

Gloucestershire Local Involvement Network (LINK)

**Access to services in
Gloucestershire for patients with
Fibromyalgia**

Focus Group Workshop Report

June 2011

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1. Introduction

Local Involvement Networks (LINK) were set up in April 2008 as part of the legislation in the Local Government and Public Involvement in Health Act 2007. One of the main functions of LINKs is to collect views from patients, carers and the public about health and social care services in their local authority area. These views are given to the Commissioners, Providers and Regulators of the services, to help improve these services.

'Access to services in Gloucestershire for patients with Fibromyalgia' was one of the issues that was raised a number of times at public and members events. Consequently, as part of the work Plan for 2010/11, it was agreed by the Gloucestershire LINK Stewardship Board that a focus group should be set up to look at it in more detail.

Fibromyalgia has traditionally always been thought of as a musculoskeletal disease or even a psychological disorder. The main feature is chronic widespread pain which can be in both sides of the body, pain above and below the waist and/or pain on palpation at 11 or more of the 18 tender point sites. Additional signs and symptoms can include the following:

- Neurological: muscle numbness, tingling, cramps and weakness, chronic headaches, TJM disorder, and sensory overload (noise and smell)
- Neurocognitive: impaired concentration and short term memory, performance, multi-tasking, cognitive overload
- Chronic fatigue: persistent fatigue with reduced physical and mental stamina which makes it difficult to exercise
- Sleep disturbance: non-refreshing sleep, insomnia, frequent awakenings and / or restless leg syndrome
- Autonomic and / or Neuroendocrine: balance, temperature instability, Renaults phenomenon, hot/cold intolerance, respiratory disturbance, IBS and Irritable Bladder; dysmenorrheal, loss of adaptability and tolerance for stress, reactive depression
- Stiffness: most severe upon wakening and periods of inactivity

2. Aim of the Focus Group

The aim of the focus group workshop was to consult with Fibromyalgia sufferers to gain at first hand feedback on their experiences in accessing appropriate health and social care services in Gloucestershire and make recommendations to the Commissioners, Providers and Regulators of these services.

3. Focus Group Membership

The members of the group came from a wide range of backgrounds and locations across Gloucestershire and represented a variety of and organisation or individual views.

The facilitator for the focus group was Judi Brown, a member of the Gloucestershire LINK Stewardship Board, who met with the Chair of the local Fibromyalgia Support Group (Fibrobabes) in November 2010 to agree the format and content of the focus group workshop. They devised a questionnaire that could be used both at the workshop and circulated to members who were unable to attend (see Appendix 1).

4. The Process

Community Adult Care Directorate and NHS Gloucestershire do not have any policies for the provision of services to treat Fibromyalgia, so a lot of investigative research had to be undertaken over a considerable period of time to gather enough information required to understand the issues.

In the absence of a coherent care pathway, the workshop was primarily constructed around a series of open questions that had the objectives of exploring the issues faced by Fibromyalgia patients and encouraging them to talk about their experiences.

In preparation for the workshop, copies of the questionnaires were sent to all LINK members who were known to have Fibromyalgia and to all members of the local support group organisations.

Ten of these people attended the meeting held at the end of November 2010. They received a short presentation about Gloucestershire LINK explaining the aim of the workshop, its objectives and how their views would be used. This was followed by an open discussion using the questionnaire as a guideline. Issues and experiences were captured to form the basis for this report, supplemented by six questionnaires and eleven e-mail responses or comments received at Members' events, submitted separately by people who could not attend the workshop.

Necessarily, the workshop report is entirely qualitative, but it is important to acknowledge that there was a high degree of unanimity within the group concerning the issues raised and experiences shared.

5. Summary of General Group Discussions

There was a lot of general discussion about Fibromyalgia from the outset. To encourage group members to share their experiences freely, this discussion was allowed to run its course. Many of the issues were also explored in the subsequent discussions of specific questions contained in the questionnaire. However, there were some wider issues raised that are summarised here:

5.1. Members Experiences of the Symptoms of Fibromyalgia

- Fibromyalgia can start as a viral infection but it can also be triggered by an accident such as a fall or whiplash etc.
- We have so many nerves and the Fibromyalgia attacks every part of our body.
- The key issue is that Fibromyalgia sufferers have brain damage through premature ageing. The younger you are when you get it, the more brain damage you are likely to experience. Therefore treatment is needed quickly as it can slow this ageing process down.
- Everyone has different symptoms – there is no one pathway or diagnosis. I would not have a diagnosis except that I work for the NHS and I was so bad at work one day, that I self referred to Physiotherapy, who told me I needed to see a rheumatologist.
- There is a question about whether Fibromyalgia is a disability and therefore comes under the Disability Act

5.2. Members Believe Fibromyalgia is Hereditary

- My father had Fibromyalgiasitis but we now know it was Fibromyalgia. My brother has it, and now my daughter as well.
- My 15 year old daughter is now showing signs of Fibromyalgia
- I have no help. I live with my 14 year old daughter who is also showing signs of Fibromyalgia. There are only us, no family and no carer. I am so concerned because I am repeatedly told it is not hereditary, but it is.

