

# FINAL

## Appendix 5: Current Services

### Ayrshire & Arran

There is no dedicated service, reliant on one Consultant in Infectious Diseases seeing all referrals. It is a one-stop shop and patients receive advice on symptom management. Approximately 1 new patient a week (40 per year). A previous survey of GPs to establish the number of CFS patients on their lists undertaken by NHS Ayrshire and Arran, concluded there were approximately 1100 to 1200. These figures are in line with the general prevalence percentage given in the report of the Short Life Working Group.

### Borders

There is no local specific service so patients will be handled in primary care with potential referral to secondary care to exclude other conditions. The new Long Term Conditions Strategy will of course apply to CFS and sets standards for information, support and continuity of care, amongst other areas.

### Dumfries & Galloway

The Board has been very active in this area:

- Undertaken a GP survey to find out numbers of sufferers.
- Worked hard to change view of CFS locally, and to move from a specialist to a primary care service.
- Undertaken training and development for primary care, psychology and neurology services.
- Are currently trying to establish a MCN, but have not progressed as much as would have hoped.
- A local GP is chairing a working group producing a good practice guide for primary care.

### Fife

A needs assessment of sorts (survey of GPs) undertaken in 1997. The data is now old, but informed the development of services. It is thought that the number of sufferers in NHS Fife is consistent with suggested figures ie 2-4% of population.

A Clinical Nurse Specialist undertakes regular clinics and provides training to develop knowledge of CFS/ME.

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### ME/CFS CNS Service:

- present referrals total reaching 400 since inception of service
- referral rate has remained fairly constant at 8-10 per calendar month on average
- waiting time is approx 5 months
- no additional help in terms of staff or funding for service delivery
- support groups in Fife remain and still have good regular attendance
- input to initiatives like GP Best Practice Guidelines, Parliamentary Cross Party Group and NHS Fife reference groups in adult care, primary care, social work, mental health, paediatrics psychology and health psychology and psychiatry
- other areas requesting advice and information include occupational health agencies, private employers, schools and universities
- age range of referrals have been from age 10 to 84 years
- typical time of input usually 6-8 months
- disposal and ongoing support still scarce, using agencies like Pain Association, Pain Society Scotland and Arthritis Care because they are locally available and provide direct contact and support that are not locally available through other ME/CFS dedicated agencies
- no patient satisfaction survey or service audit carried out in last 2 years
- many patients report to that biggest problem is social isolation and miss the help that a friendship circle would bring
- no befriending agency will accept referrals unless they are allocated social worker and often only those with mental health needs have priority
- many patients are not mental health issues but no formal support structure for those people is available and access to what little there is has been made complex and time involving
- no benefit from clinical lead as Fife does not have one and remains a nurse service only

### Forth Valley

Would have liked, but have been unsuccessful in developing, a service similar to the Fife model. There is currently an ad hoc service, where a clinical psychologist, and a consultant psychiatrist (liaison psychiatry team) sees small numbers of referrals.

It is felt that currently those with mild or moderate symptoms are targeted, and that little is done to help those with severe symptoms.

### Greater Glasgow & Clyde

There is a service on an ad hoc basis provided by the liaison service (One session per week). This is dependent on the willingness of individual practitioners. The exact number of sufferers is not known. Those seen by tertiary care are often referred back to primary care.

Much work is undertaken by The Centre for Integrative Care, Glasgow Homoeopathic

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Hospital which provides a number of care pathways.

1. The Wellness Enhancement Learning Programme ([www.thewel.org](http://www.thewel.org)) provides diagnostic guidance to the referring professional, but is structured primarily as a therapeutic not diagnostic service. After one-to-one holistic assessment, people who may gain and wish to participate join a 7 week half-day group-based programme. The core process is asking how the self-healing and self-recovery potential can be activated and supported, by sharing information and resources on areas ranging from nutrition, energy pacing, meditation aimed at physiological support as well as deeper calming, introductions to mindfulness and cognitive skills, and a supported self-enquiry into what is needed to bring change and improve our self-care. A review and improvement cycle has evolved the course, and the current version now supplies a full manual and DVD/CD pack to ease home re-enforcement, plus some web based resources. A formal patient-centred evaluation using both qualitative and quantitative measures has established high levels of satisfaction and useful gains in wellbeing, coping and symptom reduction in the majority of the participants. Around 70% of people also choose to go on to a second full course of 8 weeks training in Mindfulness Based Cognitive Therapy. Again, evaluation has shown useful results. Higgins M, Hopkins D, Reilly D, Mercer S. Evaluation Report of the Pilot Phases of The Wellness Enhancement Learning Programme for Patients with Chronic Fatigue Syndrome CFS-ME, 2009. Published on [www.thewel.org](http://www.thewel.org)
2. There is a homoeopathic medicine pathway by separate referral with one-to-one therapeutic relationship and consideration of homoeopathic medicine prescribing. UK wide audit has shown useful result sufficient to change the quality of daily living in 59% of people treated. Thompson EA, Mathie RT, Baitson ES, Barron SJ, Berkovitz SR, Brands M, et al. Towards standard setting for patient-reported outcomes in the NHS homeopathic hospitals. *Homeopathy* 2008;97(3):114-21.
3. There are a small number of beds using an integrative care model for people with a range of complex and severe needs, and at times people with CFS-ME are admitted.

