

Worcestershire M.E. Support Group Membership (Helpful-Unhelpful)

people with M.E. (Myalgic Encephalomyelitis), CFS (Chronic Fatigue Syndrome), PVFS (Post Viral Fatigue Syndrome) and FMS (Fibromyalgia)

(Information taken from completed membership questionnaires - September 2003 / August 2004)

Post code	m/f	d.o.b.	onset	diagnosis	diagnosis of	diagnosed by (GP and / or Consultant)	helpful	unhelpful	additional Info
DY11	m	1941 - 1960	-	none	CFS	Con - Dr Alastair Miller			
WR14	m	before 1940			FMS		Two only sources of success - a. one of the scan type therapies (I believe radio-sound or similar) now unobtainable). b. present one - unofficial herbal remedy - seems to be good for fibromyalgia.	Most Doctors - all recommended pills/potions - diets - acupuncture - ointments (inc one stupid doctor's trial run of psychiatry, plus much much more).	
WR2	f	1941 - 1960			PVFS	GP	Listening to others.		
PL3	f	1941 - 1960	1989		M.E.				
WR11	f	1961-1980	1989	not yet	suspected CFS/PVFS		Milk thistle tincture; nurozan memory tablets; Omega 369 capsules. Pacing, slowing when necessary; core balance strength exercise; walking; Tai chi. Soups; nutrition.	NHS staff - uncooperative. Exercise - usual ones, esp aerobic. Rigid plans. Yoga. Medication - anti-inflammatory, antibiotics. IBS medication.	
DY12	m	1941 - 1960	1975	1985	M.E./CFS	J D Vries			
WR5	f	1961 - 1980	1984	1985	Royal Free Syndrome		Digesics & Nurofen for muscle pain; Phenergan for sleep. Rest.	Exercise. Even ironing or hoovering can cause widespread muscular aches. Exercise also results in poor sleep and anxieties. Osteopathic massage; homeopathy - diluted virus in drops; Chinese medicine; Acupuncture; Reiki; Reflexology; Removal of amalgam from teeth; 'vital' toddies.	

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WR14	f	1941 - 1960	1985	1985	PVFS	Dr Dyer, Worcester Royal.	Conservative Management and careful pacing.	Endlessly hearing about CBT and graded exercise which are not appropriate for real M.E. CBT was never intended as a therapy for people with severe physical illness. The 'inventor' of the technique has said so himself. Graded Exercise is totally inappropriate in genuine M.E. As Dr Ramsay said "if GE cures it, it wasn't M.E."	
DY13	f	1941 - 1960	1984	1987	M.E.	Con - West Suffolk Hosp, Bury St Edmunds	Homeopathy	GPs	
DY11	f		1984	1987	M.E.	Con - Dr Booth			
WR14	f	1941 - 1960	1986	1987	M.E./CFS/ PVFS	Consultant - Richard Lewis	Rest/pacing. Living within energy limits pain killers.	homeopathy. overdoing/pushing myself despite symptoms.	Ill in bed all the time.
DY13	f	1961 - 1980	1987	1987	M.E./PVFS	PVFS - GP Dr Horton M.E. - Con Dr Miller	Rest / pacing		
WR14	f	before 1940	1987	1987	M.E.	GP	Supportive doctors - I have had four due to house moves. Also Dr Glover and his team at Southmead Hospital (Glos). Support from my family, especially my husband. Belonging to M.E. Groups in Gloucestershire. Books on M.E., especially Dr Charles Shepherd's book. Abstaining from alcohol. Oat bread instead of wheat bread. Gaviscon; paracetamol; glucosamine with condroitin.	People telling me about cures. Depression tablets - I have never suffered from depression - prescribed twice only. In the 80s I tried Evening Primrose Oil to no avail.	
WR2	m	1941 - 1960	1980s	1988	M.E./CFS	Con - Dr Stevens, Neurologist	Melatonin	Psychiatrists	

