MERGE

Myalgic Encephalomyelitis Research Group for Education & Support

Who Cares? A Submission to the Short-Life Action Group of the Scottish Executive

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A Submission by MERGE to the Scottish Executive's Short-Life Action Group on CFS/ME

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Executive Summary

Action on four fronts – alluded to in the report of the Chief Medical Officer's Working Group of 2002 – could have clear beneficial effects on the provision and delivery of care to people with CFS/ME. First, a national **health-needs assessment** should be undertaken as a prelude to provision of an adequate network of services. Second, the creation of **skilled multidisciplinary teams** to support rehabilitation programmes and adjustment to illness and disability would be a cost-effective development. Again, particular attention should be given to health and social care at the **early stages of illness** when the intervention of primary care services can be most effective. Lastly, as regards the development of services, a **grouping for planning purposes**, possibly with other people subject to chronic ill health, may be feasible for people with CFS/ME.

Commissioning and management of care

At the initial stages of the illness, GPs are probably best placed to manage the overall clinical intervention for patients with CFS/ME, but the "seven minute appointment" puts pressure on the consultation, increasing the sense of frustration. More use could be made of other support staff in the primary care team – as suggested in the recent NHS document, *Making the Connections* – to support patients through the uncertain period prior to a definite diagnosis being made. In particular, at the point when CFS/ME first becomes a 'potential' diagnosis, a **named nurse** (with day-to-day responsibility for the **co-ordination of care** inputs) within the primary health care team should be appointed to assist and support patients through this uncertain period and beyond. Within the District Nursing Service encouragement, training and education should be provided to individual staff to take up CFS/ME as a **specialism** within their generic workload. In this way, local knowledge and expertise could be accrued at a primary health care level. For those patients most severely affected, consideration should be given to the need to involve **social work care management** services. Local authority social work departments and health boards should be instructed to include the category of **"**chronic illness**"** in their **joint planning** endeavours, and to provide the same level of planning detail as for other community care client groups.

Hospital-based specialist services, based in a dedicated unit, should be provided for people with CFS/ME in each geographical region. The unit would have a **designated consultant** responsible for overseeing services, and would have access to the services of a **paediatrician with a specialism** in CFS/ME. Each hospital-based clinic would contain **nurse specialist(s)** with an educational and clinical role.

The introduction of the Community Care Act 1990 and subsequent legislative developments has resulted in **statutory rights** for adults to a community care assessment and, arguably, relevant service provision to meet any needs identified. Similar developments have taken place in children's services as well as for carers. People with CFS/ME should be made aware of their rights in these areas and that, where required, they are entitled to be supported by **independent advocates** in their pursuit of them. Formal care pathways must ensure that evidence is provided to show that **social care needs** have been considered in constructing the care plan.

Due to the impact of the illness on their education and their social relationships, management of CFS/ME has a particular urgency in children. Each child with CFS/ME should be known to the community paediatric services, and many should be referred early by the GP for specialist advice from a **designated paediatrician** with a specialism in CFS/ME. A **management plan** should be constructed according to individual needs, and it should contain provision for regular, supportive follow-up by a multidisciplinary team, including the GP, nursing staff, professions allied to medicine, and social workers.

Supports for individual needs assessments

Specific training in CFS/ME should be provided for staff at all levels. The development of a **skilled multidisciplinary team** approach will be an important element in supporting staff as well as patients. A **formal record of arrangements for care** between the GP and other care professionals should be kept, with the patient receiving a copy. Where services such as cognitive behavioural therapy and graded exercise therapy are to be made available, it is crucial that the ***criteria* for access** to these are clearly specified and available for inspection by professionals, patients and carers. These criteria must be linked to good-quality **evidence-based practice**, and be demonstrably appropriate for a particular individual. Consideration should be given to the provision of **good employment practice advice** on the management of all aspects of CFS/ME in the workplace, and this should be circulated to all tax-funded employers. A **standardised grading/categorising system** for CFS/ME patients should be developed based on validated instruments: it could be used for assessment purposes by all clinicians and other health care professionals.

