MorE tortoise than hare!

a Report on Health Services
for Adults and Children with ME & CFS

by

the Welsh Association of ME & CFS Support

WAMES

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Abstract

As a result of being advised by the Health Minister, Dr Brian Gibbons in meetings and correspondence that LHBs were responsible for the commissioning of services for patients with ME & CFS we undertook a mapping exercise with all 22 Local Health Boards in Wales and Health Commission Wales via a questionnaire. These questionnaires have subsequently led to the findings that are presented in this report and can be found at Appendices 1 and 2.

We had a 91% response rate from LHBs and an 82% rate to the questionnaire.

Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS) and Post Viral Fatigue Syndrome (PVFS) are listed at G93.3 Conditions of the nervous system in the World Health Organisation's classification of Diseases ICD10.

ME & CFS affect approximately 11,830 adults and children in Wales. A comprehensive breakdown of the number of adults and children in each Local Health Board area is at Appendix 3.

Less than 176 CFS patients are treated each year in Wales, 80 at the 2 North Wales CFS clinics and 96 patients at the Bronllys Hospital. The patients seen at Bronllys are a mixture of chronic pain and CFS patients and therefore the total number of CFS patients treated at Bronllys is going to be smaller. This is a paltry 1.5% of the ME & CFS population of Wales.

Just 8 patients return to work from the 80 seen each year in North Wales, this does not necessarily mean they return to their previous employment or their previous level of health.

The cost to Wales both human and economic is estimated at £614,681,260. A breakdown of the estimated cost to Wales by LHB can be found at Appendix 4.

There are three clinics in Wales, two in the North and one in Mid Wales each of which selects patients for treatment. They also offer a management package based on ME and CFS as a psychosocial illness. These packages are only suitable for a very small subset of patients or those well on the way to recovery.

This report confirms what we, as a group working with patients with ME & CFS in Wales, already know.

- There are few services, none appropriate for all
- few champions
- little interest from professionals to change the situation
- no collection of incidence figures

This report highlights both the immediate need for appropriate specialist services and the high cost to Wales, both human and economic.

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Tables

1. Overview

In addressing the need for appropriate services for both adults and children with ME and CFS in Wales we must dispel the myth that this condition does not contribute to death. In 2003 a Coroner in North Wales gave the cause of death of a patient as "*Death due to heart attack due to Chronic Fatigue Syndrome*". Again in 2006 a Coroner has placed CFS on a death certificate. The cause of death is stated as: '*Acute aneuric renal failure due to dehydration arising as a result of CFS'.* The pathologist further said *'ME describes inflammation of the spinal chord and muscles. My work supports the inflammation theory. There was inflammation in the basal root ganglia.'*

2.1 Make-up of Health Service in Wales

The Health Service in Wales is made up of Twenty two Local Health Boards (LHBs) as one of its responsibilities has the commissioning of services in primary care and also in secondary care. Health Commission Wales (HCW) is responsible for the commissioning of specialised children's services which are not commissioned by the Local Health Boards in Wales. This includes services for children with neurological conditions.

2.2 Process of collection of data

A mapping exercise was undertaken in April 2006 by ourselves of all twenty two Local Health Boards (Appendix 1) and Health Commission Wales (Appendix 2) by letter to ascertain both the provision, or perceived provision, of specific services for both adults and children with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS). These letters were followed up if no reply was received.

In February of 2007 an email was sent to all LHBs who had responded to the first enquiry to ensure that all data that was held was current. These emails were followed up by telephone calls due to problems with the NHS email system. Thirteen LHBs responded to the enquiry, only one LHB had anything to add.

The letters to the Local Health Boards were separated into six questions and further separated into adults and children's services. The purpose of this was to find out if there was any difference in the commissioning of services for adults and children with the same condition.

2.3 Response

Twenty out of the twenty two Local Health Boards responded to the initial enquiry, although only 18 chose to answer the questions put to them. One LHB had intimated they would reply on the 17th July but no reply has been received. One LHB did respond on the 26th June saying:
"*… has had a number of questions asked regarding these services including correspondence from local MPs. I will discuss this with our CEO here and*

forward you the response we have previously provided."   Nothing further has been heard from this LHB.