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WR10	f	1941 - 1960	1986	1988	M.E.	Dr Cullis, Leicester	Rest and relaxation	most therapies	Too ill to attend meetings
WR6	f	before 1940	1986	1988	M.E.	Con - Dr James (retired)	Prozac	Too many to list	
DY10	f	before 1940	early childhood	1989	M.E./FMS	Con - Prof Adrian Williams (Q.E. Birmingham)	HRT helps everything. Pro-plus tablets gives a lift to fatigue. Tylex - strong medication for severe pain. Diazepam 2-5 mg & paracetamol 1000 mg for pain and sleep. Sodiam bicarbonate & Vit C for allergic reaction to food.	Amitriptyline. Thyroxine. Magnesium injections. Vit B12 injections.	
WR6	f	1961 - 1980	1983	1989	M.E./FMS	Dr R Davies	Zolpidem - to sleep		
WR14	m	1941 - 1960	1989	1989	M.E.	GP - Dr John Hunter (since retired)	Herbal medicine prescribed by John Hyde of Hydes Herbal Clinic in Leicester		
WR1	f	1941 - 1960	1984	1990	M.E./CFS	GP - Dr Laidlaw; Neuro-Con - Dr Milne Anderson	Reflexology / massage and aromatherapy. Diet improves by 40% & supplements.	Amitriptyline 10 years ago. Stress - unhelpful people. Unnecessary paperwork - DLA!!	
BS15	f	1961 - 1980	1990	1990	PVFS	Consultant			
B61	f	1941 - 1960	1984	1991	M.E.	Dr Shelagh James	Clomipramine for depression; magnesium injections; spiritual healing; pacing.	Aromatherapy, Enada, Efamol, multi minerals and vitamins, Q10 Intra	
B97	m	1941 - 1960	1990	1991	M.E.	GP	Amitriptyline (low dose) to help with sleep disturbance and muscle pain.		
B61	f	1941 - 1960	-	1992	CFS	GP - Dr Hall			
WR10	f	1941 - 1960	1988	1992	M.E.	Dr David Wilson	Graded activity	Drugs for sleeping - side effects.	
WR5	f	1941 - 1960	1991	1992	M.E.	Dr Richards	Small dosage of amitriptyline (helps sleeping)		

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DY11	m	1941 - 1960	1992	1992	M.E.	Consultant	Forever Freedom Drink		
WR11	f	1941 - 1960	1992	1992	M.E.	Physician at Worcester	Homeopathic Hospital, Bristol - 2 years. Diet - Anti candida. Regular afternoon rest.	Physiotherapy. Misinformed media. Lack of understanding.	
WR2	m	before 1940	1991	1993	M.E.		Rest and pacing.	Anything else	
DY11	f	before 1940	1991	1993	M.E.	Dr Booth	Lying flat on back at regular intervals. Relaxation tapes. Amitriptyline, immunical; acupuncture - needs a build up to benefit; Oceans 72 from NutriPlus kept me free from colds & bronchitis; most of all Dr Garth Nicholson's six-week doses of different antibiotics;	Growth hormone, although my growth hormone was very very low. Trying to push myself a little further each day or week; graduated exercises.	
WR10	f	1941 - 1960	1992	1993	M.E.	GP - Dr Nigel Paine (deceased)	Complementary therapies.	Negative media coverage, ie 'yuppy flu'.	
WR14	f	1941 - 1960	1993	1993	CFS		Yoga	NHS offered anti-depressants, GET and CBT - none of which seemed to have any bearing on my conditions - I didn't take them up.	
DY13	f	1941 - 1960	1994	1994	M.E./PVFS	Dr Chew			
WR14	f	1961 - 1980	1994	1994	M.E./CFS	GP			
WR10	f	1941 - 1960	1970	1995	M.E. & OP poisoning	M.E. - Dr E Dowsett OP - Dr G Jamal (2000)	Nutrition, pacing, complementary therapies (homeopathy, osteopathy, acupuncture, passive physiotherapy.	Progressive exercise therapy, inflexible thinking in some medical and educational practitioners.	
B97	f	1941 - 1960	1987	1995	M.E.				Not well enough to attend meetings.
WR11	m	1961 - 1980	1993	1995	M.E./CFS	Con - Dr Alan Franklin (deceased)	Advice & medication given by Dr D Dowson. Amitriptyline.	Diets which exacerbated food intolerance & allergy. Immunocal.	