Development of care pathways

There is an urgent need for a generic template CFS/ME care pathway which can be adapted to suit local or personal needs and circumstances. Importantly, in the development of the care pathway the emphasis should be on **improving the quality of service provision** as opposed to managing or reducing costs. Widespread involvement in the development of the pathway – professionals, patients, carers and voluntary organisations – should be ensured. Ownership of the care pathway process should be held by the national or regional commissioning body, and implementation of the pathway should be backed-up by the authority of that body. It will be important to ensure that **distinct pathways or sub-pathways** exist to accommodate the needs of carers (as distinct from patients), and children (as distinct from adults). An **audit/evaluation of the outcomes** of the pathway should be built into the pathway system to ensure that standards and quality of service are met and maintained.

Utilisation of patient and support group expertise

Patients, support groups and voluntary organisations could assist in the **development of surveys** to assess the impact of the needs of carers, and participate in seminars by voluntary organisations. Voluntary organisations and local health councils, with appropriate patient and carer input, could have a role in ensuring that the care pathway on CFS/ME is **implemented** at a local level.

These suggestions/recommendations do NOT constitute a position statement since the development of detailed care pathways specifically tailored to CFS/ME is, unfortunately, at too a rudimentary stage for firm positions to be taken. Rather, they are aimed at informing and clarifying the deliberations of policy makers.

PREFACE

In *Unhelpful Counsel*, MERGE's position document of April 2002, we welcomed the publication of the Report of the Working Party on CFS/ME to the Chief Medical Officer for England (hereafter referred to as the CMO's report), mainly for the recognition that it gives to ME as an illness and the need for proper diagnosis and treatment. However, for a variety of reasons, we considered the report to be inadequate overall.

The narrowness of the remit – concerned exclusively with patient management – excluded full consideration of the research evidence regarding pathophysiological mechanisms of disease. On the basis of a small number of clinical trials, it allowed undue prominence to be given to two management strategies, cognitive behavioural therapy and graded exercise. The specific efficacy of neither strategy is convincingly supported by the systematic review evidence, and nor is the pragmatic efficacy supported by survey reports from CFS/ME patients. The report also fails to highlight sufficiently the contribution to be made by other agencies and professions, in particular the range of services available from voluntary organisations and social work departments.

Crucially, the CMO's report did not address the central problem namely the diagnostic construct, "CFS", which most probably includes several heterogeneous patient groups, thereby limiting the generalisablity of any specific management strategies or therapeutic interventions. Overall, the report gives a general impression of optimism which is misleading, omitting important data on the most-severely ill patients and downplaying the fact that less than 10% of patients report substantial recovery.

Nevertheless, MERGE acknowledges that even with these limitations, the CMO's report moves the debate forward in several key areas, notably the pressing need for improvements to the health and social care of people with CFS/ME. For this reason, we welcome the formation of the Short-Life Action Group of the Scottish Executive which has a remit to investigate the commissioning and management of care using the conclusions of the CMO's report and the best evidence-based practice as a basis, and to seek answers to the following specific questions:

- In what ways can the **commissioning and management of care** for patients of all ages be improved?
- What supports could be offered to the primary health care team and to local authority and other partners in **assessing individual needs** to help patients with CFS/ME and their carers?
- How can **care pathways** for patients with CFS/ME in Scotland be set up to give people access to the care they are assessed as needing?
- How can the expertise of patient and support groups best be utilised in partnership with the statutory organisations, to **explain the disorder**, and the impact it has, to the public and professions, and to offer support to those affected and their carers?

This document represents the rapid "consultation" paper which MERGE was invited to submit by the Short-Life Action Group. It is NOT a position statement since the development of detailed care pathways specifically tailored to CFS/ME is, unfortunately, at too a rudimentary stage for firm conclusions to be reached. Rather, it contains suggestions/recommendations aimed at informing, and hopefully clarifying, some of the deliberations of the Short-Life Action Group of the Scottish Executive.

