

ME in Wales

2008-2009: the WAMES Review

Our vision is for a Wales where adults and children with ME and CFS and their carers, are taken seriously and treated with respect, where diagnosis, treatment and services are accessible without a battle.

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Cymdeithas Cefnogi
ME & CFS Cymru

Welsh Association of
ME & CFS Support

ME (Myalgic Encephalomyelitis) is a potentially disabling and chronic neurological condition which affects the brain at a physical, mental and emotional level. The major characteristic is that symptoms become worse after physical and mental exhaustion and can fluctuate, leaving patients and families alike confused and frustrated. The term Chronic Fatigue Syndrome (CFS) is sometimes used interchangeably with ME but is also sometimes used as an umbrella term for unexplained illnesses with a strong fatigue element. There is currently no cure and no treatment which helps all patients.

Introduction

2008 and 2009 have been a time of change as WAMES has built on the constitutional changes made in 2006 and altered the way the management committee works. We have clarified our roles, made it easier for new volunteers to slot in to our work and advertised our volunteering opportunities more widely.

In 2009 the discovery in the USA of the XMRV virus in people with ME and CFS got the researchers scrabbling to recreate the

results and gave much hope to those with the condition and their families. The outcome of that discovery is still unclear but it is exciting to see so many people discussing ME research seriously.

Another step forward for people in Wales was taken by the Health Minister in August 2009 when she announced she was setting up a Task & Finish Group on CFS/ME services.

Aim and objectives

Our goal remains the same as we aim to give a national voice to people with ME & CFS, and their carers and families, in order to improve services, awareness and support in Wales.

We will do this by:

- campaigning for recognition of ME as a neurological illness in line with the WHO (World Health Organisation) classification and the results of biomedical research
- campaigning for health, education, social care services, benefits and research.
- raising awareness of ME
- offering support to young people with ME
- providing information in Welsh and English for patients & professionals
- aiding local support groups

The challenge

- There are an estimated 12,000 people in Wales with ME and CFS.
- Wales has no ME health specialists.
- Doctors & other health professionals receive little or no training in the illness.
- The neurological and chronic nature of ME is not widely recognised.
- It is difficult to find an accurate diagnosis.
- It is difficult to find help with devising a management plan.
- It is difficult to access benefits, social care and appropriate education.
- The treatments offered (e.g. some drugs, behavioural and exercise therapies) can be inappropriate.
- There is a need for good quality research into all aspects of ME in Wales, especially epidemiology and service provision.

Highlights of 2008 & 2009

Task & Finish Group

On 6th August 2009 the Health Minister announced she would be setting up a Task & Finish Group on CFS/ME Services. To begin with she commissioned a review of guidelines and care pathways for services, and asked for an assessment of existing services. We were pleased that 2 WAMES publications were included in the evidence review.

WAMES is pleased that the Health Minister considers CFS/ME to be a chronic disease, the management of which is a high priority for the NHS in Wales and that prompt diagnosis and appropriate treatment should be available to all in Wales.

The Task & Finish Group sought views on an appropriate care pathway for use by doctors and how services could be developed to comply with the NICE guidelines in a clinically and cost effective way.

WAMES responded to the first consultation in December 2009 outlining our concerns and recommendations:

There is no published care pathway which fully meets the needs of people with neurological ME.

- The NICE guidelines contain inadequate and inaccurate information – not ‘fit for purpose’. There are no existing services which cater specifically for adults, children or young people with neurological ME. There are no domiciliary services. Severely affected patients and those with mobility problems or who are in relapse are often even refused home visits by the GP or nurse when they are unable to attend the surgery. There are no diagnostic services.
- A new approach needs to be developed which will give early diagnosis and management advice to patients close to home and needs to be underpinned by thorough and ongoing education of the participating GPs, district and community nurses and therapists in order to avoid the current situation where incorrect diagnoses are being given, inappropriate advice is being given about rest, exercise, education etc. and accusations of abuse or neglect are still being made about parents of ill children.

- CBT (Cognitive Behavioural Therapy) and GET (Graded Exercise Therapy) are neither appropriate nor cost effective treatment options.
- How care for people with ME fits into the Chronic Conditions Model and the role that individualised management plans, GPwSI (GPs with Special Interest) and specialist neurological nurses could play.