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WR14	f	before 1940	1994	1995	M.E.	Osteopath.	Protein at every meal. Sessions with Bio-energy practitioner, as M.E. caused by sleeping in electro-magnetic field, polarising energy cycle and stress, but Treatment necessary by Seka Nicolich, in London) to stop steady decline.	Stress, both mental and physical, caused energy problems.	housebound. extremely low energy. in bed most of the time
B97	f	1981 - present	1990	1996	M.E.	Con - Dr Alan Franklin (deceased)	Main thing that has been most helpful over the years has been osteopathy for the pain.		
WR6	m	1941 - 1960	1991	1996	M.E.	Con - Dr A Miller	Homeopathy; acupuncture; traditional Chinese medicine; osteopathy; relaxation/visualisation; frequent small meals freshly cooked. Gentle exercise; sunlight; warmth	Distance travelling for medical appointments; anti-depressants.	
WR10	f	1986	1995	1996	CFS & Neuro-toxic poisoning	CFS - Dr A Franklin (deceased) OP - Dr Jamal (2000)			
WR10	m	1984	1995	1996	CFS & Neuro-toxic poisoning	CFS - Dr A Franklin (deceased) OP - Dr Jamal (2000)			
WR2	f	1961 - 1980	1995	1996	M.E.	GP - Dr M Cullen, Lowesmoor	Time off work, Complementary therapies - aromatherapy, reflexology, homeopathy, cranial osteopathy, Brine Baths.		
WR5	m	1961 - 1980	1989	1997	M.E.	Con - Steve Sirman, Neurologist, Selly Oak Clinics	Cranial Osteopathy; CBT at Worcester Newtown Hospital; deep relaxation; lack of physical activity; flat screen computer; car and blue badge; 5m valium to sleep, 2 gms Vit C - up to 6 gms daily, zinc, Vit B, Binkgo Biloba, Efamarine.	Spasmonal for IBS; Kidderminster M.E. Unit; Amitriptyline, Physiotherapy	

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DY9	f	before 1940	1996	1997	M.E.	Mr Delamair	Dettox diet. Irritable Bowel problem nearly cured whilst on dairy free diet (main problem - cheese). Supplement minerals and vitamins - healthy fresh diet. Heat. Aromatherapy oils in bath daily - not shower. Aromatherapy massage. Go with it, don't try to fight it. Once improving, exercise. Prayer & positive attitude to the future. Listening to various symptoms, talking in a group of M.E. sufferers. Also, reading materials, library etc	People with negativity towards M.E. Friends not understanding the situation when you 'look' well. Alcohol over excess.	Two Hepatitis B vaccinations at onset of M.E.
DY14	m	1961 - 1980	1995	1998	M.E.	Con - Dr Booth			
DY11	f	1941 - 1960	1996	1998					
WR13	f	1941 - 1960	1997	1998	CFS/FMS	Con - Dr A Miller	Reflexology with aromatherapy oils. Marjoram oil in hot bath. Medical herbalist for pains. Psychotherapist - using cbt. Stretching exercises taught by a physiotherapist.	Acupuncture - very painful due to sensitive nerve endings. Amitriptyline - made me feel worse.	
WR6	f	1941 - 1960	1997	1998	M.E.	GP - Dr I Teague (1998) Con - Dr A Miller (1999 confirmation)	Complementary Therapies. pacing - learning to live within the boundaries it places on me.	Anti-depressants, antibiotics and most conventional medicines.	
WR2	m	before 1940	1997	1998	M.E./CFS	Dr Holehouse and Dr Miller	Anti-depressant. & Kidderminster clinic under Dr Miller	Usual misunderstandings	
WR6	m	1941 - 1960	1998	1998	CFS	GP	Magnesium injections. Diet to help IBS symptoms.	Acupuncture, homeopathy, Bowen Technique, etc.	
WR6	f	before 1940	1987	1999	M.E./FMS	Con - Dr A Miller	16 sessions of cognitive therapy and support, and my positive approach to life.	Any medication, especially anti-depressants.	

