

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

Worcestershire ME Support Group's input - Project Group Meeting, 15 April, 2016

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

We attended the 'Review of Neurology Services in Worcestershire' meeting, held in September last year. Our discussions are recorded in the 'Big Conversation' with the Top Priorities on page 7, and the ME/CFS Pathway on page 23. We are two members of the Worcestershire ME Support Group, (a person with ME, and a carer of a person with ME), and the pathway illustrated at the meeting is as we understand it. A report following this meeting was placed on the Worcestershire ME Support Group's website - <http://worcsmegroup.weebly.com/blog/nhs-services-for-neurological-conditions-excluding-mecfs-report-from-meeting>

There have been changes to the Worcestershire ME Support Group since the Review meeting. On the CFS/ME pathway, it states that the support group holds meetings in five locations in Worcester. At the time of the meeting it was five locations in Worcestershire, but has since reduced to 3 locations in Worcestershire (Worcester, Droitwich and Malvern). Also, 'Discharged from the service' on the pathway, should be after the 'follow up 1 year later'.

The accepted bid, with our group's letter of support, for a Herefordshire and Worcestershire CFS/ME Local Multi-Disciplinary Team (LMDT) can be seen on our group website - <http://worcsmegroup.weebly.com/blog/archives/06-2004> Also, available on our website, are extracts from newsletters plus Group Reports following Herefordshire & Worcestershire CFS/ME Multi-Disciplinary Team (LMDT) meetings, in Oct 2010, and Jan 2012. For ease of reference we have attached the salient points from the 2010 and 2012 meetings at **Appendix (01)**

At the time of the last H&W CFS/ME Steering Group meeting in January 2012, the Worcestershire CFS/ME Service comprised of:

- Sue Gordon-Saner - Occupational Therapist / Co-ordinator (part time - 15 hours pw)
- Sue Jones - Physiotherapist (part time - 15 hours pw)
- Dr Helen Ayres - Psychologist (part time - 7½ hours pw)
- Sara Morris - Occupational Therapist (part time - 8 hours pw)
- Debbie Masson - Occupational Therapist (part time - 10 hours pw).

We realise that there have been many changes in the last four years, including the closure of the Herefordshire CFS/ME Service. In January 2012 we heard that "the service is very under resourced but it is receiving more referrals - the Worcestershire CFS/ME Service referrals were 140 during 2011, compared with 81 during 2010." We realise the pathway has changed since 2012, with people being invited to an Information Session, and then some not going any further, and others then attending group therapy or one-to-one sessions.

- How many people have been seen by the CFS/ME Clinic during 2012, 2013, 2014 and 2015?
How many of these people were diagnosed with ME/CFS?
- How many referrals have there been from the Herefordshire area?
- How many people have been referred to the CFS/ME LMDT by the CFS/ME Clinic during 2012, 2013, 2014 and 2015?
How many of these people attended the Information Session?
How many then continued with the group therapy or one-to-one sessions?
- How many people are on the current waiting list for the ME/CFS Clinic, and the LMDT's Information Sessions?

**All Party Parliamentary Group on ME (APPG on ME)
Inquiry into NHS Service Provision for ME/CFS (March 2010)**

The Report's first recommendation: -

http://worcsmegroup.weebly.com/uploads/2/9/2/4/2924979/appginquiry2009-100310-appg_report_final.pdf

The Department of Health should undertake research to determine accurately the numbers of patients with ME/CFS.

- Are records kept locally, by GPs and at the CFS/ME Clinic?
Do the three Worcestershire Clinical Commissioning Groups know how many people in Worcestershire have a diagnosis of ME/CFS?

Our Group submitted a response to the APPG on ME's Inquiry in June 2009, and we were invited to attend the Oral Hearing. Also, the NHS Worcestershire CFS/ME Service (part of the Herefordshire & Worcestershire CFS/ME Local Multi-Disciplinary Team (LMDT) responded to the Inquiry.

