

## Worcestershire ME Support Group

### Review of Current NHS Services for People with ME/CFS in Worcestershire

#### Worcestershire ME Support Group's Report following Project Group Meeting, 15 April, 2016

#### Worcestershire CFS/ME Local Multi-Disciplinary Team (LMDT)

Anita Roberts took the meeting, and said she wanted to talk about the CFS pathway, to see if anything could be changed to benefit patients and the service providers.

At the meeting -

Anita Roberts (Commissioning and Contracts Manager, NHS Redditch & Bromsgrove CCG); Melanie Roberts (Community Care Service Delivery Unit Lead - South, Worcestershire Health & Care NHS Trust); Dr Mirella Ling (Consultant Physician Infectious Diseases, CFS/ME Consultant, Worcestershire Acute Hospitals NHS Trust); Marina Townend (Specialist OT Team Lead, CFS/ME LMDT, Worcestershire Health & Care NHS Trust); Dr Helen Ayres (Psychology, CFS/ME LMDT- Worcestershire Health & Care NHS Trust); Sue Fairhurst and Alex Granville (CFS/ME patients), Ian Logan (Chair, Worcestershire ME Support Group) and Jill Pigott (member of Worcestershire ME Support Group).

Apologies were received from -

Jo Kenyon (Deputy Director of Operations - Medicine/Director Manager - Specialty Medicine, Worcestershire Acute Hospitals NHS Trust); Simon Gartland (Deputy Director of Commissioning, NHS Redditch & Bromsgrove CCG); Gill Mobbs (Head of Integrated Community Services, Community Care South Worcestershire, Worcestershire Health & Care NHS Trust); Carolyn Carver (member of Worcestershire ME Support Group).

Our **Group's input** for this meeting was circulated to people involved in the Project Group, prior to the meeting. Plus our '**Summary of Key Points**' was handed out at the meeting, and circulated afterwards particularly for those who were unable to attend.

Dr Mirella Ling brought information on numbers of patients seen at the ME/CFS Clinic at Kidderminster Hospital, by herself and Dr Mark Roberts, during the last few years.

ME/CFS Clinic at Kidderminster Hospital - 5 patients a week, increased recently to six a week

	Financial Year				Grand Total
	2012/13	2013/14	2014/15	2015/16	
Worcestershire	192	180	170	182	724
Herefordshire	2	3	17	20	42
Other (outside Worcestershire and excluding Herefordshire)	16	23	26	33	98
Grand Total	210	206	213	235	864

Dr Ling said she doesn't do home visits, and understands Dr Roberts doesn't either. We emphasised that people with severe ME are unable to attend the ME/CFS Clinic, or the CFS/ME LMDT sessions. People of all levels of severity and complexity need advice and care.

Extract from our group's "Summary of Key Points" - "The All Party Parliamentary Group (APPG) on M.E. is currently leading an inquiry into the lack of social care provision for people with M.E. Action for M.E.'s recent Close to collapse report, indicates that 97% of people with M.E. are eligible for a social care package under criteria set out in the Care Act, yet only 6% receive one."

Extract from our group's input for the meeting - "hope it's outreach can be extended for those with long term severe ME - the current pathway doesn't seem appropriate for this group"

## Worcestershire ME Support Group

Dr Ling talked about the weekly ME/CFS clinic, the type of patients - saying it isn't for FMS, and if a patient has mainly FMS, or needs pain management, she can refer them to the correct department, and/or a pain clinic, rather than the GP having to make another referral. Dr Ling mentioned that from the six seen weekly, two to three have a confirmed CFS/ME diagnosis, and if these people live in Worcestershire, they are referred to the LMDT - they are rarely followed up by the ME/CFS Clinic. She added that with most of the CFS/ME patients she sees, they initially had a viral event.

Prior to the meeting, with the agenda we received a **CFS Pathway dated 2014**, and at the meeting an **updated CFS Pathway** was discussed - but there were only a few copies and we didn't see this at the meeting. A copy of the updated pathway discussed at the meeting, was received after the meeting, on 20 April. The discussion was about CFS. We pointed out that there are ME/CFS Specialist Services throughout the country, whereas today's agenda, and the pathway we received is about CFS. Further discussions referred to CFS/ME.

It was suggested that it would help if GPs had an electronic proforma to complete when they refer patients to the CFS/ME Clinic, giving them CFS/ME information - currently GPs write a referral letter. It was felt this would help with the diagnosis process, and improve GPs' knowledge of ME/CFS.

Dr Helen Ayres said the waiting times were huge when she first joined the service. We weren't given any figures - so we do not know the number of people who have used the service during the last few years.

Marina Townend and Helen Ayres explained the pathway, and all aspects were discussed. -

After diagnosis, patients and a family member / carer are invited to an Information Session. Information Sessions are held in Pershore and Bromsgrove, alternate months, lasting 2 hours.

Following this, patients are invited to a 1:1 session, before the Lifestyle Management Group sessions or further 1:1 sessions. The Lifestyle Management group sessions are now held in various locations throughout the county.

Lifestyle Management Group sessions are held weekly. We pointed out that this is sometimes too frequent for some people, and the meetings are too long. We were told that having them weekly helps to keep the momentum going, and they have had very few people not attend the sessions.

The length of the Lifestyle Management Group sessions was discussed, and it was suggested that there could possibly be two 1½ hour Information Sessions in the future instead of the current one 2 hour session, and the Lifestyle Management Group sessions could possibly then be shorter.

Discussions took place about having more information for patients available online, with a possibility of videos, but there wasn't any mention of how people without internet access would cope.

Patients are still being discharged back to their GP - without the GP knowing how to help, and the patient often not receiving further management.

Recovery after Management monthly sessions are now held at Worcester University - it was said it is only for people who have been through the current service, as the service has changed so not suitable for other people. Numbers of people at these sessions vary between 2 and 10.

Discussion took place concerning transition of children to the adult service. Further information will be sought on the current arrangement.

It was agreed to have another meeting in six months.

Ian Logan and Jill Pigott  
Worcestershire ME Support Group