

ME in NI.

NHS services for the 7000+ ME patients in Northern Ireland are poor, and are still deteriorating. The liaison psychiatrist at the City Hospital's CFS Clinic retired in 2010; his popular and long-serving Senior Occupational Therapist left the specialty in 2011; the remaining consultant largely restricts himself to diagnosis-and-discharge.

Ministerial and Departmental press releases say that comprehensive medical support is provided here by GPs, rheumatologists, neurologists, etc. However in general these ME services exist only in the imaginations of the civil servants who draft such statements.

Patient charities here have lobbied for implementation of selected aspects of NICE CG53: prompt diagnosis, ongoing specialist management, medical support for social security claims, domiciliary support for the severely-affected, etc. (But *not* for CBT or GET). Individual Health Ministers have been sympathetic, and have instructed the Department of Health to commission adequate services for ME patients. However three separate Stormont initiatives have fizzled out since 2008, perishing on the rocks of NHS indifference at Trust level.

There are two very active patients support groups: ME Support Northern Ireland in Belfast, and Newry & Mourne ME/FM Support. Antoinette Christie and her sister Jeanette Marley and others provide the leadership and do the heavy lifting in Belfast; Joan McParland and others have the same roles in Newry. These three ladies are highly motivated, and their enthusiasm is infectious.

Besides running well-attended local meetings, both groups find the greatest need is for telephone support to the isolated housebound, and for practical assistance with benefit applications and appeals. Many patients are in a very distressed state, and a number are suicidal.

MESNI has begun seminars to train CAB and other benefit advisers in the nuances of ME, and in applicable case law. These sessions are financed by *Féile Joe*, a suicide-prevention charity in Co. Armagh with a special interest in ME. Since May 2010 Newry & Mourne ME/FM has run three packed medical conferences including speakers from the US like Dr. Judy Mikovits and Dr. Derek Enlander. Another GP medical education event is planned for 2013. Conference funding has been provided by the Heritage Lottery Fund, Newry & Mourne Council, and *Féile Joe*.

Two of these conferences had active participation by two heavyweight MLAs; (MLA = MSP). Besides informing patients about the latest medical research, these events draw normally-isolated ME patients together, and restore their faith that at least some doctors and politicians are taking their plight seriously.

There was bad news in September, when it emerged that the DHSS had withdrawn its annual financial grant for the Northern Ireland ME Association. NIMEA had one full time employee, and provided basic services to a membership of about 500. Currently there is no sign of the Stormont grant being renewed, and the NIMEA office is closed at present.

Both MESNI and the Newry & Mourne groups raise large amounts for MERUK biomedical research. Both post on the lively MEANI Facebook page <<http://www.facebook.com/groups/245412298880729/>> which attracts active contributors from Scotland, England, the Isle of Man, the Republic of Ireland, Australia and the USA.

Both groups energetically lobby the Minister, the Assembly Health Committee, MLAs and MPs, and councillors in local government. Elected representatives, the press, and the general public are usually receptive and sympathetic. However the best political advice is that we will make no significant impact on the NHS until we greatly increase and refine our lobbying effort.

Unfortunately in 2011 and 2012 members of the Wessely school generated a great deal of negative publicity for ME patients nationally, in the mainstream print and broadcast media. This in turn has stigmatised the entire ME community in the UK, and makes patients and their relatives reluctant to put heads above the parapet. One successful Autism charity representative told us we must face down such unmerited stigma. If we don't help ourselves, no one else will, she said. "No-one coming to rescue you", was her stark warning.

I rather think that warning applies to all ME patients throughout the UK.

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