1. USING THE CONCLUSIONS OF THE CMO'S REPORT AND THE BEST EVIDENCE-BASED PRACTICE AS A BASIS, CONSIDER WAYS OF IMPROVING THE COMMISSIONING AND MANAGEMENT OF CARE FOR PATIENTS OF ALL AGES?

1.1 Key issues from The CMO's report concerning the commissioning and management of care.

Three key suggestions of the CMO's Working Group have a particular relevance to the remit of the Short-Life Action Group. The CMO's report recommended that a **health-needs assessment** be undertaken as a prelude to provision of an adequate network of services. Indeed, the organisation of primary care services creates a unique opportunity to conduct prevalence studies on the national scale required to generate the necessary data. Such studies could be usefully augmented by community-based studies to detect and quantify variations in prevalence between communities, and to validate predictions from national studies. Again, specific social care research could be commissioned to elucidate areas of greatest need, including the need for practical support.

Importantly, the CMO's report highlighted the need for an integrative and shared approach to management. It delivered a clear statement that, "**the development of a skilled multidisciplinary team** to support rehabilitation programmes and adjustment to the disease and disability is considered to be a cost-effective development that will reduce referrals to secondary care consultants. This team should have the capacity to develop a local network of services to support in particular the severely affected, house-bound and bed-bound patients who are currently unable to access services".

Last, the CMO's report drew attention to the **uncertainty that surrounds the early period of contact** with primary care services. The delay in reaching a diagnosis, a perceived lack of support from some GPs and care staff, and a lack of good quality communication and information are all seen to result in a fairly negative experience for many patients. Clearly, the development of pathways to care must pay special attention to this crucial early phase of contact between the patient and the services he/she needs.

The CMO's report refers to the development of services. The current guidance on community care planning calls for health boards and local authorities to engage in joint planning and commissioning of services. In general, this process is concentrated on the main service user groups identified in the original community care planning guidance, i.e., older people, and people with one or more of the following: learning disabilities, mental illness, physical disabilities, and drug and/or alcohol addiction. While the CFS/ME patient grouping may be too small to stand on its own in terms of community care planning, a grouping for planning purposes, with other people subject to chronic ill health, may be feasible. At the moment, there is no evidence of such detailed planning or resource commitment, although one or two local authorities *do* make mention of such a grouping in their joint plans, e.g., Perth and Kinross.

1.2 MERGE's recommendations on the commissioning and management of care

1.2.1. Initial stages of illness: management and co-ordination of primary care

While GPs are probably best placed to manage the overall clinical intervention for patients with CFS/ME, the "seven minute appointment" puts pressure on the consultation, increasing the sense of frustration. More use could be made of other support staff in the primary care team – as suggested in the recent NHS document, *Making the Connections* – to support patients through the uncertain period prior to clear diagnosis being made. In this way, local knowledge and expertise could be accrued at a primary health care level.

Recommendations

(a). GPs should continue in their role as the primary source of health care management for patients with CFS/ME, given the existing structure of the NHS.

(b). A programme of **GP education** on the diagnosis and support of patients, including *proactive* symptom management by clinicians, should be instituted.

(c). Improvements in the availability of **useful information** on CFS/ME should be made available to patients and healthcare workers

(d). At the point when CFS/ME first becomes a 'potential' diagnosis, a **named nurse** within the primary health care team should be appointed to assist and support patients through this uncertain period and beyond (see Figure, "*One Suggested System of Referral for CFS/ME Patients*"). The role for the named nurse would include the provision of advice and support in terms of symptom management, as well as help in managing the anxiety and stress that inevitably accompanies the early phase of illness onset.

- The named nurse would have day-to-day **responsibility for the co-ordination of care** inputs including ensuring that any referrals to other agencies for support services, e.g., social work, are made timeously. The nurse would also liase with the specialist nurse based at the nearest CFS/ME hospital unit (cf. Section 1.2.2.).
- Within the District Nursing Service encouragement, training and education should be provided to individual staff to take up CFS/ME as a ***specialism*** within their generic workload. There should be at least one nurse within each GP practice with CFS/ME as a specialism, given that the CMO's report has estimated that a general practice with a population of 10,000 patients is likely to have 30 – 40 patients with CFS/ME, about half of whom may need input from services. Such nurses would act as a source of advice and support to GPs and other local staff within the primary care matrix.