Three out of the report's 11 recommendations relate to training - for GPs, medical students, and all healthcare professionals i.e. dieticians, nurses, occupational therapists, physiotherapists and psychologists.

The Final important APPG Recommendation concerning Severe ME:

Specialist referral services must ensure that high priority is given to the needs of the severely affected, especially in relation to domiciliary services and in-patient facilities for assessment and management.

The Development of another NHS ME and CFS Service

Norfolk and Suffolk ME and CFS Service Development

A website that has been set up by Patients and Carers containing news on the development of ME and CFS Services in Norfolk and Suffolk.

<http://nandsme.blogspot.co.uk/p/homepage.html>

Topics include, "The Current ME and CFS Service" and "What we want"

For ease of reference we are attaching an extract from their home page at **Appendix (02)**. We would particularly draw your attention to the "What we want" list, as many of those bullet points are relevant for this Worcestershire review.

Current Information

Also, **Appendix (03)** - recent messages received by the Worcestershire ME Support Group.

Worcestershire CCGs' "The Big Conversation"

Finally, **Appendix (04)** gives extracts from the The Big Conversation - a review of Neurology Services in Worcestershire.

Page 7 ME / CFS Top priorities

Page 23 ME / CFS pathway

Caroline Carver & Jill Pigott
Members of Worcestershire ME Support Group

Herefordshire & Worcestershire CFS/ME Local Multi-Disciplinary Team (LMDT) meeting (Oct 2010)

KEY POINTS

- Dr Ling pointed out that the NICE Guideline stated to offer referral within 3 to 4 months of onset and we needed to follow this guideline. Sue Gordon-Saner added that it became very important to be able to help prior to the six month stage, particularly when patient's employers were involved as a consultant's diagnosis means this can help regarding disability discrimination.
- once the pathway and referral are agreed upon they could be made available to the two counties' Gps.
- The proposed pathway suggests that once patients have received management treatment from the LMDT they are referred back to their GP for "Ongoing Support". It was pointed out that a large number of GPs are not able to give support to people with ME/CFS, prior or after diagnosis, as they do not know how to treat people with ME/CFS's symptoms.

Remarks from members on their forms, included on our handout circulated at the meeting:

- Too ill to receive treatment from the LMDT
- Has been stable for many years, but reduced energy makes careful pacing essential. Recent recurrence of ME symptoms worrying. I must emphasise that my ME never went away, but I adjusted my lifestyle to the capabilities it left me. I was unable to get back to work and have never received any treatment. I was just told to rest.
- I could not get treatment as was told I'm not in catchment area
- As I do not live in Worcestershire I do not qualify for the LMDT sessions
- My condition worsened because I tried to work as well, and it was too much, and I had a very severe relapse Jan/Feb 2010 so back to square 1. Trying to put what I learnt into practice but not easy.

- No real interest or help from NHS except for treatment of intercurrent problems. Significant improvement not achieved until I consulted Dr Barry Durrant-Peatfield * who diagnosed problems with my adrenal glands. I was advised to take Bovine glandular supplements which produced a marked improvement within six months and continuing slow improvement over 3 years. I can now cope with daylight all day whereas before I stayed in a curtained room except at meal times. My biggest problem remains my legs which pack up after 40-50 paces which can be done twice per day.
- Found group therapy meeting too long. Not well enough to attend all sessions, so did not see the Dietician.
- GP sympathetic but no help whatsoever from medical profession. Live alone, work part time, no social life as no energy left.
- Every day living should not be this hard
- My illness fluctuates. This year has been better, but only a little. Previous years worse. Always relapses especially triggered by virus or emotional trauma.
- My GP has been a rock in sorting me out. It was a long process but he was spot on and still is. My wife works at KGH and wanted a second opinion. I saw Dr Roberts, 20 mins £150 later "your doctor is spot on with all his analysis".
- Xxxx's progress with the LMDT team has been slow yet favourable and she has certainly benefited from the teams efforts. Her experience with her GP has not been so good. Whilst acknowledging the condition his input has been negligible and having a sympathetic demeanour, he has stepped out of the picture and left it to the team.