Not all the LHBs that replied chose to answer the questions put to them. Two declined and one gave information on what future, not current service provision would be. Replies received from LHBs have been transferred into a results table for ease of reading and referencing. (Appendix 3).

Health Commission Wales have neither acknowledged receipt of nor replied to the letter of 31st May. This letter has been followed up by telephone and HCW have said they would have required substantially more time than was allotted to them to enable them to answer the queries if they were able to respond at all.

Another letter was sent to Health Commission Wales on the 16th August. In reply to this letter HCW assert they do not commission services for children and young people with ME and CFS in Wales.   They tell us that services for this group of patients should be commissioned by the LHBs and where there are no services in Wales use of the gatekeeping arrangements with hospitals in England should be used. They also tell us they have a "*panel which considers referrals related to individual patients where the treatment is not covered by a contract or service level agreement."*   There have been no referrals of patients with ME and CFS to specialised services but the HCW database would have to be checked to confirm this statement. This is contrary to the information held in Welsh Health Circular WHC (2003) 63[1] regarding what services HCW are responsible for http://new.wales.gov.uk/docrepos/40382/dhss/WHC(2003)63.pdf?lang=en also to the LHBs understanding of the commissioning of specialised children's services. It does not appear that Health Commission Wales commission any specialised services for adults with complex chronic fatigue therefore there are no transition services from children's to adult services, if in fact, they did exist.

One LHB chose to answer the questions with a report of what services NICE will recommend when in fact NICE will not pronounce on these services until August of 2007 at the earliest.

One LHB has since devised a protocol for the management of ME & CFS patients in their area. This protocol is not appropriate for all patients as the treatments suggested have not been trialled on some patients such as the severely affected and children. This protocol is being offered as a blanket approach and one which all GPs are advised to prescribe before 'Out of Area Treatment' referrals are applied for.

2.4   Accuracy of responses

Sufficient evidence has been gleaned from the Local Health Boards, from various documents and gathered from patient experience to enable comment to be made on specialised children's services in Wales where they relate to children with ME and CFS.

There seems to be confusion in some LHBs as to what services there are for adults and children with ME and CFS in Wales. There also seems to be confusion over which group of patients existing services are aimed at.

2.5 Breakdown of results

The following table is a breakdown of adults and children with ME & CFS in each LHB in Wales using the prevalence figures of 0.4%. The total population of Wales is given as 2,958,600 on the Welsh Assembly Government's website. Prevalence is therefore estimated as 11,830 adults and children with ME & CFS in Wales. The population total is taken from the Welsh Assembly Government's 2005 mid year figures. http://new.wales.gov.uk/topics/statistics/wales-figs/population/2005mye-la/?lang=en

LHB	Population	Adult Patients	*Severely affected adults	**Child Patients	*Severely affected children
Anglesey	68,934	248	62	28	7
Blaenau Gwent	68,413	247	62	27	7
Bridgend	130,772	471	118	52	13
Caerphilly	170,238	613	153	68	17
Cardiff	319,702	1152	288	128	32
Carmarthenshire	178.119	641	160	71	18
Ceredigion	78,258	282	71	31	8
Conwy	111,521	401	100	45	11
Denbighshire	95,991	346	87	38	10
Flintshire	150,230	541	135	60	15
Gwynedd	117,985	425	107	47	12
Merthyr Tydfil	54,868	197	49	22	5
Monmouthshire	87,704	316	79	35	9
Neath Port Talbot	135,586	488	122	54	14
Newport	139,573	502	126	56	14
Pembrokeshire	117,490	423	106	47	12
Powys	131,498	473	118	53	13
Rhondda Cynon Taff	231,622	833	208	93	23
Swansea	226,369	815	204	90	23
Torfaen	90,303	325	81	36	9
Vale of Glamorgan	122,932	443	111	49	12
Wrexham	130,482	470	118	52	13
Sub Totals		†10,652	2,663	†1,182	298
Totals	2,958,590	† + † = 11,834			

*Severely affected means adults and children who are confined to their beds or homes due to the severity of their illness.

** Child means anybody aged 16 and under.

3. Adult & Children Services

3.1 Results relating to Children

There are no specialised or specific services commissioned for children and young people with ME and CFS in Wales either by individual local health boards or by Health Commission Wales.