(e). For those patients most severely affected, i.e., where there are complex care needs requiring service provision from a number of different organisations, consideration should be given to the need to involve **social work care management** services.

(f). Local authority social work departments and health boards should be instructed to include the category of **"chronic illness" in their joint planning** endeavours, and to provide the same level of planning detail as for other community care client groups, e.g., planning assumptions and clear objectives (with resource commitment).

1.2.2. Specialist and Hospital Services

There are very few consultants with specialist knowledge available to take onward referrals (from GPs), a fact highlighted in the CMO's report. Of those available, many are geographically difficult to access. The tiredness and fatigue often associated with CFS/ME compounds the difficulty of accessing tertiary care. As in primary care, time constraints are a continuing difficulty within an appointment-based system resulting in a perception that appointments are rushed and less than ideal. Liaison between primary care and specialist services is often seen as inadequate and insensitive to the needs of the patient. Those severely-affected by CFS/ME are particularly badly served, as the CMO's report recognised.

Recommendations

(a). **Hospital-based specialist services**, based in a dedicated unit, should be provided for CFS/ME patients in defined regions of Scotland. In each region, there would be a designated consultant responsible for overseeing services, and the unit should also have access to the services of a paediatrician with a specialism in CFS/ME.

(b). Working practices within such centres of excellence should be sensitive to the difficulties experienced by **patients travelling long distances**, and consideration should be given to the contribution modern technology has to make in this area, e.g., tele-medicine.

(c). Each hospital-based clinic should contain **nurse specialist(s)** with an educational and clinical role. They should provide specialist knowledge and advice to primary care staff and other carers, as well as liasing with named nurses in primary care practices to ensure that practice advice permeates through the care system. They would work alongside the designated consultant (see Figure, "*One Suggested System of Referral for CFS/ME Patients*").

(d). Management strategies targeted at the **severely-ill and long-term affected** should be devised. In line with the recommendations in the CMO's report, these should include:

- the provision of technical aids since problems can often be severely compounded by the lack of relatively simple technical solutions
- follow-up consultations by phone with a named nurse or consultant

(e). Given the establishment of the NHS help-line, this service should include information and advice for patients on coping with the consequences of CFS/ME.

1.2.3. Social Care Aspects (Service Models)

The CMO's report makes clear that "an assessment by social services is needed when there may be a need for social care provision….. The prognosis given by the medical practitioner will be crucial in such cases and will need to be realistic without disheartening the patient." The introduction of the Community Care Act 1990 and subsequent legislative developments, has resulted in **statutory rights** for adults to a community care assessment and, arguably, relevant service provision to meet any needs identified. Similar developments have taken place in children's services and for carers. Further work is required to ensure that people with CFS/ME are aware of their rights in these areas and that, where required, they are supported by **independent advocates** in their pursuit of them.

The comments in the CMO's report regarding the experiences of people with severe CFS/ME highlights the support that could be offered by social work services, particularly those services designed to reduce or eradicate social isolation and barriers to community participation, e.g., home help, social care officers, shopping and befriending, day care services and occupational therapy. Confusion regarding the different roles of hospital-based occupational therapists and their community counterparts needs to be clarified. The **care management services** provided by social work departments could also be particularly useful where **needs are complex** and service provision is from a number of different agencies or professions and where co-ordination and regular review are a necessity.

The provision of respite services is a thorny issue in most regions, crossing professional and agency boundaries. Although the CMO's report refers to respite care, it makes no attempt to clarify what it means by the term or to specify the service range referred to. The provision of **respite care** in the community for social care purposes is a social work responsibility, subject to social and (at this time) financial assessment. It comes in many forms and can include services brought to the family home, services provided in a formal service setting, e.g., day care facilities, or it can involve more general activities. Opportunities for residential or nursing home respite care are more limited, but should be made available. Services may be provided to meet the needs of either or **both the patient and the carer**. Admission to hospital for respite purposes (which is free), where there are healthcare needs to be met, is a health care responsibility but may, on occasion, be negotiated through the offices of a social work care manager if it is part of an overall package of care. Bearing in mind the principle that needs should be met in the most appropriate environment, admission to hospital respite provision should only take place when there are clear medical or nursing needs which can only be met in a hospital environment.