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HR4	f	1941 - 1960	1995	1999	CFS	Con - Dr Rees	Dothiepin 50 mg - helps with pain relief. Reflexology- message for balancing hormones, temperature, headaches, etc.	Trying to exercise - except very simple yoga tape. I have found Angela Steven's tape "Yoga the gentle way" very helpful.	
WR5	f	1941 - 1960	1996	1999	CFS	GP - Dr Richards			
WR3	m	1941 - 1960	1997	1999	CFS	Con - Dr A Miller	NHS Acupuncture (from 3 weeks onwards)	Chinese Astrology Acupuncture	
WR4	m	1961 - 1980	1997	1999	M.E.	GP - Dr Milner Con - Dr A Miller	Pacing, reducing the amount of things I do. Aloe Vera juice for digestion.	Expert Patient Programme. Acupuncture. Anti-depressants caused daytime drowsiness and didn't help sleeping	
WR9	f	1961 - 1980	1998	1999	CFS	GP - Dr A Georgiou	Counselling; spiritual healing; massage; Reiki; Prozac (short term & cyclical); Guarana (herbal stimulant); Evening primrose oil.	Acupuncture - extremely painful. Herbalist remedies (eg St Johns Wort etc).	
B97	m	1941 - 1960	1998	1999	M.E./CFS FMS	GP - Dr Parkinson / Con - Prof Kendall	Amitriptyline. Some analgesia. Gabapentin initially.	Q10, Co-enzymes, Enahada etc. all alternative medication tried.	
WR3	f	1985	1998	1999	CFS	Con - Dr A Franklin (deceased)	Eliminating negative pressures.	Past. Education non knowledgeable or aware.	
HR8	f	before 1940	1998	1999	M.E.	GP - Dr Jonathan Pearce (diagnosis on phone)	Liquorice, CoQ10, Efamarine multi vit/mineral, magnesium ascorbate (vit.c.powder), B12 sublingual, B6 Immunocal, malic-acid, diazepam, selenium, zinc.	Ordinary painkiller and prescribed anti nausea drugs, motilium & metaclopramide & wrist bands.	I have severe M.E.; bedridden, cannot attend meetings,
WR1	f	1961 - 1980	1999	1999	PVFS	GP	Rest. Dothiepin Understanding GP. Healing. Herbalism. Accepting my illness. Speaking to someone else with M.E. CAB. Bach Flower remedies. Balancing 'doing enough' with 'not doing too much'.	Osteopathy. Personnel Manager at work.	
WR14	f	1981 - present	1999	1999	M.E.	GP			

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DY11	f	1941 - 1960	1983	2000	FMS	GP - Dr P Thompson	Complementary therapies, especially craineology. Relaxation techniques. Pain relief - medication. Probiotics / Aloe Vera / Immune system boosters.	Lack of information and time and discussion. Counselling (believe correct kind may have helped), Disbelieving attitude by professionals.	
DY14	f	1981 - present	1990	2000	M.E.	Con - Dr Newrick (Endocrinologist)	Dr Sarah Myhill, Knighton	Graded exercise; Cognitive behaviour therapy; Kidderminster Hospital.	Severe M.E.
WR4	m	before 1940	1993	2000	M.E.	Con - Dr A Miller	My carer (wife) Forever Living's Aloe Vera.	Expert Patients Programme.	
WR7	f	before 1940	1994	2000	M.E./CFS	Con - Dr Spillane, Neurologist	Rest at intervals during the day. Amitriptyline. Cipramil, Clonazepam - for leg pain.	Exercise - except walking.	
B98	f	1961 - 1980	1998	2000	CFS	Con - Prof L Findley	Help groups, M.E. magazine	Vit B injections.	
DY12	f	1941 - 1960	1996	2001	PVFS	Con - Dr Booth & Con - Dr A Miller	Nothing specific.	Vit B supplements - no difference. Anti-depressants even low dosage.	
WR14	f	1941 - 1960	1997	2001	M.E./CFS/PVFS	Con - Prof Pinching, St Barts, London	Self Management techniques; yoga, anti-depressants, HRT		
DY10	f	1961 - 1980	2000	2001	CFS	Con - Dr Newrick	Roderick Lane's book 'The Adam & Eve Diet' - treating adrenal stress; reflexology; metamorphic technique; cranial sacral therapy' aromatherapy.	My GP.	
WR4	f	1941 - 1960	2000	2001	M.E.	GP	Reiki. Reflexology. Metamorphic therapy.	Stupid people who tell me to have an early night!	
WR11	m	1961 - 1980	2000	2001	M.E./PVFS	Con - Prof Richard Lewis	Acupuncture at a Chinese Doctors only thing that has helped in first 3 years. Started acupuncture again in May 2004, date of 1st relapse. Taking 50 mg amitriptyline.	Doctors surgery - when started to feel ill in May 2004 all I was told was that there is nothing new, and signed me off for one week, have now been off work from 18 May to present.	
WR4	m	1961 - 1980	2001	2001	CFS	GP - Dr Milner Con - Dr V Patel (Nuneaton)			