6. Summary of Questionnaire Responses

1. Overall, what has been your experience of health provision for Fibromyalgia in Gloucestershire?

- Diagnosis is often made by a pain consultant who then prescribes a drug and sends the patient off telling them to take the drug, and off they go.
- I went to my doctor who diagnosed high blood pressure. She wanted to give me tablets. I asked her about my Fibromyalgia. The doctor said we do not need to worry about that because Fibromyalgia won't kill you, but high blood pressure will so let's just concentrate on that. I left very angry. Fibromyalgia attacks muscles and the heart is a muscle.
- You get put into a room with a medical team of four – very intimidating.
- My Fibromyalgia was diagnosed 20 years ago. My doctor now attributes every symptom I present to Fibromyalgia.
- First problem is diagnosis. You know you have something wrong with you, like being forgetful, but it can be put down to other things. This has gone on for 20 years and when you are finally diagnosed, medical staff still do not recognise it as Fibromyalgia.
- **Overall, the experience of health provision for Fibromyalgia in Gloucestershire was reported as not been highly unsatisfactory, primarily because of poor diagnosis.**

2. Has it been good, bad or mediocre?

- **Experiences were said either to be very good for those who had been referred to the specialist services provided by Dudley and Bath or, more commonly, very bad.**

3. Thinking about GPs as your first point of call for support, what has been your experience?

- Given lots of blood, tablets and offered a stay in Wotton Lawn.
- Mitrovalve Prolapse is a common problem.

- In Gloucestershire, the only thing treatment offered is pain management.
- All members were unanimous that treatment in Gloucestershire is not good.
- Pain treatment in Gloucestershire does not include injections or hydrotherapy.
- Members have tried CBT (Cognitive Behavioural Therapies) and pain therapy with very limited success.
- “Fibro Fog” is on a level with Parkinson’s. Dopamine, a drug given to Parkinson’s patients does help.
- It is known that some of the medication given creates suicidal thoughts.
- One member, admitted to hospital after a suicide attempted, was pushed into a corner and ignored. Then when someone did come and talk to them, was treated like a child and as an inconvenience. The nurses will not talk to them; they will not even consider suicide as a problem resulting from Fibromyalgia.
- Doctors do not look at the body as a whole, which they need to do for Fibromyalgia patients. Instead, doctors just look at one symptom at a time. For example, they look at allergies, or they look at a painful joint without considering the Fibromyalgia and without considering the patient as a whole person.
- In Gloucestershire, most of the group were only sent to the pain clinic for help. Only three were sent to rheumatology.
- The general pain management clinic is a 30 minute drive away. Normally I can only drive for 20 minutes so when I get there, I fall asleep and miss the talk. I fall asleep all the time
- Pain management staff try to change your way of thinking. They tell us it is our fault because we keep doing things that make us tired. For example, my hands do not work well and I find ironing my shirt difficult. I was told I should not be so fussy, to change my way of thinking and not iron my shirt.
- A member is afraid of trying new drugs because she has had serious reactions to the drugs already tried.
- A member is prescribed morphine patches for set period. They suffer from withdrawal symptoms and problems when they are taken off.
- **The experience has not been good as most GPs lack proper understanding, information or guidance.**

4. Where have GPs referred you for specialist consultation?

- One member has to go to the Royal United Hospital, Bath because the Rheumatology department in Gloucester wrote to her to say they do not know enough about Fibromyalgia. “Bath talk to America who know much more about Fibromyalgia. Bath Royal has a proper Fibromyalgia clinic”.
- One member attends Russell’s Hall Hospital, Dudley (Professor Raphael) for pain treatment. She stays in the hospital for 6 days every 6 months for Lignocaine infusions. Patients travel from as far away as Scotland to Dudley, where three beds are kept purely for Fibromyalgia patients.
- It is believed there is a clinic in Wolverhampton Hospital that will provide the same treatment as Dudley.
- Everywhere regarding individual symptoms: Endoscopy, Surgical and Medical Outpatients, ENT, Allergy Testing, Gynaecological Outpatients.
- **Except where a few patients have been referred to specialist clinics out of county, referrals have been to a wide variety of consultants.**

5. What has been your experience of these consultations?

- Good for one symptom at a time – e.g. hysterectomy resolved pain - but it moved to somewhere else.
- There is no follow up with a specialist, if you are lucky to see one in the first pace, so there is no feedback on how a patient responds to medication.
- Multiple medication sensitivity is a serious problem experienced by some Fibromyalgia sufferers. This makes it difficult to treat other diseases patients may have like asthma. Therefore ready access is needed to specialists who deal with these complications. If these other illnesses are not treated it makes the Fibromyalgia worse.
- **Consultants within the county too seem to lack information, understanding or guidance.**

6. What would you like to happen to improve your experience?

- I cannot understand why we cannot get screening.

- There needs to be a counselling service for Fibromyalgia patients.
- More information for patients
- More information for GPs.
- Early diagnosis.
- More specialists.
- A clinic with a multi-disciplinary team for people with Fibromyalgia, ME and MS.
- A forum for patients with Fibromyalgia so that they can discuss what drugs they are taking, what is happening and share the outcomes.
- If I want treatment, I have to look on the computer to see what treatment is available to help me. I then go to my doctor and tell him what I need. This is wrong, he should look himself.
- **These aspirations speak for themselves.**

7. Have you ever had a Fibromyalgia Care Pathway for Gloucestershire shown or explained to you?

- **Universally, the answer was 'no'.**

8. Have you been given any policy documents to check whether you may be eligible for specialist treatment?

- It appears the Arthritis Society has issued a leaflet that is given to some patients to tell them what to expect (on diagnosis). However, patients are not told the leaflet is out of date and currently being re-written. (It is thought the leaflet might be in the rheumatology department of GRH).
- The leaflet appears in different formats and giving different information. It does NOT refer to the impact of having Fibromyalgia.
- There is a lack of information and what information there is, is confusing.
- There is a lack of information for patients and for GPs.
- **In summary, the answer to the question was 'no'.**

9. Has the Interventions Not Normally Funded (INNF) process ever been explained to you for seeking access to specialist treatment?