Welfare benefits were afforded their own priority by the CMO's Working Group, and this is reassuring. However, the complete separation of this advice from the main report was not helpful. In addition to their practical support services, many social work departments have specialist welfare rights teams to assist people in applying for benefit and, crucially, to appeal against refusal of benefit. Both social work staff and other welfare advice agencies, such as Citizens Advice Bureaux, would benefit from **advice and training** on the various aspects of CFS/ME as they relate to the benefits system.

Finally, local authorities, health boards and NHS Trusts, are major employers in most locales in the United Kingdom. In their human resource function they are subject to the same constraints and pressures as other employers in terms of how they manage employees with CFS/ME. As an arm of government, however, they present as a substantial target for the delivery of **good employment**

practice in managing this complex illness. The CMO's report is light in terms of provision of advice for employers. Further consideration to this issue by the Short-Life Action Group would be a welcome extension to the CMO's report, as would the issuing of advice on good employment practice to all tax-funded employers working under the jurisdiction of the Scottish Executive.

Recommendations

(a). The development of a care pathway should include clear and unambiguous advice regarding the need for **multi-disciplinary health and social care assessment**.

(b). The models and protocols (care plans, etc.) - designed as part of the administrative framework supporting the care pathway - should include an element recording that **patients have been consulted** about their care, and that their views have been taken into account.

(c). The care pathway must ensure that evidence is provided to show that **social care needs** have been considered in constructing the care plan, i.e., it should be an 'opt out' process as opposed to an opt in one.

(d). To avoid confusion, there needs to be greater clarity regarding the different and often over-lapping roles of health and social work occupational therapists.

(e). Information regarding **statutory rights** to social work assessment and direct service provision should be made available to people with CFS/ME and their carers.

(f). Local authorities, health boards and NHS Trusts should be advised to include people with chronic illness in **service specifications** for advocacy services.

(g). Social work care management services should be used in those cases where needs are complex, call for a number of different service inputs, and require regular review.

(h). The whole range of residential and community-based **respite care** options should be available to people with CFS/ME, with hospital respite services only used where there are needs which can only be met in a hospital environment.

(i). The welfare rights paper submitted by the CMO's Working Group to the Department of Work and Pensions should be made available to interested parties.

(j). Information regarding the welfare advice services available should be developed at a local level and circulated within the CFS/ME community.

(k). Training should be provided to welfare advice staff on issues relevant to CFS/ME.

(l). The Scottish Executive should consider issuing advice on **good employment practice** in the management of CFS/ME to all tax-funded organisations.

1.2.4. Children and Young People with CFS/ME: the Special Case

Due to the impact of the illness on their education and their social relationships, management of CFS/ME has a particular urgency in children. The CMO's report was particularly strong on management recommendations for children and young people, and these form the basis for most of MERGE's own recommendations. One important aspect is the **co-ordination of care** with these patients and their parents/carers by community children's nursing teams which would include a named nurse or health visitor.

Recommendations

(a). Each child with CFS/ME should be known to the community paediatric services, and many should be referred early by the GP for specialist advice from a **designated paediatrician with a specialism in CFS/ME**. Where the specialist advice comes from will be determined by the final care pathway structure adopted, but could be from a paediatrician or from a specialist CFS/ME clinic as discussed above (see Figure, "*One Suggested System of Referral for CFS/ME Patients*").

(b). A **management plan** should be constructed according to individual needs. This should contain support for self management, including provision for fluctuations. It should include regular, supportive follow-up by a multidisciplinary team, including the GP, nursing staff, professions allied to medicine, and social workers.