Worcestershire ME Support Group

- I don't see how a GP can give ongoing support as provided by LMDT even if a patient has improved - those services do not exist within the GP practice - it's too specialized, that's why we get referred in the first place ! Also I feel that referring a patient back to the GP undermines the recovery programme - I think its a step backwards.
- To give ongoing support, GP needs directions from LMDT as to how to progress. My GP knows my symptoms, but does not know how to treat them, just feels that the LMDT has the answers. LMDT cannot know how well their services benefit patients in the long term because patients are not asked. Could LMDT be changed to a name that is understandable to the patients.
- As you know xxxx is bedbound. She receives no help from LMDT whatsoever and we understand they don't do home visits. This means they do not cover the very severely affected. An unacceptable response from the unit. xxxx is drug intolerant. They have proved damaging to her health when tried.

The specialist Dr Roberts only visited privately (that is he had to be paid and this by the very severely affected). He was useless as he took the psychosocial paradigm and if there is a new one I hope he or she is not guided by NICE guidelines which presume the psychological model for treatment. What do LMDT do for the severely affected and bedbound or housebound? These are the patients in most need of help and are the most neglected by the NHS.

- The APPG on ME Group Inquiry Report stated - "it is vital that further biomedical research is undertaken to help discover a cause and more effective forms of management for this disease". This recommendation also mentioned the XMRV research. With our LMDT being based in the Worcestershire PCT's Infectious Diseases Department, we feel we are in a prime position for research to be undertaken here, leading to treatment. What plans are there for the Worcestershire PCT to become involved in the current research? Many pwme have sent off blood tests for XMRV - when will this be able to happen locally?

Herefordshire & Worcestershire CFS/ME Local Multi-Disciplinary Team (LMDT) meeting (Jan 2012)

KEY POINTS

- Sue Gordon-Saner reported that many of their patients develop fibromyalgia alongside CFS/ME, and they do not have the resources to give as much time as is needed, for this condition.
- She said that they "have experience of pain management, but there are discrete needs for chronic pain, and we have not got the resources to give it enough attention as needed.
- She added, that there seems to be some resistance within the GPs to refer to two specialist services.

Our members: Group membership questionnaire (Sept 2010 - August 2011)

- We had 80 members in our group last year, and a total of 59 members completed the second page of the group's membership questionnaire with questions about their medical treatment. Of these 69.5% were female. The average length with ME/CFS is 15 years. 16.7% were under 18 at onset.

The average age of onset is 38.7. The average current age is 53.

- Of the 44 who recorded information about the consultant who diagnosed them, 38.6% were diagnosed by either Mr Miller or Dr Roberts. 53.1% of 49 were referred to Sue Gordon-Saner - 83% (where known) by Mr Miller or Dr Roberts.
- For referrals to the LMDT (between 47-52 responses) referrals to group therapy was 23.5%, to OT 1:1 was 34.6%, to Physio 1:1 was 22.4%, and Psychologist 1:1 was 2.1% (one person).
- Following the LMDT management treatment (between 20-22 responses), Straight afterwards 30% improved, and 10% worsened. Since the treatment 27.3% improved, and 22.7% worsened.
- For all members 30% have improved over the years and 26.5% worsened (49 responses).
- 58.2% do not see their GP on a regular basis (55 responses)

Remarks from members (received during the few days by email/phone, prior to the meeting)