Health Commission Wales in two documents list 'complex chronic fatigue' as a condition for which children should be referred and treated by Rheumatology service. In "Commissioning Tertiary and Specialised Services for Children and Young People"[2], May 2004 CFS and ME are listed under both rheumatology and mental health. It is noted within the listing that an incidence figure of 50 – 100 children are affected by CFS and ME in a practice of 50,000 per PCT. It is unclear where these figures have been derived from. It is also noted that children with this disorder require multi-disciplinary team care. The information on this webpage does not accord with the reply received from Health Commission Wales. The information held within this report is also confusing because it lists the same condition under two headings, neither of which is neurology wherein the World Health Organisation places ME & CFS.

As there are no specific services for children and young people with ME and CFS and no specific adult services appropriate for all then the Key Actions in the NSF for Children, Young People and Maternity Services[3] cannot be met and the Welsh Assembly Government falls short of its claims that "*All children and young people receive equitable access to appropriate, high quality health care irrespective of where they live, their ethnic group, their language or their social circumstances."* This quote is taken from Chapter 7 "Standard – Access to Services" of the "Children's & Maternity Services NSF Acute and chronic illness or injury" section.

There is no consensus amongst Local Health Boards as to the appropriate speciality to which to refer children and young people. It must be remembered that ME and CFS are listed under G93.3 Conditions of the nervous system in the WHO's ICD classification of diseases, yet we have a situation in Wales where two LHBs refer all children to mental health teams, although these are not specialised services for children with ME and CFS. In the rest of the country there are no services at all.

In an ideal world all children in Wales should be referred to a neurologist as a first port of call following a diagnosis or to confirm a possible diagnosis of ME and CFS, as they would with any other neurological condition or to a paediatrician with a special interest in ME and CFS in line with the RCPCH Guidelines on CFS/ME.[4] Our research tells us however, that most GPs are not confident about making a diagnosis. This is in part due to the fact that ME and CFS are not covered in medical schools nor covered appropriately in a GP's continuing education. It has also been our experience that GPs appear not to be interested in taking part in continuing education on ME and CFS.

The LHBs who responded with regard to children mostly mentioned Health Commission Wales as the body responsible for specialised neurological services for children. Two LHBs refer all children with a diagnosis of ME/CFS to the Child & Adolescent Mental Health team. One LHB would consider a referral for children via the IPC system due to the lack of appropriate services in their area.

3.2 Results relating to Adults

Five LHBs replied that there were specific specialised services for adults with a diagnosis of ME and CFS in their areas although when the services referred to were explained it was found they were not actually specific services for this group of patients but services aimed at any patient with fatigue as a symptom.

There are two clinics in North Wales. There seems to be some confusion over the services with not all people working for LHBs knowing about the services even though they fall within the remit of their own LHB area.

Two LHBs fund adults to go to a physiotherapy department in Cardiff for a treatment known as Multi-Convergent Therapy (MCT). One of these LHBs does say that this clinic is not a specific ME service but a service for any patient with unexplained medical symptoms. Therefore it cannot be said that this is a specialised or specific service for ME and CFS patients.

Personnel in another LHB appeared not to know of services in their area. This service is not a dedicated service due to lack of referrals but is a combined service with chronic pain patients.

There is an outreach neurological team in the South West of Wales who see patients with ME but this is not a specific service for them.

3.3 General comments and transition

Although specialist children’s services are commissioned by Health Commission Wales they do not appear to commission services for adults. Therefore there are no seamless transitional services from children’s to adult services. This is contrary to statements made in Section 7 Standard – Quality of Services of the NSF for Children, Young People and Maternity Services[5] “….The transfer from children's services to adult services is planned with the young person and their parents/carers to ensure a smooth transition” and 7.28 of the NSF for Children, Young People and Maternity Services.

The services which are available to both adults and children with ME & CFS in Wales can only be described as scant. Where there are services for adults they are either inappropriate for some, selective or both and therefore cannot be described as services for ***all*** patients. As has already been said there are no specialist services for children in Wales.