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WR2	m	1990	2001	2001	M.E./CFS	Dr Castling, Worcestershire Royal	Views on the internet from: a. other sufferers, my sons own age b. information from your website And, Dr Castling understanding	Local GPs countrywide who: a. were unable to identify/help my son. b. The whole system's lack of understanding and stubborn reluctance to move away from 'yuppie flu' c. Educational format within school.	
WR6	m	1988	2001	2001	CFS	GP - Dr Teague Con - Dr Frost, Paediatrician	Pacing, rest, withdrawal from school except in measured doses. At first high doses of multi-vitamins, essential fatty acids. Vit C seemed to fight off colds.	Reflexology - Simon thought there was no benefit.	
DY11	f	1941 - 1960	2001	2001	CFS/FMS	GP - Dr Gates Con - Dr Miller			
WR5	f	1941 - 1960	not sure	2002	M.E./FMS	Con - Dr Miller			
WR14	f	1961 - 1980	1981	2002	M.E./FMS	Con - Dr Sarah Myhill, Knighton.	Dr Myhill's approach, homeopathy, cranial - sacral therapy, pacing, rest, supplements, diet modification, amitriptyline (low dose = sleep.	Physiotherapy	mornings are my best time.
WR14	f	before 1940	1990	2002	M.E.	GP - Dr B.A. Tuck	Pacing. Care with blood sugar. (severe arthritis as well). Acupressure & some help with homeopathy - thought this does not help with severe pain.	Being told medically to be more active when at the lowest time of day. Unable to take anti-inflammatory drugs for widespread arthritis. Homeopathy affects are different due to 25 Atenolol tablet for b/p and heart irregularity - low does. More helpful before the Atenolol 25.	housebound
WR14	f	1941 - 1960	1996	2002	CFS	Con - Dr Miller	Pacing; going to bed when necessary; using a wheelchair when very tired or in pain and want to go out; gluten and dairy free diet; Having a GP who listens; Atenolol for heart palpitations; Tramadol for nerve pain.	People who think ME/CFS is purely psychological; local anaesthetic injections, (ie at dentist); being pushed to do too much; psycho-analyst/cbt therapy.	

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WR4	f	1961 - 1980	2000	2002	M.E./FMS	GP - Dr Bellamy			seeing consultant on 17.11.03
DY12	m	1941 - 1960	2001	2002	CFS	Con - Dr A Miller	Bowen Technique. Echinacea & 500 vit C daily.	Anti-depressants	
WR9	m	1961 - 1980	2001	2002	CFS	GP - Dr Leddy			
WR10	f	1961 - 1980	2001	2002	M.E./CFS	Con - Dr A Miller			
B60	f	1961 - 1980	2002	2002	M.E.	Con - Professor Williams	Homeopathy; massage; graded exercise.	Vitamin infusions.	
WR10	f	1961 - 1980	2002	2002	M.E./CFS/ PVFS	GP - Dr Grant, Mr Geraint Fuller			
WR12	f	1961 - 1980	1990	2003	CFS	Dr A Miller & Dr Sarah Myhill	Nutritional therapy for dizziness and general fatigue. Angela Stevens tapes.	Graded exercise at too higher level. Magnesium capsules = constipation and severe eye problems.	Severe M.E. Most of the time in bed.
WR14	f	1941 - 1960	1996	2003	CFS	Con - Dr A Miller	Aromatherapy massage and yoga.	Ignorance	
B43	f	1961 - 1980	1998	2003	M.E./FMS	GP			
WR14	f	before 1940	1998	2003	M.E.	GP - Dr Sefton-Fiddian, Con - Dr A Miller	Nothing	Graded Exercise, Vitamins	
WR2	f	1941 - 1960	1999	2003	CFS	Con - Dr James, Endocrinologist at Worcester Royal.	Reacted badly to flu vaccination in November so a Dr Smallbone sent me a homeopathic remedy to counteract this bad reaction. Dr Smallbone uses orthodox treatment with complementary medicine. He lives in Buxton and gives telephone consultation.	Flu vaccination.	