- My GP referred me to Dr Ling in March 2011 when I needed support for my ESA appeal. I was diagnosed by Dr Miller in 2001, and I had a thorough consultation with Dr Ling last year who arranged blood tests, and gave me a supporting letter. My GP also gave me a very supportive letter - she had been helpful with work related support, but should I have any questions about ME/CFS treatments all GPs within our practice just tell me I would need to contact the LMDT.
- I have seen Sue Gordon-Saner and attended Group Therapy sessions, plus am now seeing Sue Jones. I am very grateful to Sue Gordon-Saner for her support with occupational health at work. I found the group therapy useful for being in touch with other people in the same situation. Unfortunately I am now discharged from the LMDT, although I have been told I can phone if I need help.
- My GP was also supportive with work related issues, but is not able to help with any ME/CFS treatment questions.
- I was referred recently to the CFS clinic in Kidderminster with Dr Mark Roberts by my GP Dr Henry (Abbey Medical Practice, Evesham) and received an appointment for the 31st Jan. Then I received a letter stating that my appointment was cancelled as it was "not appropriate" for me to attend the clinic! My GP is investigating what is going on, but I have to admit I was stunned - after all, if you have CFS/ME then you should be registered with the clinic surely? Even if they can't do much for you.
- My daughter and I recently had a consultation with Dr Ling, via referral by our GP at our request. This was not initial diagnosis of course - simply to gain information in connection with another health problem. The waiting time was 2-3 weeks as I remember and we found this quite quick and helpful.
- I have been very lucky in that I have regular appointments with Sue Gordon-Saner every 2-3 months. Talking things over helps me gain a better understanding of my condition, but putting into practice some of her advice I find very difficult.

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Sue referred me to Sue Jones for physio and I saw her twice this year. The exercises she gave me are useful, but the Bowen therapy session was less so. I decided to try acupuncture, so we have agreed that I try that first and go back to her if/when I feel this is not helping sufficiently.

- Sue Gordon-Saner referred me to Helen Ayres. I saw Helen 12 times between November 2010 and August 2011. I found Dr Ayres to be an approachable person, but I found the sessions in sum to be the most opposite possible of helpful. I feel they eroded my self-confidence and self-esteem and therefore I could not recommend my personal experience to anyone else. I have immense respect for Sue Gordon-Saner and Sue Jones, who show dedication beyond the call of duty. We need more of them, more like them, more trained by them, and more hours of them.
- When the M.E. suddenly became much worse in May 2010 I consulted Dr Myhill as a postal patient. Now 18 months later after following her advice re supplements, change of diet, the regular use of an infra red sleeping bag as well as having mercury fillings removed and chelation therapy to rid the body of mercury nestling in various organs I am so much better!! I did not have any help from my GP - he was sympathetic... "Our practice cannot go along with the theories of this woman who has had disciplinary measures taken against her by the GMC".
- At the time I was willing to try anything; I only agreed to see Dr Roberts as I was hoping he would recommend a prescription for magnesium and Vit B12 to be given by injection which at the time Dr Myhill was unable to do. The consult was a total waste of my time and what very little energy I had. He completely dismissed Dr Myhill's recommendations and referred me to the dangers of putting my trust in her. He mentioned Dr Shipley!!!! He didn't have a clue "you would benefit from doing a little bit extra every day" !!! He did offer me the services of the team. I was so angry I refused. The initial results of the mitochondrial function test in June 2010 had confirmed I had an extremely low score; quoting from Dr Myhill's letter to aid my application for DLA..."therefore by these tests she has an extremely marked disability which equates to 20/100 on the disability scale.

The Development of another NHS ME and CFS Service

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Topics include -

- The Current ME and CFS Service
- What we want

The Current ME and CFS Service

ME and CFS are classified by the World Health Organisation (ICD10 G93.3) and the UK Department of Health as a neurological illness.