Patients with no referral path, due to lack of services, find they have nowhere to go for investigation of their symptoms and appropriate management of their condition. GPs are poorly trained and many feel impotent when people with ME and CFS visit them in their surgeries. Some show a reluctance to learn about the condition either from continuing education training, their patients or from appropriate medical literature and this increases the isolation that this patient group feel. Some GPs are reluctant to investigate or refer on to specialists for specific symptoms of ME and CFS believing they are perpetuating the patients' mistaken beliefs that there is something physically wrong with them patients therefore can become more and more ill, despairing and more entrenched in disability. Patients can become unfairly known as 'heartsink patients' due to their thick files and lack of obvious treatment.

We know of no other condition in which patients are put through a selection process for a management programme that is not going to cure them but just help them, at best, to manage their symptoms better. This could be seen as a rationing of services, or at worst, an attempt to only treat those patients for whom the service providers see a high success rate.   The complete lack of appropriate and non selective services for adults and children with ME & CFS in Wales is deplorable and should be addressed immediately.

4. Collection of Data

None of the LHBs who responded collect data on the number of patients diagnosed with ME and CFS in their area.

The figures of approximately 11,380 patients we have used to estimate the number of patients with ME & CFS in Wales is taken from figures used in the English CMO's Report on CFS/ME from 2002. A quarter of this number will be severely affected and housebound or bedbound.

Health Commission Wales have given figures of 50 – 100 children in a practice of 50,000 patients with complex chronic fatigue. This would indicate a total prevalence of children with complex chronic fatigue in Wales of 567 using an incidence of 50 children per 50,000 and 1,133 if an incidence figure of 100 children per 50,000 is used. We have estimated a total of 1,182 children in Wales with ME & CFS using the same figures as have been used in the English CMO's Report of 2002. Approximately 25% of this number of children will be housebound or bedbound.

In an "Update on Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME)"[6]. to the Health & Social Services Committee on the 5th November 2003 the then Health Minister, Jane Hutt, said as one of her recommendations that the Assembly would *"Assess the current needs and service provision across Wales."* To date to our knowledge no such assessment has taken place except by ourselves.

5. Epidemiological Studies

Few prevalence studies have been carried out on the exact numbers of patients with ME & CFS in the United Kingdom.

In the USA a surveillance study of CFS patients was carried out through physicians in four cities to “determine the prevalence, incidence, course and impact of the illness.”[7] The minimum prevalence rates discovered ranged from 2.0 to 7.3% per 100,000 of the general population

These figures were used in the Report to the Chief Medical Officer for England in the report of the CFS/ME Working Group of 2002.

In England pilot research observatories have been developed to allow the collection of prevalence figures to enable more accurate numbers of patients to be collated and also to see if subgroups exist.

6. Out of Area Treatment Referrals

Ten of the LHBs said they would sanction ‘Out of Area Treatment’ referrals for adults with ME and CFS if their GPs felt it was necessary.

Of the eighteen LHBs who responded there were just twenty seven ‘Out of Area Treatment’ referrals for specialist advice for adults with ME and CFS in four years. (Figures collected 2002 – 2006). This equates to one and a half referrals per LHB over the four year period and 0.375 of a referral per LHB per year. Considering the numbers of patients with ME and CFS in Wales this is a pitiful number of patients who are being granted ‘Out of Area Treatment’ referrals. It is not known how many patients were refused OATs although we are aware of several such patients.

There have been no ‘Out of Area Treatment’ referrals for children in Wales, and only one LHB said it would sanction ‘Out of Area Treatment’ referrals for children. It is not known whether referrals for children have not been requested or if they have been refused because Health Commission Wales are responsible for commissioning specialist services for children.

With the total lack of appropriate services throughout Wales it would be interesting to know where the rest of the patients access treatment, if they do at all.

7. Clinical Champions

There is a distinct lack of doctors in Wales who are willing to become Clinical Champions for ME and CFS. In the replies received only two LHBs were able to identify clinical champions and they were people, not necessarily doctors already working in the field. These prospective clinical champions were willing to work with adult services only.

We are aware of one other doctor who is willing to champion a service.

This means there is a paucity of professionals willing to come forward to work with adult patients and none for children.

8. Cost to Wales

The financial cost to Wales of individuals with ME and CFS who are unable to work is roughly estimated at £585,805,000. Figures of £55,000 per adult as given by a member of one of the North Wales clinics have been used to calculate this total. Add to this figure the cost of a parent having to give up work to look after their child with ME or CFS, which is estimated at £28,375,809 there is a potential total loss to the Welsh economy of £614,180,809.