(c). Information and education about the illness and available services should be given as early as possible, most probably by the named nurse or nurse specialist.

(d). Use should be made by GPs of their capacity to access the **domiciliary visiting service** by consultants, as mentioned in the CMO's report.

(e). Provision should be made for an **individually-tailored education** programme or for a return to school or college as recovery proceeds. This could be facilitated by a referral to the Education Welfare Service to ensure that education is minimally disrupted.

2. USING THE CONCLUSIONS OF THE CMO'S REPORT AND THE BEST EVIDENCE-BASED PRACTICE AS A BASIS, CONSIDER WHAT SUPPORTS COULD BE OFFERED TO THE PRIMARY HEALTH CARE TEAM AND TO LOCAL AUTHORITY AND OTHER PARTNERS IN ASSESSING INDIVIDUAL NEEDS TO HELP PATIENTS WITH CFS/ME AND THEIR CARERS.

At present little or no support is available to the primary health care team and other agencies in assessing the need of CFS/ME patients, so **provision of supports** must be created from the ground up. The most important aspects of good clinical services for patients in primary care are seen as a *supportive attitude* and *early diagnosis*: accordingly, inputs (training and advice) to facilitate the development of supporting attitudes and hone clinical skills would be most beneficial. As the CMO's report makes clear, there must be an acceptance of the need to provide the additional sources of advice and support that primary care teams need within health service management and commissioning structures.

2.1. MERGE's recommendations on supports for individual needs assessments.

(a). Specific training in CFS/ME should be provided for staff at all levels. The development of a **skilled multidisciplinary team** approach will be an important element in supporting staff as well as patients.

(b). A **family of leaflets** on a range of subjects should be commissioned to provide information/education about the nature of the illness, its consequences and treatment. Of particular importance is high-quality information on good practice for primary care and tertiary level staff.

(c). A **formal record of arrangements for care** between GP and other care professionals should be kept, with the patient receiving a copy.

(d). Where services such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET) are to be made available, it is crucial that the *criteria* for access to these are clearly specified and available for inspection by professionals, patients and carers. These criteria must be linked to **evidence-based practice**, and be clearly appropriate for a particular individual.

(e). Consideration should be given to other useful therapies, including Arts Therapies, which would extend the therapeutic options available.

(f). Consideration should be given to the provision of **good employment practice advice** on the management of all aspects of CFS/ME in the workplace. This should be circulated to all tax-funded employers.

(g). The report submitted to the Department of Work and Pensions by the CMO's Working Group should be made public when available as it may contain valuable information for patients and their advocates.

(h). A **standardised grading/categorising system** for CFS/ME patients should be developed based on validated instruments: it could be used for assessment purposes by all clinicians and other healthcare staff.

3. USING THE CONCLUSIONS OF THE CMO'S REPORT AND THE BEST EVIDENCE-BASED PRACTICE AS A BASIS, HOW CAN CARE PATHWAYS FOR PATIENTS WITH CFS/ME IN SCOTLAND BE SET UP TO GIVE PEOPLE ACCESS TO THE CARE THEY ARE ASSESSED AS NEEDING.

Care pathway development is an intricate, multi-staged process. While a few relevant models exist, e.g., for chronic illnesses, these are at a comparatively rudimentary stage, and it is clear that the urgent need is for a *generic template care pathway* for CFS/ME which can be adapted to suit local or personal needs and circumstances. Importantly, in the development of the care pathway the emphasis should be on **improving the quality of service provision** as opposed to managing or reducing costs. Points relevant to the development of care pathways are also discussed in Section 1.2.3. (a,b,c).

3.1. MERGE's recommendations on the establishment of a care pathway

(a). **Widespread involvement** in the development of the pathway – professionals, patients, carers and voluntary organisations – should be ensured.

(b). Ownership of the care pathway process should be held by the **Scottish Executive**, and its implementation of the pathway should be backed-up by the authority of the Scottish Executive.

(c). A **consultation exercise** should be undertaken using an early draft of the recommended care pathway so that major problems can be identified and rectified at this pilot stage.