There is agreement between Patient/Carer LINK members, the NHS and Norfolk LINK that the current 'Therapy Led' service is inadequate, although we appreciate that service staff are doing their best in difficult circumstances. The level of service falls below that which is offered to people with other long term conditions, for example Multiple Sclerosis, and does not does not comply with all of the Quality Requirements in the National Service Framework for Long Term Neurological Conditions

What we want

Patients and Carers have told us via our 2009 Patient Survey and local support groups that the Norfolk and Suffolk ME and CFS Service should:

- be led by a biomedical consultant
- use the Canadian Clinical Case Definition for diagnosis
- care for people of all ages and all levels of severity and complexity
- include physical testing and scans
- provide ongoing care and regular reviews
- offer advice on pacing, rest, activity management and nutrition
- provide care closer to home
- prescribe and monitor medications
- carry out a full functional assessment taking into account light, sound, chemicals, aids and equipment
- provide details of symptoms & functioning to assist people in dealing with educational authorities, employers, social services and benefit claims
- provide support and information for carers
- identify and ensure appropriate referrals for co-morbid conditions and symptom control
- provide training for Healthcare Professionals, especially GP's

Messages received by the Worcestershire ME Support Group during **Spring 2016**.

Friday 1 April. - I planned to go to the RAM session on the afternoon of Wednesday 30 March, as it is more convenient for me during school holidays. I phoned the CFS/ME Service contact number just before Easter to confirm that I would be there, but I haven't heard back. Late on the morning of the 30th, I had an email from the Worcestershire ME Support Group letting people know that the CFS/ME Service website had been updated - including this year's RAM dates. I checked, and found that afternoon's session had been cancelled.

It's good to hear about the proposed CCG project and hope its potential will be fulfilled, especially for new patients. Also hope it's outreach can be extended for those with long term severe ME - the current pathway doesn't seem appropriate for this group.

Diagnosed in June 2013 by Dr Roberts at his clinic in Kidderminster - no follow-up whatsoever. I had no idea as to what to expect following diagnosis and whether I would receive any follow-up at all. Advised by Dr Roberts not to contest my dismissal from my job due to poor health - I was dismissed from my job in July 2013. Applied for benefit - this was turned down and I did not and have not contested this since this time. I have attended my GP on a few occasions since this time, but not specifically for help with my CFS. I asked my GP about registering as having a disability, but apparently this has now changed and GPs do not do this any more.

I had been investigated for fatigue and muscle weakness on a number of occasions prior to this diagnosis over many years before, but with no definitive diagnosis. The final straw was an inner ear infection in September 2012 which floored me, with constant migraines, nausea, dizziness and severe jaw pain - hardly able to talk, eating sloppy diet as jaw movement very restricted due to the pain. I was barely able to get up from a couch where I spent the next six months. Luckily I did start to improve after about 12 months, but recently my physical health has started to deteriorate again: energy levels - poor already and deteriorating, pain in arms, shoulders, back, hips increasing, bladder and bowel symptoms worsening. Sleep - very poor, disturbed and recurrent nightmares.

Marina Townend has recently asked if I would like to be referred to the service and I have said yes. Not sure yet whether I need to be re-referred from my GP, I will wait to hear from her.

I was seen about eighteen months ago by a psychology assistant as the occupational therapists had left the service. I waited over a year to see Dr Helen Ayres who suggested I attend her psychology group - whilst I feel I benefited well from occupational therapy sessions with Sue Gordon-Sane and Sue Jones, I do not feel this new approach to ME/CFS of psychology is of benefit to M.E. There seems to be no service to manage my fatigue, so I just see my GP now.

Access to dietician was nigh on impossible.

I think sessions are only held at Pershore and Bromsgrove. Wider coverage of the area would be an improvement, otherwise many of us need a carer to take us to the sessions.

My son is desperate for a drug to deal with his brain fog, and I too find that this is the symptom which distresses me most. We have both been looking at Modafinil (only licensed for narcolepsy!) but there are few studies and they are not encouraging. Apparently students and academics manage to buy it online and take it, but they are healthy to start with and effects on them would therefore be different.

I attended CFS/ME group therapy sessions during 2007/8, and was also referred to a dietician and a physiotherapist.