The human cost to individuals and families is immeasurable and should not be underestimated or forgotten.

This money and the expertise of the patient and parent are being lost to the local economy and to the economy of Wales.

The figures quoted do not include the Carers Allowance of £46.95 per week given to people who care for a sick or disabled person for over 35 hours a week, nor does it include the cost of educating children at home or any additional equipment the adult/child with ME or CFS would need to enable them to live as independent a life as their condition will allow.

Here are some examples of how this money could be spent in Wales:

You could pay the salaries of:

- 12,203 GPs at £50,332 pa http://www.wales.nhs.uk/page.cfm?pid=4269
- 9,059 Consultants at £67,801 pa http://www.wales.nhs.uk/page.cfm?pid=4269
- 12,795 Dentists at £48,000 http://www.bda.org/about/committees.cfm?ContentID=156#salary

You could perform:

- 133,518 hip replacements at £4,600
- 19,415 heart transplants at £31,635

http://news.bbc.co.uk/1/hi/programmes/breakfast/4898158.stm

and treat:

- 29,247 women annually with herceptin at £21,000 per 1 year treatment

- 61,418 men with brachytherapy at £10,000 http://icwales.icnetwork.co.uk/0100news/health/tm_headline=prostate-cancer-still-denied-treatment&method=full&objectid=18602875&siteid=50082-name_page.html

It is important that appropriate services are provided for this group of patients both to allow the patient to care for themselves and their family in the best way they can, for them to contribute to the local and national economy and for children to access appropriate education and go on to contribute fully to the local and national economy. In saying this however, it is important to point out that by providing appropriate services it is possible to get all patients back into work as not all patients will be able to return to work because their condition is so chronic. Neither will all patients, even if they do return to work, be able to work full time or return to the same position they previously held. They will therefore need ongoing support.

The two North Wales clinics claim that they are cost effective as the savings made by the successful treatment of two patients pays for the running costs of one clinic per year. There are however no validated studies to prove or disprove this claim.

Below is a chart showing the financial cost in each individual Local Health Board area for individuals with CFS and ME and is based on the total number of patients in each Local Health Board as given in Table 1. This does not show the human cost to families nor does it show the cost to the Local Authority for social care and education for children who are too ill to attend school or for the projected loss of salaries when these children become adults.

The figures used to calculate the total cost of lost parental earnings have been taken from the Office of National Statistics and are based on average Welsh weekly earnings of *£469.80.[8]

The figures used as a basis for calculating the cost to the Exchequer of **£55,000 per annum were given to us by one of the North Wales clinics.

LHB	**Adult**	****Cost to nation in £**	**Children**	***Average loss in £ of parents salary**
Anglesey	248	13,640,000	28	684,029
Blaenau Gwent	247	13,585,000	27	659,595
Bridgend	471	25,905,000	52	1,270,339
Caerphilly	613	33,715,000	68	1,661,213
Cardiff	1151	63,305,000	128	3,127,010
Carmarthenshire	641	35,255,000	71	1,734,502
Ceredigion	282	15,510,000	31	757,318
Conwy	401	22,055,000	45	1,099,332
Denbighshire	346	19,030,000	38	928,325
Flintshire	541	29,755,000	60	1,465,776
Gwynedd	425	23,375,000	47	1,148,191
Merthyr Tydfil	197	10,835,000	22	537,451
Monmouthshire	316	17,380,000	35	855,036
Neath Port Talbot	488	26,840,000	54	1,319,198
Newport	502	27,610,000	56	1,368,058
Pembrokeshire	423	23,265,000	47	1,148,191
Powys	473	26,015,000	53	1,294,769
Rhondda Cynon Taff	833	45,815,000	93	2,271,953
Swansea	815	44,825,000	90	2,198,664
Torfaen	325	17,875,000	36	879,466
Vale of Glamorgan	443	24,365,000	49	1,197,050
Wrexham	470	25,850,000	52	1,270,339
Totals	10,651	£585,805,000	1,182	£28,375,809

9. General comments on Services

There are two CFS clinics in North Wales offering a management programme only. They do not offer a diagnostic service. The service is described in more detail below. All patients go through a selection process. Patient testimonies tell us that these clinics do not offer the services that they expected, nor did they find them of benefit. These clinics could not be described as appropriate for all patients.