Once the group finished the information gathering stage they sent their report to the Health Minister. No timescale was given for the next stage of the process.

WAMES patient & carer survey

In 2008 WAMES began a survey of patients' and carers' experiences of ME & CFS services in Wales to provide evidence to support our campaigning.

Key health care results:

Only 17% receive ongoing and follow-up care from a health professional – no neurological support.

51% have stopped discussing their condition with their GPs.

The most cited reason was that their GP did not have the knowledge to help them, followed closely by the GP being disinterested.

About the people with ME:

71% were female	24% were male	the rest didn't specify	
34% were age 40-54	30% age 55-64	14% 65+	12% age 12-25

Severity of symptoms:

16% mild or mild-moderate	37% moderate	26% moderate-severe
21% severe-very severe		

Diagnosis:

42% ME 23% ME/CFS 11% CFS
 others a mixture of CFS, ME, PVFS, FM

We also asked patients whether they received social care, benefits and education.

About the carers:

59% of carers who answered the question were over 55 years of age.
 49% who had approached Social Services for help has not been offered a Carers Assessment.
 Only 10% had their needs recognised as a carer and received services.

Partnerships & Consultations

WAMES continued to work with the WNA (Wales Neurological Alliance) and the LTCAC (Long Term Conditions Alliance Cymru) contributing to consultations and taking part in surveys of self-care and neurological services. We have been on the planning group for a series of WNA Study days on pain for professionals. A study day in North Wales proved to be a very fruitful way of meeting health professionals and answering their questions about ME.

Telephone and email enquiries

The changes in the way that Benefits are assessed resulted in an increased number of requests for help from people whose Benefit applications had been turned down. Rather than helping ill and disabled people back to work, many were made more ill by the stress of having to fight appeals and complain about inaccurate medical assessments.

Other enquiries also increased dramatically in numbers, the most common one concerning adults with ME was about access to health services, followed closely by queries about social services and local support groups e.g. few people know that they can request a 'community care assessment' from Social Services.

The most common request for help concerning children remains the threat of inappropriate referrals to the child protection arm of social services, which can occur when doctors do not know that children can get ME & CFS or that children can be severely affected and be unable to attend school. Parents are still being suspected of having harmed their children by encouraging and/or causing them to be ill, once called Munchausen Syndrome By Proxy (MSBP), now renamed Functionally Induced Illness (FI). This is a major cause of stress for parents and can take hours of our time providing the necessary information and support to parents to enable them to deal with the situation.

Some of the enquiries have been referred from English based charities which don't possess the necessary detailed knowledge about health, social care or education in Wales.

Income and expenditure

Donors

Mid & West Wales ME group
Sharon Price fundraising

Income 2008	£257.47
Income 2009	£191.94
Balance (31 st Dec 2009)	£4925.42 (General Account £739.08 Young Persons Account £4186.34)

Future plans

Service development

We will continue to work with the Task & Finish Group to present the patient and carer perspective of services and information about biomedical research.

Medical guidelines

The CFS/ME guidelines developed by NICE in 2007 are due for review in the autumn of 2010. We will maintain our involvement with the Guideline Development Group in an attempt to influence changes which make the guidelines more appropriate for people with neurological ME.

Awareness and information campaign

WAMES will apply for grants to fund the production of bilingual information sheets and new website.

Recruitment drive

We will continue to invite more people to get involved:

- Volunteers to help in many ways both large and small
- Supporters can:-
 - Give us information about ME in Wales
 - Sign up for our campaign newsletter
 - Spread the word – ask us for posters and leaflets
- Fundraisers

Our Organisation

Secretary	Jan Russell 01970 636515 enquiries@wames.org.uk
Treasurer	Liz Chandler liz@wames.org.uk
Youth & Care Officer	Sylvia Penny 0290 2051 5061 sylvia@wames.org.uk
Young People's contact	Michelle Penny michelle@wames.org.uk
Webmaster & publications	Tony Thompson

It is the policy of WAMES that the majority of trustees are people with ME.

Patron	Lord Barry Jones
Adviser	Dr Betty Dowsett

Website www.wames.org.uk

Message Board <http://health.groups.yahoo.com/group/WAMES/>