- Is there an ethical framework for Fibromyalgia?
- Is there anything in the policy “Interventions Not Normally Funded” for Fibro patients? We do not think so.
- Fibro patients have a major chemical sensitivity therefore the process to get treatment is difficult and not covered in INNF.
- Because Fibromyalgia is not funded, members have to pay for their own allergy testing.
- **In summary, the answer to the question was ‘no’.**

10. Thinking about the effects, what has been your personal experience of Fibromyalgia?

- Symptoms of Fibromyalgia can mask other illnesses. It is common for other illnesses not to be picked up as every symptom is blamed on the Fibromyalgia.
- As a child I was always in ENT. I also had very painful legs, which the GP used to say was growing pains, but it wasn't.
- Sometimes I am in so much pain. Chronic pain feels like acute pain, and depending on where it is, could be caused by something else.
- It is not easy to cope with because of the way it all affects you. Crying because you cannot go dancing, your lifestyle changes even though you do not want it to.
- It appears dentists seem to know more about Fibro than doctors. Before I was diagnosed, I went to the dentist for a filling (a teenager). The 2 pain killing injections did not work and the dentist slammed down the instruments and stormed out of the room. Very traumatic for a teenager.
- A lot of members have Endometriosis and sub-fertility. One member tried for five years for a baby. They had a daughter and were told they were lucky to get one child. Now we can see she has Fibromyalgia as well.
- We sometimes think we have early onset Alzheimer's but in fact it is the Fibromyalgia. Our senses are affected as well. Everything becomes fuzzy, known as “Fibromyalgia Fog”.

- Sometimes when trying to cross the road, my brain does not consider I need to look for cars and nearly get run over.
- A 45 year old Fibromyalgia sufferer in Stroud is seriously contemplating suicide.
- It is recognised that Fibromyalgia patients consider self harming, attempted suicide, suicide thoughts and carry these through.
- Quote “I wish to God I had succeeded in committing suicide. I was just ignored in Gloucester”.
- The pain is so intense and the support is so little. The only thing that stops me committing suicide is my daughters and grandchildren. It does help going to Dudley, as the nurses and doctors on the rheumatology ward know a lot about Fibro and how to help, but it is not a miracle cure. It does not take away your pain.
- The hospital keeps trying to treat one member for depression, digging back into her past life to try and say that there are things there. In fact, any depression is caused by the way her life has been affected. She cannot do the things she wants to do which has had a huge effect on her lifestyle
- One member does not know how she has managed not to kill herself accidentally. She forgets so much. She forgot to pick up the oven glove and burnt her hand on the cooker. She put a dish down on top of the cooker because she forgot she shouldn't, and it exploded.
- Fibro patients are all prisoners of pain, just like being a prisoner of war. It is a constant battle to try and get across how they are feeling.
- One doctor said: “What’s the point in diagnosing something we can’t treat?”
- **Personal experiences have invariably been awful, with patients enduring chronic pain, disorientation (Fibro Fog), depression and in some cases suicidal thoughts, with no respite and little support from the medical profession.**

11. What would you like us to recommend to NHS Gloucestershire?

- One member pays £25 for six half hour session in the hydro pool in GRH. It is the only pool in the county, it can only be used at lunchtime and charges are applied. The attendant is not responsible for ensuring patient safety at these session and users are concerned for their safety.
- The Pain Management Group tells everyone that hydrotherapy will not help

Fibromyalgia patients even though it is well known it does help. Consequently they do not provide.

- **The group had tired significantly by this late stage of the workshop, but some key recommendations had already emerged from the previous discussions. These recommendations are shown below.**

7. Conclusions

For the facilitators, the workshop was a very moving experience. Group members were all keen to share their experiences and did so passionately and coherently. Many of these very personal stories were very moving and distressing and told with great pain and passion. It was therefore extremely difficult to record all the issues that were raised and convey the distress that these were causing. However, some very consistent themes emerged that can be shared with confidence.

- 7.1 Fibromyalgia is a painful, disorientating, disabling and distressing chronic physical condition. It is not a mental condition, although long-term isolation, lack of support or proper treatment can cause mental issues to arise.

"I am too tired and in pain so don't attempt much housework, but how do I explain that to Social Services when they see me walking a bit or driving?"

"There is a well-established suicide rate among people who just cannot take life under these circumstances and I was pushed to become suicidal for these reasons when I first became ill".

- 7.2 There is a high level of dissatisfaction amongst patients about the poor service provision for Fibromyalgia in Gloucestershire.

"The memories of the last ten years: the total frustration of feeling so ill, in so much in pain, so helpless, so muddled, so exhausted; not being able to walk properly, or remember anything, and going for help to be told again and again there is nothing wrong with me. The terrible grief at losing the person I was".