There is an inpatient service based at Bronllys Hospital, Brecon. The approach from this clinic is described in more detail below. Briefly this service offers a programme of group Cognitive Behavioural Therapy (CBT), Graded Exercise Therapy (GET) and relaxation. All patients go through a strict selection process before being accepted on the course. It is accepted by the clinic that not all patients are suitable for this programme.

The other treatment that has been mentioned previously in this report is Multi Convergent Therapy (MCT). This is explained in more detail below. One of the LHBs in whose area this treatment is offered has already offered the information that this treatment is not aimed specifically at patients with ME and CFS but at any patient with medically unexplained symptoms. The other LHB in whose area this clinic falls has not specified the patients for whom this treatment is suitable or aimed at.

10. Treatment Options

10.1 Cognitive Behavioural Therapy

There have been two studies one showing that CBT is no better than counselling[9] and the other showing that counselling is cheaper that CBT.[10]

There is also recent evidence to suggest that group CBT, which is one of the treatments offered at both North Wales clinics and at Bronllys Hospital, does not improve cognitive function nor quality of life[11] Furthermore CBT has not been trialled on the severely affected nor children and cannot therefore be seen as a treatment suitable for all patients.[12]

10.2 Graded Exercise Therapy

Graded exercise is a therapy in which the patient increases their aerobic capacity by increasing the amount of exercise they can tolerate. Graded exercise has not been trialled on the severely affected nor on children and again GET cannot be seen as a suitable treatment for all patients.[13]

10.3 Multi Convergent Therapy

Multi Convergent Therapy (MCT) has only been trialled on small numbers of patients and involves CBT, Connective Tissue Massage, meditation and fitness training. The patients were collected mainly from a ‘Chronic Fatigue Clinic[14] although there is no such clinic within the hospital where this treatment is offered nor close by. One of the LHBs in whose area the centre which practices MCT is based have already offered the fact that MCT is suitable for anybody with medically unexplained symptoms and not specifically for ME and CFS patients.

10.4 Pacing

Pacing[15] has been shown through patient surveys to be the most beneficial and preferred method of managing their condition. Pacing is defined as finding a level of activity, both mental and physical, by which a patient can manage their condition without exacerbating their symptoms. Pacing is also sometimes defined as listening to your body and not increasing your activities regardless of an increase in your symptoms either mental or physical. Some patients also practice switching. Switching is defined, for example, as a patient whilst undertaking a physical activity tiring they switch to using their brain for reading or listening to music. The opposite is also true by switching from a mental activity on tiring to a physical activity.

11. Overview of Existing Services

11.1 Bronllys Hospital

The CFS inpatient clinic based at Bronllys Hospital in Brecon is not a diagnostic service. Entry to the management programme offered at Bronllys is by a selection process and it is accepted that not all CFS patients are suitable for this programme.

The treatment protocol used at Bronllys can be found at www.wales.nhs.uk/sites3/documents/470/new**cfs**.doc and consists of a 3 week inpatient programme of graded exercise, group cognitive behavioural therapy, relaxation and education in improving sleep hygiene. This is done over 5 days with patients returning to their own homes at weekends to practice what they have learnt in the week.

As there are not enough CFS patients being referred to Bronllys to warrant separate courses an integrated course is being run with chronic pain patients.

11.2 North Wales Clinics

There are two CFS clinics in North Wales. Patients are selected using the Oxford criteria and by way of an interview. These two clinics are not diagnostic clinics. The treatment protocol is listed below.

The benefits to the eighty patients who go through the two clinics in North Wales a year is minimal. There is no published data on the results of the clinics nor are they audited although it is said that eight patients per year are able to return to work after treatment. This is just 10% of the patients seen annually. There is no long term follow up of these patients and it is not known if they return to their former employment. Some patients have said that returning to work has meant that their family and social life has been totally lost.

12. Treatment Protocols

12.1 BrynSeiont Clinic, Caernarfon & Connah's Quay Clinic, North Wales

Clinics are held every week barring the summer recess. Each treatment session lasts 8 weeks and each session for 2½ hours. They do not treat housebound patients. These are adult clinics and they do not treat children.

