Formal Statement

In March 2008, Barbara Robinson of Suffolk Youth and Parent Support Group, following contact with patients from across Suffolk and Norfolk approached the Suffolk Health Overview & Scrutiny Committee with request that concerns about the Norfolk and Suffolk ME/CFS Services formed part of the HOSC forward programme for the year.

Quoted from the paper to HSOC;

Norfolk and Suffolk Patient Representatives
Concerns regarding ME/CFS Service (Local Multi Disciplinary Team)
Hosted by Gt. Yarmouth and Waveney PCT, Formerly Waveney PCT.

Request for Scrutiny and Overview Support

Background

We, Norfolk and Suffolk, Gt.Yarmouth and Waveney Patient Representatives have long standing unresolved issues, prior to October 2006 with Waveney, and now carried over to Gt.Yarmouth and Waveney PCT which was set up in October 2006.

Since April 2005 Patient Groups have worked tirelessly to assist the service staff and the PCT to resolve difficulties. ME/CFS Service staff and Suffolk and Norfolk Commissioners have been extremely supportive to the Patient Groups. Despite the these best efforts the following problems remained. .................

Current Concerns
In more detail:

1. Failure to advise Scrutiny and Overview of variance to Service Provision detailed in the March 2005 Service Model and to funding deficits and difficulties.
2. Failure involve Patient Participation in these changes (March 2005 - to PEC Committee)
3. Inadequate on going management of ME/CFS LMTD and feedback to patients, service staff and to the Department of Health Service Development Team
4. Failure to address clinics difficulties, to address long term concerns highlighted by 'both patients, clinical staff and others, including senior officials at the Department of Health
5. Inadequate communication has led to confusion for referring GPs, service staff and patient distress and potential for patient harm.
6. Quality standards specified within the National Service Framework (For Long Term Conditions) 2004 as applied to ME/CFS have not, in our view, been met.
7. Service development and expansion agreed by Waveney PCT following the successful bid to the Department of Health, 2004-2006 Service Development programme have not been supported and actioned.
8. Failure to act appropriately to advised risks to the service, especially financial risks. This resulted in the service being suspended for a number of months during 2007.
9. PCT management's failure to manage the service competently resulted in the loss of key

1 letter of concern* to CE Mike Stonard and Chair Bernard Williamson in March 2007

10. Inadequate oversight and ongoing commitment to the legally required Partnership Board model of patient Involvement, job descriptions, CRB checks, confidentiality clauses and Patient Representatives job descriptions appointments.

With regard to:


Great Yarmouth and Waveney Joint Health Scrutiny Committee

16 January 2009

Item no. 6

Norfolk and Suffolk CFS/ME Services

Suggested approach from Keith Cogdell, Scrutiny Support Manager

- Patients and carers do not wish people to assume the documents above are an acceptable way forward to patients or reflect the patient view. They DO NOT!
- Just to say patients strenuously objected to the Norfolk OSC Proposed Way Forward, especially the “Background” comments but were prevented from objecting due to OSC rules for timing of submission of information to the committee.
- To enable patients to move the issues forward, we had been awaiting information from the PCT (since October 17th 2008), LINKs also made request under Freedom of Information. The PCT failed to supply the information on time, possibly in breach of the 2001 Health and Social Care Act.
- Our local set up, OSC/HOSC remit is changed annually, under constant review and is very complicated.
- This process I have to say has been going on for 3 years and is not finished yet!
- We now have the active support and guidance of Norfolk LINKs who have been extremely helpful and efficient.

24/01/09

Barbara Robinson