(d). It will be important to ensure that **distinct pathways or sub-pathways** exist to accommodate the needs of carers (as distinct from patients), and children (as distinct from adults).

(e). An **audit/evaluation of the outcomes** of the pathway should be built into the pathway system to ensure that standards and quality of service are met and maintained.

4. USING THE CONCLUSIONS OF THE CMO'S REPORT AND THE BEST EVIDENCE-BASED PRACTICE AS A BASIS, HOW CAN THE EXPERTISE OF PATIENT AND SUPPORT GROUPS BEST BE UTILISED IN PARTNERSHIP WITH THE STATUTORY ORGANISATIONS, TO EXPLAIN THE DISORDER, AND THE IMPACT IT HAS, TO THE PUBLIC AND PROFESSIONS, AND TO OFFER SUPPORT TO THOSE AFFECTED AND THEIR CARERS.

Support groups and patient-based organisations are an **important resource**. Given the lack of awareness of CFS/ME among healthcare professionals in the past, such groups - which include voluntary organisations with particular expertise - have an important role to play, at least in the early development of pathways and for the initial raising of awareness of the illness among professionals. The patient experience of health and social care systems and of the illness itself carries its own powerful message. As the CMO's report stated: "New mechanisms are being put in place to support patients, including a Patient Advice and Liaison Service and an increased emphasis on the role of patients as experts".

4.1. MERGE recommendations on the utilisation of external experience

(a). Patients, support groups and voluntary organisations could assist in the **development of surveys** to assess the impact of the needs of carers, and participate in seminars by voluntary organisations.

(b). A **family of leaflets** covering the nature and impact of CFS/ME, including the direct patient experience of illness, should be commissioned from voluntary organisations with the appropriate expertise.

(c). Voluntary organisations and local health councils, with appropriate patient and carer input, could have a role in ensuring that the care pathway on CFS/ME is **implemented at a local level**.

(d). Patients and voluntary organisations could be involved in the **training** of relevant health, social care and voluntary personnel.

(e). A video could be produced as a **training resource** to highlight the experience of patients to illustrate good and bad professional practice at different stages of the illness.