The protocols for both North Wales clinics are broadly the same:

GP referral only, these are non diagnostic services, therefore a GP has to have made the diagnosis first.

Fibromyalgia and M.E. are viewed as one and the same disorder at these clinics. If the patient has suffered with depression in the past this is seen as a possible pre-cursor to developing M.E. in the future.

When patients are referred to either of these clinics before they are accepted for treatment they have an appointment with the lead professional(s) who assess the patient's suitability for the course. Not every patient is found to be suitable. The reasons for this were not given, nor were the details of the initial assessment divulged other than some PROMs forms including the Short Form 36 (SF36) are completed by the patient before the initial assessment. We understand the Oxford criteria is also used in patient selection, although this criteria is a research and not clinical criteria.

This is a multi-disciplinary approach with a GP, Psychologist, a physiotherapist and a dietician involved in the sessions or, as is the case in Connah's Quay all the above excepting a GP.

The treatments offered at these clinics are spread over 8 weeks and are described as group sessions which last for 2½ hours. They do not see the programme they offer as the same or similar to the Expert Patient Programme although on examining both programmes there are several similarities.

It was stressed they do not offer a cure for CFS, only management of the condition although they see success as returning patients to the workplace.

The subjects covered over the 8 weeks sessions are subject to slight change but the general themes are:

1. Cognitive behavioural therapy – talking to patients and teaching them how not to over rest or overdo activities

2. Assertiveness training

3. Teaching patients how to eat a good diet

4. Sleep and sleep hygiene

5. Relaxation therapy

6. MCT

7. Acceptance

8. Mindfulness exercises to teach the patient to live for the day

9. Breathing re-training

10. Treatment of anxiety

11. Pacing up/no GET programme

12. Pre-emptive resting

A drug treatment which may be used for sleep is amitryptiline.

Patients are encouraged to keep a diary which can be discussed with one of the professionals, individually, if required.

It was suggested that the success rate of the approximate 80 patients who go through these clinics per year is a 70% significant improvement with just 8 patients able to return to work.

There are some differences in the interpretation of some management options. At bullet point 10 Pacing up/no GET programme is stated. Pacing is a management tool in which the patient listens to their body whereas GET is a management tool in which the patient carries on without listening to their body. There have been no research studies carried out on Pacing as the patient practices it, although this is the favoured management tool used by patients. There are a few poor studies on GET but these studies cannot be said to be suitable for all patients as has been highlighted in the English CMO's Report of 2002.[13]

12.2 Expert Patient Programme

The Expert Patient Programme[16] can be accessed by anybody suffering a long-term health condition. Patients attend courses that last for 2½ hours over 6 weeks. Courses are taken by two trained volunteer tutors, some, if not all, have long-term health conditions themselves.

These courses help patients to manage their conditions by teaching them coping strategies such as:

♦ How to recognise and act on symptoms
♦ Reduce stress
♦ Recognise the importance of using medication properly
♦ Get the most out of the health services by using them effectively
♦ Manage the distress and depression that can come with a long term health condition
♦ Take appropriate physical exercise
♦ Manage relationships with health professionals, family and friends
♦ Manage a healthy diet

The courses are free and attendance is voluntary. There have been some pleasing results from people attending these courses.

13. Appropriate Management/Treatment

When patients, whether they be adults or children, present at their GP surgeries with the possible symptoms of ME & CFS we consider that early management advice is crucial to aid recovery and to prevent decline into chronicity. Early diagnosis, advice to rest in the early stages and symptom control can be beneficial. Patients prefer to manage their condition by pacing themselves.

A multi disciplinary approach to this illness is also advised. The involvement of a dietician, referral to a consultant if necessary for investigation of symptoms and a counsellor to help patients come to terms with the limits of their condition if necessary, are all ways in which GPs can help.

Where a child is the patient the same advice as above is relevant as well as supporting the family through a very difficult time. If necessary, referral to a paediatrician for confirmation of the diagnosis of ME and CFS may be advisable to enable appropriate medication to be prescribed for pain etc. Medical certificates to excuse the child from games lessons and liaison with the school and LEA to input suitable education for the child are also an important part of the management of ME and CFS in a child or young person. Education for the child or young person could be home tutoring as provided by the LEA or internet based learning, whichever is the most appropriate for the child. Some children may be too ill to be educated. Continuing support for young people when they are post 16 to access education is important if they are to reach their full potential.