- 7.3 GPs in Gloucestershire lack appropriate information and guidance on the diagnosis and treatment of Fibromyalgia.

"The leaflet appears in different formats and giving different information. It does NOT refer to the impact of having Fibromyalgia".

"One doctor said: 'What's the point in diagnosing something we can't treat'?"

"I don't want to be disabled, but the pure joy of having my illness defined, recognised, accepted and acknowledged has actually made me happy! It is such a relief".

- 7.4 There is no clear integrated pathway for the diagnosis and referral for the treatment of Fibromyalgia in Gloucestershire.

"My GP has been very good and referred me, but it is the consultants themselves who do not believe in the condition, especially neurologists. How can you trust anyone who refuses to believe you?"

7.5 There is no published commissioning policy for the service provision for Fibromyalgia in Gloucestershire.

"I couldn't have any more treatment as there were too many patients being diagnosed with Fibromyalgia and I was being taken off the list, due to not getting any more money from the Government and that he was sorry".

7.6 There is no adequate or consistent service provision for the treatment of Fibromyalgia in Gloucestershire.

"I feel let down by the system and that there is no help for people with this awful disorder in Gloucestershire".

7.7 There is no up to date information for patients in Gloucestershire, either on the effects of or treatments available for Fibromyalgia.

"But because of Fibromyalgia / Chronic Fatigue no one will believe you and they put everything down to stress, anxiety or depression and it's seen as purely mental illness".

7.8 There is no information for patients in Gloucestershire who are seeking access specialised services for the treatment of Fibromyalgia.

"Is there anything in the policy 'Interventions Not Normally Funded' for Fibro patients? We do not think so".

7.9 Where patients have accessed good services out of county - for example in Royal United Hospital, Bath or Russells Hall Hospital, Dudley – they have done so through their own initiative and effort.

"Bath talk to America, who know much more about Fibromyalgia. Bath Royal has a proper Fibromyalgia clinic".

8. Recommendations

Having considered the report and conclusions from the focus group, the LINK would make the following recommendations to the commissioners and providers of services in Gloucestershire:

- 8.1 In Gloucestershire, Fibromyalgia should be recognised as a chronic and disabling physical illness that can have a significant effect on the mental health and well-being of the individual. Information about its diagnosis and treatment should be made available to all GPs and patients, to avoid the present inconsistencies of service provision.
- 8.2 A jointly commissioned care pathway should be developed and published that addresses both health and social care needs. This should be done in consultation with patients and their carers. Consideration should be given to a multi-disciplinary approach to diagnosis and service provision.
- 8.3 The clinical criteria required for referral to a specialist clinic (such as in Bath and Dudley) should be easily available both to patients and clinicians. This would help avoid some of the present protracted discussions with NHS Gloucestershire.
- 8.4 Patients with Fibromyalgia should be able to access counselling services to enable them to cope better with this debilitating long term condition.
- 8.5 Financial support should be available for the development of a support organisation and community group for patients with Fibromyalgia, building on existing forums such as 'Fibrobabes'.

Appendix 1. Gloucestershire Local Involvement Network (LINK) Fibromyalgia Workshop Questionnaire For Fibromyalgia Sufferers

1. Overall, what has been your experience of health provision for Fibromyalgia in Gloucestershire?

2. Has it been good, bad or mediocre?

3. Thinking about GPs as your first point of call for support, what has been your experience?

4. Where have GPs referred you for specialist consultation?

5. What has been your experience of these consultations?

6. What would you like to happen to improve your experience?

7. Have you ever had a Fibromyalgia Care Pathway for Gloucestershire shown or explained to you?

8. Have you been given any policy documents to check whether you may be eligible for specialist treatment?

9. Has the Interventions Not Normally Funded (INNF) process ever been explained to you for seeking access to specialist treatment?

10. Thinking about the effects, what has been your personal experience of Fibromyalgia?

11. What would you like us to recommend to NHS Gloucestershire?

Please return the completed form by email to gloslink@grcc.org.uk as soon as possible.

Appendix 2. Patients' Personal Stories

A Gloucestershire Patient's Story - 1

I am a 52 year old woman and in 2004 or roundabouts I was diagnosed with Fibromyalgia. I had been suffering with pain and tiredness in all my muscles, and was exhausted all the time. I had also been diagnosed with an under-active thyroid so most of the problems were put down to that. I didn't get any better with the Thyroxin so I went back and forth back to my doctors, and was told it was my age, depression and the under active thyroid.

I went back again to my doctors and this time saw a locum and he diagnosed Fibromyalgia. This was also confirmed by my doctor. I have had no help with this disorder, and have only been sent to the Pain Management Clinic in Cheltenham once. I saw a consultant there, and he also diagnosed Fibromyalgia. I was given acupuncture for the problems in my neck but that wasn't for the Fibromyalgia, but after 6 weeks, the acupuncturist told me I couldn't have any more treatment as there were too many patients being diagnosed with Fibromyalgia and I was being taken off the list, due to not getting any more money from the Government and that he was sorry.

After that I have had no treatment apart from painkillers with the Fibromyalgia. My doctor, although caring, admits that there is no cure and not really a lot he can do. Every time I go I get given antidepressants which I don't need as its the Fibromyalgia that makes me depressed, and all the tablets that I have been given have given me side effects, one of which is weight gain. I have also been given Epilepsy drugs as they were supposed to help with the nerve endings which caused the pain. After trying two lots they made me feel awful as I couldn't function at all on those. In fact the Fibromyalgia got worse.