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WR2	f	1941 - 1960	2000	2003	FMS	Con - Dr Miller	Sleeping better after metamorphic technique. Obtaining news from members in newsletters. Its good to get newsletters, as Doctors don't seem to come up with ideas and Dr Miller has seen me improve, so unless I get worse he is not really interested!		
WR14	f	1961 - 1980	2000	2003	M.E./CFS	Con - Dr A Miller	Herbal medicine from a herbalist. OT helpful.	Anti-depressants.	
B61	m	1993	2002	2003	PVFS	Con - Dr Nathavitharina			
WR10	f	1961 - 1980	2002	2003	M.E.	Dr Katherine Young			
WR8	f	1961 - 1980	2002	2003	CFS	Con - Dr Jenkins, diabetic and metabolic centre			
WR5	f	1941 - 1960	2002	2003	CFS	Con - Dr A Miller	Positive thinking; pacing; learning to say no; rest; organic food; Malvern water; taking no medication; getting up at a regular time; Relaxation; Reiki; Indian Head Massage; Vit C; Stress reduction; trying to do as many pleasurable things as possible; setting myself small daily targets.	Sleeping tablets; Lack of positive diagnosis - based on exclusion. GP who thinks its all depression. Consultants who have no knowledge of M.E. Lack of holistic view of health of the body in Western medicine. Lack of knowledge about what causes ME/CFS/FM. Lack of funding for research. Being visited by an Occupational Therapist with no real knowledge or understanding of the illness.	
DY10	m	1961 - 1980	2002	2003	CFS	Dr Wilkie	Exclusion diets, pacing, friends.	Just about everything.	
WR3	f	1941 - 1960	2002	2003	M.E.	Con - Dr A Miller			

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CT1	f	1961 - 1980	2003	2003	PVFS	Con - Prof Findley (Essex)	Cognitive behaviour therapy; graded exercise programme; amitriptyline	Homeopathy	
WR3	f	1941-1960	1990s	2003	CFS/PVFS	GP - Dr Milner	Starflower oil, ginseng, magnesium, St Johns Wort - daily. Co-enzyme Q10, alpha Lipoic Acid, L Carnitine - when condition worsens. Homeopathy - via Homeopathic doctor. Peace and quiet! Yoga and Pilates when well enough.	Vaccination - pneumovacc, meningococcal, hepatitis physio. I feel it is these vaccinations that have caused CFS in me, although being asplenic has meant post viral fatigue has been a problem at times.	
WR10	f	1961-1980	1986	2004	M.E./CFS	Con - Prof JE Davies / Dr Miller	Solgar vitamins - omnium, zinc citrate 30 mg, calcium, magnesium, cod liver oil, selenium, sibenam ginseng. Bach remedies - various. Acupuncture - for pain relief. Reiki - fortnightly. Dothiepin - taken at night.	Meetings, noise, appointments, etc, - anything which causes stress. Exercise. Anaesthetic trigger point injections, as given by private con - Prof J E Davies. (these are effective when received accumulatively, but couldn't afford to do that)	
DY11	m	1941 - 1960	2002	2004	CFS/PVFS	GP - Dr Tarzi	The knowledge that others are experiencing the same symptoms. So many organisations I had no idea existed.		
WR5	f	1941 - 1960	2002	2004	CFS	Con - Dr Jenkins, Endocrinologist at Worcester Royal			

DISCLAIMER

Please note

Views and opinions expressed in this document are the personal beliefs of the individual contributor.

They may not represent the feelings of all members, and are not necessarily those of the Worcestershire M.E. Support Group.

The committee and Worcestershire M.E. Support Group do not endorse or recommend any particular treatment, therapy or practitioner. Practitioners and treatments mentioned are for information only.

Any treatment, tests or remedies mentioned may be tried at your own risk, but preferably after consultation with your GP.