14. Recommendations

1. We would like to work with both the Assembly and Local Health Boards to foster interest in and identify professionals to champion appropriate services.

2. We call on the Welsh Assembly Government to undertake a prevalence study of G93.3 ME & CFS patients using the World Health Organisation’s ICD10 classification of diseases so that accurate figures of patients, both adult and child, can be gathered.

3. We would like domiciliary services developed for the severely affected person with ME.

4. We would like appropriate services for children and appropriate transitional services for young people in line with the recommendations in the NSF for Children and Young People and Maternity Services.

5. ME, CFS & PVFS to be included in medical school training so that all new doctors, nurses, physiotherapists and Occupational Therapists completing their training feel qualified in diagnosing and managing both adults and children with these conditions.

6. All GPs to undergo post graduate training in ME, CFS & PVFS to ensure they feel confident in diagnosing and managing these conditions in adults and children in their practices.

16. References

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15. WAMES Pacing leaflet www.wames.org.uk

16. Expert Patient Programme: http://www.eppwales.org/

Appendix 1

Appendix 2

Appendix 3

Cymdeithas Cefnogi
ME & CFS Cymru

Welsh Association of
ME & CFS Support

28th April 2006

LHB Letter

Dear

We are writing to you on the advice of the Health Minister, Dr Brian Gibbons. We are conducting a mapping exercise of all Local Health Boards in Wales with regard to the provision and commissioning of services for both adults and children with the condition of Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) at both primary and secondary care level.

To this end I wonder if you would please answer the following questions specific to your own LHB area. In your reply can you specify whether the services you commission, if you commission any, are for children (16 and under) or are adult services and whether they are primary or secondary care services.

1. Are there any specialist services in your area for?
   - Adults
   - Children with ME/CFS

   are they :
   - Primary or
   - Secondary Care Services

2. Does your Local Health Board collect figures on the number of
   - Adults
   - Children

   with a diagnosis of ME/CFS?

3. In the absence of any specialist services for patients with ME/CFS in your area does your LHB commission and pay for any “Out of Area Treatment” referrals for?
   - Adults
   - Children

4. (a) If your LHB does commission “Out of Area Treatment” referrals for ME/CFS patients how many have you sanctioned in the financial years?
   - 2001
   - 2002
   - 2003
   - 2004
   - 2005

4. (b) How many were for?
   - Adults
   - Children

5. Are you in discussions with any health professionals with regard to the inputting of specialist ME/CFS services?
   - Adults
   - Children

6. Are you aware of any health professionals in your LHB area who would be willing to champion a service for
   - Adults
   - Children

   With ME/CFS?

We would like to work with Local Health Boards and others to raise awareness of ME/ CFS and attempt to identify clinical champions in both primary and secondary care, would you be prepared to work with us to this end?

I look forward to your reply.

Yours sincerely

Sylvia Penny
Co-Secretary

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WAMES

Cymdeithas Cefnogi
ME & CFS Cymru

Welsh Association of
ME & CFS Support

16th August 2006

Health Commission Wales

Dear

Mapping exercise on Special Services for children with ME and CFS

We have been advised to write to you as Medical Director of Health Commission Wales.

We wrote to Mr Andrew Ferguson on the 31st May 2006, copy letter enclosed, requesting information on specialist services commissioned by yourselves for children and young people with Myalgic Encephalomyelitis (ME) and Chronic Fatigue Syndrome (CFS) in Wales. We have been advised by several Local Health Boards that the commissioning of such services is the responsibility of yourselves.

Having received no acknowledgement of the letter nor a reply to our questions I progressed this letter by telephone with Mr Ferguson in late July. It is with regret that Mr Ferguson could not give me a timescale for a reply. In fact he intimated that we would not receive a reply for considerable months to come.

Would you kindly look into the matter for us and advise us when we could expect a definite date for a reply to our questions from yourselves please? This will then enable us to include this information in a report for presentation to the Welsh Assembly Government and others.

I look forward to your early reply.

Yours sincerely

Sylvia Penny
Co-Secretary