I have been seeing the 2gether team after seeing a psychiatrist in Cheltenham who made me feel worse, as he said the Fibromyalgia was in my head and that basically I was a menopausal woman and I was depressed. I did complain about the letter he sent as he had said quite a few incorrect things. He did send me to the 2gether team in Tewkesbury and I have been receiving CBT but it isn't for the Fibromyalgia but for my fear of going places and other reasons.

I feel let down by the system and that there is no help for people with this awful disorder in Gloucestershire.

A Gloucestershire Patient's Story - 2

All my problems and most of my pain are during the night. Most days I have taken at least one painkiller, one dopamine tablet (I have an orthostatic tremor) and now an anti-depressant by the time my husband leaves for work. I feel better when I stay up, but most days I don't go

out until after lunch, by which time I have taken another Gabapentin & Dopamine, so am looking and feeling reasonably ok.

People say how well I look, but I feel like saying: “you don’t see me curled up in pain 3/4/5/6 o’clock in the morning!”

I am too tired and in pain so don’t attempt much housework, but how do I explain that to Social Services when they see me walking a bit or driving?

A Gloucestershire Patient’s Story - 3

I am writing to make my points of view about Fibromyalgia and treatment. To be honest I have had very bad experiences so far, but my own doctor has been very helpful and supportive. Some other doctors at my local hospital and within the practice have treated me very badly. I had to move surgery when I was given little help and left with other problems. Diagnosis was delayed due to having Fibromyalgia / Chronic Fatigue, which has been deemed by many doctors and psychiatrists as purely mental illness.

My own background is one of being well educated with a Degree and HNC and have served as a local Councilor. I fell ill after a series of incidents including pesticide exposure over a period of several years. I had some head injuries and Glandular Fever around the time that I became very ill, around 2000. By 2003 I also had a pelvic abscess which may have existed for some time prior but no one would take me seriously when I became very ill. But because of Fibromyalgia / Chronic Fatigue no one will believe you and they put everything down to stress, anxiety or depression and it’s seen as purely mental illness. This seems to be the preference of doctors and psychiatrists that if the etiology cannot be found then the patient is to blame.

The history of psychology is one littered with virtually every well known or established illness having been labeled as a mental illness until the etiology is fully understood. The history is pretty dark and would make a good degree thesis or book, with the tendency for psychology to support some pretty horrific ideas at times. It could also be said that bias is towards he who pays the piper, supported with mainly subjective psychobabble. They have supported so many negative elements in the past including the conversion of gays in the 70’s and frontal lobotomy of black people in the 60’s to name but a few. MS was once ‘Hysterical Paralysis’ and Polio was ‘Hysteria’. Now they attack people with Fibromyalgia. They seem to have established a Mental Health Taliban. The likes of Simon Wesley are being paid by insurance companies to stop insurance claims by those with similar illnesses such as ME and Chronic Fatigue.

In reality, the treatment of people with these conditions (and they may all be the same thing, just variations) is not just one of lack of help, it is one of abuse. When you are ill with Fibromyalgia / Chronic Fatigue / ME, you not only have to manage illness with little or no help but are put in the stressful position of having to fight for help when too weak to do so. The worst opponents are doctors and psychiatrists. You also have to put up with fairly insulting or negative remarks from doctors who have little training or understanding. You may be in extreme pain every day and suffering from many other problems but you become a prisoner

of this 'kangaroo court' who cruelly and repeatedly make life as difficult and stressful as possible. But there are some areas that have much more supportive regimes and Gloucestershire is not one of them. It has one of the worst reputations.

There is a well established suicide rate among people who just cannot take life under these circumstances and I was pushed to become suicidal for these reasons when I first became ill. The only thing that I found when I became ill was cruelty and abuse. I can prove delays in treatment and have been taken into hospital on four occasions when the infection that I have had since 1993 has flared up and made me very ill when it became systemic. On four of those occasions I was not believed until a scan had proven the infection. I would not rate my chances if I had a heart attack or other life threatening problem, because if you develop Fibromyalgia / Chronic Fatigue / ME you lose your human rights to be treated with respect, trusted or believed because everything you develop is just Fibromyalgia or Chronic Fatigue (which is seen as a bi-product of depression) ... and that this is all psychological.

For this reason this disease is a very dangerous thing to happen if you are unfortunate enough to develop it. I would say that in general many Doctors are breaking their Hippocratic Oath to do no harm. They have little understanding and little patience and somehow seem to have come to totally unfounded conclusions that they have no right to, purely subjective views which are little more than 'old wives gossip'. They are doing serious harm to those suffering, causing real psychological long term problems.

I remember that I only became stressed when no one would take me seriously when I developed the multiple symptoms that come with the illness. This causes depression. I became suicidal when I realised that I could get no help and may have to live with this and have to live with abuse. If it was not for a few doctors who were not arrogant enough to make such subjective suppositions I may not have survived the early onset. I was also told by a neurologist who had little interest that 'I had too many symptoms', in other words too many to be real. But the many thousands of people suffering these illnesses have the same multiple, multi-system problems that correlate. I was indeed later found to have multiple problems including a large ischemic pelvic abscess infection that may have existed for some time (and has re-infected for the last seven years), autonomic dysfunction that was associated with the pesticides and a number of other problems including Fibromyalgia. When I originally reported the pesticide exposure to the neurologist, he was not interested. I was told that the pesticide named would not have caused my symptoms, but no one did a survey of levels or other pesticides which were found later to be from several pesticide sources and high levels. The opinion under these circumstances was purely subjective. There are many who believe that increased chemical and pesticide use may be to blame or have a part to play in the chain of events but there is no research as there is little interest in Fibromyalgia / CF / ME (or only from the perspective of psychiatrists who can earn a living backing a government who are not prepared to pay for the burden).