I was diagnosed with ME by Dr Roberts at the Kidderminster Hospital in 2008. This was following a significant and prolonged period of ill health which began in 2006 when I was diagnosed with an Under-active Thyroid, and also Viral Hepatitis. Once the decision was made to refer me to the ME Service it took only a few months to see Dr Roberts and to be given a formal diagnosis of ME, however it took 18 months for the referral to be made by my GP.

On reflection I am aware that my first episode of ME type symptoms manifested in 1989. This was following repeated general anaesthetics (5 in total) across an 18 month period of time. ME was mentioned at this time but no diagnosis was given (same GP). I also had a prolonged period of ME type symptoms in 2000 (lasting over 12 months). On this occasion again no formal diagnosis was given - I was treated with anti-depressants.

In 2008 following formal diagnosis I attended the ME clinic group. It took about 2 months for me to be able to start attending the group. After the group ended I was informed that there would be no formal follow up support (due to the service being 'snowed under') however a voluntary group met in Pershore. I live in Evesham and was struggling with my ME and returning to work at the time. It was impossible for me to attend this group. In 2009 due to chronic pain in my feet and hands my GP diagnosed Fibromyalgia. In 2010 I was dismissed from my employment on grounds of 'Ill Health' following 4 attempts to return to work. The response in 2010 from my GP in 2010 was treatment with anti-depressants.

After 18 months I recovered to a certain level and returned to work part-time in 2012. In 2013 I attempted a return to fulltime work (please bear in mind I live alone and my work is my only income), I suffered relapse symptoms within 2 weeks and so returned to part-time work again. I did however suffer a gradual decline and in 2014 had to stop working again. I suffered a full relapse at that time and for a significant period of time was bed-bound most of the day, although I had no choice but to care for myself since I live alone and need to shop, cook etc. I received no support from my GP despite asking to be referred back to the ME service. My GP informed me that they would do no more that re-diagnose my condition.

I changed GP in 2014 due to feeling unsupported. Due to the pain I had continued to experience my new GP sent me for x rays and I was diagnosed with Osteoarthritis . My new GP also referred me for a Mental Health Assessment. Having now been assessed I can quite clearly state that I do not have any diagnosis of a clinical mental health problem. I do suffer from depression on occasions due to my circumstances. I have just started attending counselling sessions the focus of these sessions is to be family issues (my family do not believe ME exists) and my acceptance of my ME. I am also engaged in a Mindfulness course which I myself gained access to.

I have received no support from ME services since the group meetings in 2008 despite suffering chronic episodes across the past 8 years.

I hope this information is of some assistance with your endeavour to provide better ME services, I do not feel the service is adequate in particular for long-term ME sufferers. I also feel quite strongly that the people who have treated me and prescribed medications for my health issues over the last 8 years have had very little knowledge of my health condition. I find that extremely frightening.

I attended group therapy sessions in 2006/2007, having previously seen Sue Gordon-Saner one-to-one. Then in 2012 had an appointment with Sue Jones, Physiotherapist.

In October 2013 my GP referred me to a CFS/ME OT for re-assessment. I was told I had to go to a CFS/ME Information Session first. I waited, and attended this in March 2014.

Eventually in January 2015 had a re-assessment appointment - with a locum psychologist.

As from Dec 2015, now seeing Dr Helen Ayres. Psychologist. She said that OTs now run the information sessions, group therapy sessions, and groups held for people who have completed recent group therapy sessions.

The real problem is lack of any personal, 1-1 care, advice, therapy etc.

In 2012 I went on one of the group therapy sessions. I don't know if you are familiar with the course content, but meetings are a fortnight apart and at each meeting we are given information about different strategies which can help us improve and we are given homework. The meetings covered: symptoms; Sleep; Pacing; Exercise; Thoughts, feelings and emotions; Memory and concentration.

The first three made sense and I could equate with them and work I to putting them into practice. I could see how they can help me fit in what I need and what I want to fit i to my life.

