.

- 3.3 'The Rough Guide to ME/ CFS' is attached at Appendix 1. This is based on the publication 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document', Bruce M.Carruthers, Marjorie I.van de Sande 2005.

- 3.4 In November 2014, the Disability Involvement Group approached the Chair of the Health Scrutiny Panel to see whether it could provide assistance to improve

access to services for people who have severe ME. The main concerns raised were:

- Lack of clarity on what consultation has taken place with GPs on the options available to support people with severe ME and any outcomes from this;
- Concern that some GPs refuse to acknowledge ME and other conditions such as Fibromyalgia and Chronic Fatigue Syndrome as health conditions which need treatment/ support; (what guidance is provided if any?);
- Concern that some GPs don't make referrals to test for ME or other conditions such as Fibromyalgia and Chronic Fatigue Syndrome, 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; and
- The need for clarity regarding the commissioning process for integrated community services for ME and other conditions such as Fibromyalgia and Chronic Fatigue Syndrome.

3.5 The Panel has invited representatives of Nottingham City Clinical Commissioning Group (CCG), MESH (the ME Self Help Group), HWB3 (the Third Sector Health and Wellbeing forum) and Healthwatch to attend today's meeting to provide a range of information and views. This should enable members of the Panel to decide whether any further scrutiny is necessary.

4. List of attached information

4.1 The following information can be found in the appendices to this report:

Appendix 1 – Nottingham City Clinical Commissioning Group - ME/CFS Report, March 2015

Appendix 2 – Sarah Found M.E. Self Help Nottingham Report, March 2015

Appendix 3 – 'The Rough Guide to ME/ CFS', based on the publication 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document', Bruce M.Carruthers, Marjorie I.van de Sande 2005.

5. Background papers, other than published works or those disclosing exempt or confidential information

None

6. Published documents referred to in compiling this report

'The Rough Guide to ME/ CFS', based on the publication 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Clinical Case Definition and Guidelines for Medical Practitioners. An Overview of the Canadian Consensus Document', Bruce M.Carruthers, Marjorie I.van de Sande 2005.

<http://www.meassociation.org.uk/about/what-is-mecfs/>

7. **Wards affected**

All

8. **Contact information**

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