It has also been reported that in ME / Chronic Fatigue that death due to heart failure after one or two decades of living with these diseases is common, but statistics are not taken of those with these reported diseases to make any correlations or any other data necessary for scientific review. Preference seems to be a purely subjective rather than objective. Professor Malcolm Hooper has written a report for physicians and solicitors that gives detail of

suicides and heart failure. He includes Gulf War Syndrome along with ME and Chronic Fatigue Syndrome.

The provision for Fibromyalgia in Gloucestershire is dreadful, where other counties have much better provision and will take the illness seriously. I have had to travel to Bath Rheumatology, where they take Fibromyalgia seriously, and was told that it was due to brain chemistry disorder / autonomic dysfunction. So one county will treat you as mentally ill and another as a suffering disease. This is crazy.

I have been refused help at my local surgery during a crisis episode and told to see my own doctor despite being very ill. I actually managed to tape my part of the conversation when severely ill. Would you like a copy? It is on a small but very good dictation machine that I obtained because of frequent problems with slurred speech and difficulty talking.

My GP has been very good and referred me but it is the consultants themselves who do not believe in the condition, especially neurologists. How can you trust anyone who refuses to believe you? How can you expect anything except to become stressed and anxious under these conditions and then that anxiety is examined as the sole cause of illness. I recently found on a letter that a consultant did not want to perform a colonoscopy where an area of bowel thickening had been found and was highly recommended inspection by the radiologist because he said it would add to my anxiety. If I was an anxious person, and I am not, then this action would make me anxious.

There is much more and I am sure that you will find many other horror stories throughout. I can only ask that we are treated with respect and given the belief and help that we need. At present it is like being a prisoner of war or even being treated as a criminal, punished for a crime that we have not committed.

A Gloucestershire Patient's Story - 4

Am I mad? What makes my mind want to kill my body? Why did I have to do such a terrible thing to myself and make everyone hate me? I was normal once, I'm sure I was normal once. Did normal things, had a partner and children and a lovely job with a lot of friends. But it seems like that was another person. All I wanted to do was dying and now I am in a police cell? Did I kill someone else instead? Why am I alive and in a police cell when I all I wanted to do was die...to end the pain, seek the peace and know relief. I felt it, after the drugs and booze come up, pouring through my nose as well as my throat, I settled down into a blissful blackness.

The cell is not really here, because I am not really here. I can feel – just a little – like the cold and the wet of my clothes. I can hear – it's the sound of a baby wailing – I am sure it is me, but I don't know if I am using my voice. I can hear pissing, loud pissing into an open bucket, but I can't think why or where it comes from. When I look up I can see someone in uniform watching me. I don't know who or why. I am trying to bring X back because I know I need her help, but I just can't find her. When the wails stop I stare at the blue plastic bed I'm huddled on. I see tiny creatures running about, they are little people, and they frighten me.

Then in it comes again.

The memories of the last ten years: the total frustration of feeling so ill, in so much in pain, so helpless, so muddled, so exhausted; not being able to walk properly, or remember anything, and going for help to be told again and again there is nothing wrong with me. The terrible grief at losing the person I was.

Ten years ago I had everything. I had a fantastic, dynamic career, a loving partner, a beautiful home, plenty of money. I was running my own advertising creative consultancy with clients in London and the South West. I would travel the country picking up briefs, presenting my concepts, giving workshops on creativity, lecturing at universities, making TV and radio commercials, creating websites and brochures and working alongside the best in the business.

But then everything changed. It started with a skiing accident in Bulgaria where I knocked myself out on the slopes. I was unconscious for a while and had to be caterpillar lifted off the slopes and spend a couple of days on a drip in a very basic clinic. It was very traumatic and my partner was very put out that I had spoilt his sport. Up till then, we had enjoyed lots of activities together, sailing, skiing, backpacking, and gardening – all these things are lost to me now. My body is crippled, exhausted, broken – and it all started that day on the slopes.

When I returned to England I had balance issues for a while and my GP gave me an MRI scan but said I was OK. I returned to work but within weeks I noticed that I had a lot of pain in my legs – my knees and ankles were sore but not inflamed and I used my private medical insurance to see a top rheumatologist. He took blood tests that ruled out Rheumatoid Arthritis and left it at that. It was 1999.

By 2001, the pain had spread into my neck and shoulders, hips, pelvis and coccyx. I was having trouble driving long journeys and was overwhelmed with exhaustion and pain. I had also been referred to the Community Mental Health Team and had been diagnosed with Depression and put on medication – I was really struggling to work and my income was taking a huge hit. My GP diagnosed Polymyalgia, give me surgical stockings and put me on steroids as well as anti-depressants. I began to put on weight.