### Highland

Services for these patients are delivered through generic services throughout NHS Highland.

### Grampian

A Working Group reviewed the provision of services for patients with ME-CFS in 2003. The result of this process was the provision of information to General Practitioners on the recognition and treatment of patients with these conditions. In terms of specialist services, no consultants have named responsibility for ME-CFS. There is no single entry point or a co-ordinator. Co-ordination with other partners depends on the General Practitioner. No needs assessment has been undertaken.

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## Lanarkshire

The services currently provided for ME-CFS sufferers in Lanarkshire are as follows:

- Most of the key primary care interventions for CFS/ME are available in Lanarkshire, although levels of awareness and knowledge of these interventions can vary considerably between practitioners
- The Infectious Diseases Unit at Monklands Hospital provides a service to assist with confirmation of the diagnosis. Typically around 50 CFS/ME patients are seen at Monklands Hospital each year
- Physiotherapy services at Monklands Hospital provide support and advice with a programme of graded exercise therapy
- The Infectious Diseases Unit at Monklands Hospital offer advice and support to GPs and patients on a programme of cognitive behavioural therapy
- The Psychiatry Unit at Hairmyres Hospital accepts referrals from GPs for assessment for CFS/ME and confirmation of the diagnosis. Typically around fifty patients are seen at Hairmyres each year.
- There is an occupational therapist attached to the Psychiatry Unit at Hairmyres who supports and advises CFS/ME patients with their rehabilitation.
- The social work departments at North and South Lanarkshire Councils provide assessment for community care services, including occupational therapy assessment for home adaptations.
- A voluntary support group based at East Kilbride. Advice and support is also available from other CFS/ME sufferers over the telephone

Access to these services varies depending on where the patient lives and on the level of knowledge and awareness of their GP and other members of the primary care team. At present between 100 and 200 CFS/ME patients are in contact with services other than those provided in primary care, out of a total of between 1000 and 2000 patients in Lanarkshire. Increased awareness of CFS/ME in primary care and more generally across Lanarkshire would probably lead to an increase in the number of patients being diagnosed and coming forward for treatment. It is clear that the existing services in the county will need to both expand and be re-configured in order to cope with the anticipated rise in demand for them.

*[Taken from needs assessment report, NHS Lanarkshire, 2003 – details provided are still current.]*

## Lothian

An epidemiological survey was undertaken in 2002.

A review has been undertaken of patients' service experiences and quality of life issues. This has been undertaken in West Lothian and is nearing completion in the City of Edinburgh.

Other developments as follows:

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- A primary care resource pack for GP referral.
- Self-use programme to allow more effective management of services.
- Guidance on integration of local social and health services.
- Inclusion of CFS/ME within long-term condition strategy to allow for a standard approach.
- MCN development – development of a local, accredited network and the development of a regional MCN has been discussed with Dumfries and Galloway and Borders.

### **Orkney**

Currently do not know number of CFS/ME sufferers. Services are limited and patients are referred to NHS Grampian. The Board acknowledges that they must develop services at GP level. Currently thinking of scoping a needs assessment to plan services.

### **Shetland**

There is no specialist service for ME or CFS in Shetland. Local physicians, including a consultant who specialises in Disability / Rehabilitation medicine, see patients on island, and co-ordinate care as appropriate. Any cases that cannot be dealt with locally would be referred on to more specialist services usually via NHS Grampian.

### **Tayside**

The bulk of patients are seen by GPs. Secondary services for CFS (such as they are) are unfunded. A clinical physician sees patients in research time. In addition, a Clinical Psychiatrist undertook group sessions and limited one-to one sessions. However, at time of publication this post was vacant.

### **Western Isles**

The Board has appointed a MS Co-ordinator and wish to repeat for CFS/ME. There was some intention of undertaking a local needs assessment and creating a service design group that would include a broad spectrum of involvement beyond health eg education. A long term conditions collaborative manager, part of whose remit is neurological conditions, was appointed in February 2008.