Then came "exercise" which I now realise is GET (graded exercise therapy). I had heard a lot about this, but not really known what it was or what it involved and why. The more I heard, the less sense it made. I understand about deconditioning, but if simply increasing exercise was the key which would ultimately lead us to recovery, why had I suddenly become so ill I could not take any kind of exercise for very long, having been so active all my life?

We were told to set goals. I jokingly said I would love to be able to do Scottish Country Dancing again, but that is way off. The response was that I should start working towards that goal by walking within limits, increase by 10%, when I was able to etc. No-one was able to tell me how I could fit this around other activities I needed/wanted to do, e.g shopping/gardening; no-one was able to tell me whether doing these instead some days was as good, i.e. equivalent activity, etc.

I was asked "do you mean that if you do some walking you wouldn't do other things?". Well, basically, yes, because I have to pace myself - as I was told to do at the previous meeting and which is benefitting me and which enables me to fit in more etc. The more I can fit in, the better I feel mentally and ultimately physically etc... Besides, I had been walking upstairs regularly each day, for example, but was still struggling to do this, so if exercise was the answer, why had I not got stronger with stairs? (Trouble is I'm too logical!!)

Unfortunately I missed the one on thinking etc., but now realise this was basically CBT. Again, I can fully understand how thoughts can affect health, and attitude is important, but, again, if it is that simple, why do I never know how I am going to feel each day. Some days when I suspect I have overdone it the previous day, I am fine, some days when I expect to be fine, I'm not. And sometimes I can feel almost normal for days at a time, feel really positive, do almost normal things, only to get low again eventually.

The other thing that has been lacking from this course, is consideration of feedback. We have been given homework to do, mostly putting into practice what we have been taught the week before, but instead of giving feedback and then building on that at the next meeting, we have just moved on to the next subject, making the course very disjointed and leaving it very difficult to see how everything fits together. For example, we were told one week to fill in diaries, but no-one ever looked at them to see what we were doing, where we should go next, etc.

These sessions have put into context all the controversy about CBT and GET. I had come across the former before and was unimpressed, but at that time I thought I was suffering from stress and was only diagnosed with CFS later. To put it in a nutshell, these therapies just do not make sense.

So from that point of view, this course has been very enlightening, but the actual value and usefulness is limited. We were due to meet again in three months time, but I wasn't given the date for this one. This was to discuss our progress towards our targets. I have not the faintest idea of what is a realistic target for me, because. No-one has really looked at what I am currently doing.

Just read through the article in the Worcester News asking for feedback about the condition which affects my son along with Asperger's Syndrome and depression. To date he has not received nothing more than an annual review up until he was 15, since then nothing.

My son is now 20 and once he was 16 we were simply refused an appointment, he was under Redditch at the time. As far as I remember nothing further was said.

**Extracts from
The Big Conversation - a review of Neurology Services in Worcestershire**

Page 7 -

ME / CFS

Top priorities are:

- Acceptance that the condition is neurological
- Improve GP awareness and knowledge
 - o Provide training that ME/CFS is a serious long term condition and that it is a neurological not a psychological condition
 - o Improve understanding that ME affects many systems in the body, e.g. digestive system, nervous system, urinary system etc., also pain.
 - o Acknowledge ME is a neurological condition which weakens the immune system
- Make OTs available when the patient first sees a consultant for diagnosis (with information)
- Ensure joined-up services (e.g. if, say, an ME patient has repetitive UTIs – getting referral to consultant with the information that the patient has ME, so the whole person is considered)
- Group sessions and 1:1 with OT to be held throughout the counties (locally)
- Ensure patients are not discharged from the service
- Provide a key professional who can be contacted in times of crisis to address individual needs
- Ensure RAD groups are open to all ME/CFS patients not just those who have attended the group sessions (patients who attended the sessions before 2008/9 have been told they cannot attend), and ensure more locations so they are more local for people to travel to, as it is currently very difficult for many patients

6. ME / CFS pathway