In 2003 I had gained 5 stone and was having real problems walking. I could only work a few days a week and I started running into money troubles. I applied for Disability Living Allowance but I was turned down. My partner told me that he couldn't cope with a girlfriend who had a mental illness – he could get one without, which he did. He revealed he'd had a relationship with a girl at work and she was pregnant so he was marrying her. I was devastated, heartbroken, depressed, overweight, in pain and ill and now I was all alone to face it.

My pictures start up my wailing up again. I am now up and storming the cell, I want to kill him, I want to beat the shit out of the man that did that, but I can't. He is long gone, married to someone else. It is my legacy to live with these memories. It is now my illness, my madness. I am helpless, hopeless.

My sudden movement brings an officer to calm me down, offer me tea. A woman thankfully; if it was a man I would have kicked him, hit him, screamed at him. I hate men, they hurt me. My eyes are so full of tears I can hardly see her. The pain in my whole soul is too much. I sip the tea, it stops me crying, and it calms me down. I sit and rock. I hope I can stay in here forever, they've told me the doctors will come but I don't want them. I don't want to answer any more questions, or get another diagnosis,

I just want to die. They won't let me die.

They come and get me and put me in an interview room. I don't know this officer; they have changed shifts since I came in. The door opens behind me and some people come in. They are my children. I am shocked. My children who months before have said they want nothing to do with me because I am so much trouble, because I am mental. My daughter who is getting married says she doesn't want me at her wedding. I've been waiting for my son to visit me for days and he got angry with me and wouldn't come. I don't know why they are in this room. I am confused and wary. Perhaps they have come to make sure that I get put away so I cannot ruin their lives any longer. But I don't want to ruin their lives; I want to be dead so they can live their lives without a mad mother. I am so ashamed.

By 2005, I had seen another rheumatologist and he said that I definitely did NOT have Polymyalgia; he thought it was probably Rheumatoid Arthritis and I had better come off the steroids. He prescribed Ibuprofen and said he would see me in six months. So I just carried on. I lived alone and had problems paying my mortgage. My brother helped me out financially and I managed to keep some clients, but more and more I had to do the work from home and stop driving all over the country. With a huge drop in income, my lifestyle changed completely and I hardly ever went out. I stopped having holidays restricted myself to the sofa and my desk. My depression got worse.

They lead the three of us to the cells. I have to stay here; there is nowhere else for me. I cannot look at them, I want to be dead, they are too shocked to speak, we have never been in a cell, any of us, we are a nice family, a good family, and the shame is too much to bear. My wailing starts and turns to whimpers as I remember that my children are there. I am sleepy and start to drift...then another picture.

In 2007 I finally abandoned my business and took a local admin job for peanuts in the marketing department of the local college. They had been really impressed with my CV, but when I started doing the job I was really embarrassed because I could hardly remember anything they showed me. I made so many mistakes and the young girls I worked with lost their patience with me. I could hardly function and would have to go to bed as soon as I got home from work.

I kept falling down and as my department was on the first floor I would struggle to climb the stairs. I had more and more days off and, when my probation was up, the college didn't hire me, but they did give me another three months to prove myself. I couldn't. I heard them talking about me – 'why doesn't she just go home and do her flower arranging or something, she's crap' – I'm so hurt, so embarrassed. I know they're right. I used to be creative director of one the world's leading ad agencies, I hired people, spoke at symposiums, was featured in the trade press – now I'm just an embarrassment. I can't stand the humiliation.

I am up again. I want to kill I want to hit out and damage someone. I want to die I want to not be here. I want to end the memories. But I am here. I am in a police cell with my children. I remembered what I'd done earlier that day.

I took the drugs and booze and vomited and then there were men in my bedroom. An ambulance – accident and emergency – blood tests and then I wanted a cigarette. So I left to go and buy some. There was shouting and a security man ran after me. I kept on walking. It was pouring with rain, but I knew where I was. I knew a garage on the main road. I just kept walking, but it was very wet and I didn't know where I was. I sat under a tree. A big car came and I stood up. I knew it was for me. They had a cage in the back and I asked if they were the dog police. No, the cage was for me.

Back at the hospital I was put on a bed but I couldn't stay. I saw the cupboard had a pile of plastic bags attached so I pulled one off and put over my head. I huddled behind the cupboard so they couldn't see me but then the bag was yanked off my head. I found a plastic tube and put it round my neck and threw it over the bed rail. A security guard pulled me off the bed and sat me in a plastic chair. I was still alive. I started to fall asleep then there was shouting and I was frightened, so I got up and ran out of the hospital again. Two security guards jumped on me and I was brought to the ground, but I fought them off. I knew I could beat them; I was so strong and angry. I ran and ran and ran. I heard them shout – “the police will get you.” I didn't know they meant me, I hadn't done anything wrong – or had I?

I walked and walked. It was getting light. There was no one anywhere. I heard a car and hid and saw it was not a police car, but it was speeding through the quiet streets. I had to get to my daughter's house. She had a playhouse in the garden and I could hide in there. I knew she wouldn't let me in. I knew where she lived and I just kept walking. I wasn't in pain; I walked more than I had for years with my arthritis. I felt good.

Then just before her house, the police cars came. There were two of them. I stopped and waited for them to come. One came and asked me where I was going. I told him I was going to my daughters but I didn't know the address but it was next to a pub and I didn't know the name of the pub. They asked me to wait. Then the police who had picked me up before came with their caged car. Have I got to go in there again I asked. No, just sit in the back. They told me they had to take me into custody on a 361 section for my own safety. I was in custody until they could find me a safe place.

At the police station I waited in a bay, it had a CTV camera; I wasn't scared I had seen it on TV. I thought there would be a lot of people on the other side of the doors, prostitutes and villains waiting to be charged, but it was empty. I had to stand up for ages while the desk sergeant discussed me with the police officers. He said he would release me to someone who could keep me safe. Could I give them a name? I didn't have anyone and started to cry. I don't have anyone, no one. Then I thought that may be my ex-husband might take me, I phoned him and told him he had to phone the police. I waited and then they came and told me he had phoned and wouldn't help me, so they had to put me in a cell.

In 2008 I lost my home as my brother called in his debt and I couldn't pay my mortgage. I moved to a rented house in a local village where I knew no one and was so distraught that I

broke down completely. I was in so much pain and could hardly walk. I had become incontinent and was constantly wetting myself throughout the day and during the night. I couldn't stop crying from the moment I moved in and stopped going to work.

I begged my GP for help and she got me an emergency appointment with the same rheumatologist. He once again proclaimed me 'as having nothing wrong' after examining me, but he ordered more blood tests. I was at my wits end. Then I had a call from work – they were very sorry but...they fired me of course. I was finished. I had lost everything: my career, my home, my income, my looks, my life. I couldn't stand it anymore, the terrible pain, the humiliation, the struggle, the exhaustion, the loneliness...

I bought a bottle of brandy and got all the Ibuprofen tablets in my cupboard and took the lot.

Its two years later and everything has changed in my life. Everything! And it started to change when I got a diagnosis from the rheumatologist two months after my suicide attempt. FIBROMYALGIA...??? I'd never heard of it and neither had anyone else. But that is the title he gave my illness, yes illness. I really did have a genuine illness. I wasn't mad. I wasn't making it all up. I was ill, I had a diagnosis and with it came a complete change of life in every way, shape and form.

Once I had the name of my illness I could get the information and start learning about what was wrong with me and why. There it all was, in books on websites, all my symptoms: the pain, the exhaustion, the confusion (Fibro Fog), the incontinence, the depression – all there – 'often triggered by a trauma to the head'. All of it exactly as it had happened to me. AND there they were people like me who had had very similar stories.

Because of the diagnosis I now have a Blue Badge and Disability Living Allowance, so at last I don't have to worry about working. I am disabled. I can prove it and even my children are starting to get it as they see me park in disabled bays. I don't want to be disabled, but the pure joy of having my illness defined, recognised, accepted and acknowledged has actually made me happy! It is such a relief.

I now know that I am not alone. So many other sufferers experience similar agonies of disbelief from professionals and family members. Fibromyalgia is a mystery in Britain, yet it is a horrible illness that steals your total life.

Now I have the knowledge and the tools to help me deal with it, I am glad that I survived my suicide attempt and have found a way to carve out a life that is tolerable. But until we achieve more recognition more support and more acceptance, I fear there will be many more people who find the devastation of Fibromyalgia far too much to bear.

Appendix 3. Research

Conventional Therapies

The NHS Website states that Fibromyalgia, also called Fibromyalgia Syndrome, is a chronic (long-term) condition that causes pain all over the body.

The name Fibromyalgia comes from three Latin words:

- 'Fibromyalgia' meaning fibromyalgious tissues, such as tendons (bands of tissue that connect muscles to bones) and ligaments (bands of tissue that connect bones to bones),
- 'my' meaning muscles, and
- 'algia' meaning pain.

However, the condition does not just affect the muscles, ligaments and tendons, but is felt all over the body. This results in widespread pain and fatigue (extreme tiredness).

Fibromyalgia used to be known as Fibromyalgiasitis, which literally means inflammation (swelling) of the muscles and soft tissue. However, the condition was renamed Fibromyalgia after studies found that there is no inflammation.

It is estimated that Fibromyalgia affects 1.7 – 4.5% of the population across the globe. That means that in England and Wales, there could be up to 1.76 million adults with Fibromyalgia. That equates to around 20000 sufferers in Gloucestershire.

Anyone can develop Fibromyalgia, although the condition affects more women than men. In most cases, Fibromyalgia occurs between 30 and 50 years of age, but it can develop in people of any age, including children and the elderly.

The NHS Choices Website states that, as well as medication, there are some other treatment options that can be used to help cope with the pain of Fibromyalgia. These include:

- Swimming, sitting or exercising in a heated pool or warm water;
- An individually tailored exercise programme;
- Cognitive Behavioral Therapy (CBT), a talking therapy that changes the way you think about things so you can deal with problems more positively;
- Psychotherapy, a talking therapy that helps you understand and deal with your thoughts and feelings;

- Relaxation techniques;
- Physiotherapy, when techniques such as massage are used to improve any physical problems, such as muscle stiffness or weakness; and / or
- Psychological support - any kind of counseling or support group that helps you deal with the issues caused by Fibromyalgia.

Alternative Therapies

The NHS Choices website points out that some alternative therapies - e.g. acupuncture (where thin needles are inserted into certain points around the body to help relieve pain) - claim to relieve or prevent Fibromyalgia symptoms. So far, there is a lack of evidence supporting their effectiveness. Until more research has verified that alternative therapies may have some benefit, they are not recommended for treating Fibromyalgia.