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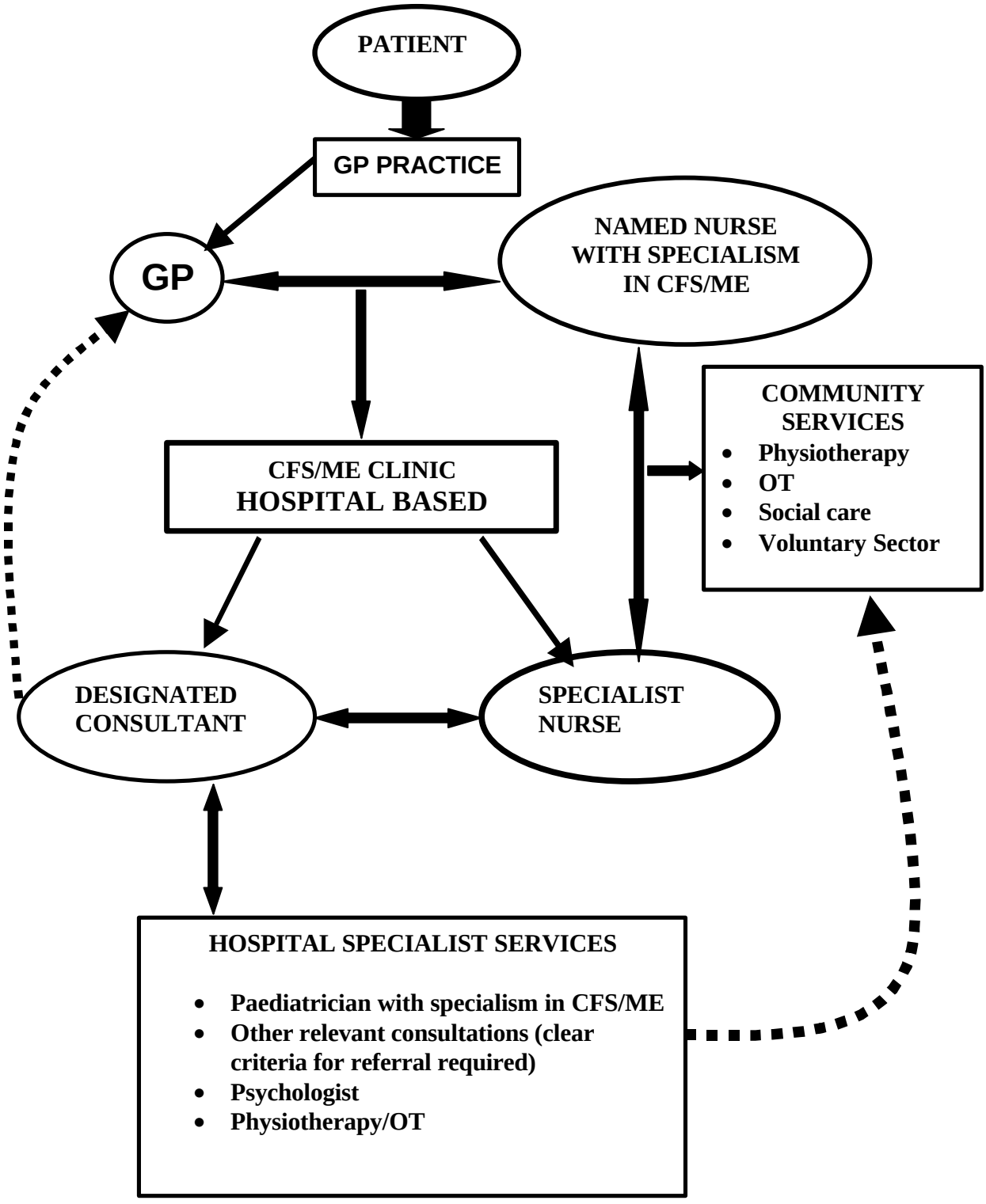

Figure*: One Suggested System of Referral for CFS/ME Patients*

POSTSCRIPT

Patient Voices

In the plethora of views about the provision of health and social care in this illness, the authentic voice of the sufferer is rarely heard. Some individual, poignant experiences are given below.

I was 18 years old when I was struck down with severe, virally-induced ME. I am now 33. It has destroyed my quality of life. My feelings of loss and helplessness are often overwhelming. My parents have to care for me and the illness has deprived me of a career, a social life and the possibility of marriage and children. I am 90% bed bound and feel wretchedly ill every waking moment. At worst I am unable to hold a conversation, watch TV or even read. My only hope is for a research breakthrough in this illness. More than anything else I want to see ME recognised and a treatment found. **Clare**.

The worst thing about having ME is, obviously, having ME. It is spending 3 years in your bedroom looking at the walls, in pain, isolated, unable to read write or talk with a brain like spaghetti. The worst thing is having a brain which no longer works and which I can't do anything about. It's like being in solitary confinement except that I haven't done anything wrong. **Josh**

The feelings of pain and sickness are with me all the time. The illness has changed my life. I can do none of my former hobbies, and am left hanging around on the fringes of a no man's land between the dying and the well. It's a double torture - having the illness and having it unrecognised. It has been said that patients like me should just move on, but after 20 years it seems to me that the only things moving on in this illness are professionals - medical and charitable - making careers out of my misery. A little humility and some humanity by those in the so-called "caring professions" would go a long way towards helping me cope with what has been a truly awful experience. ***Alex***

Appendix 1

Unhelpful Counsel?
MERGE's response to the Chief Medical Officer's Working Group report on CFS/ME

"Brutalised by their reception in doctors' examining rooms, they ceased consulting doctors, preferring instead to wait out their disease away from the medical profession's unhelpful counsel."
(Hillary Johnson, Osler's Web)

Executive Summary

The report of the Chief Medical Officer's Working Group on CFS/ME of January 2002 is an advance on the widely-criticised Joint Royal Colleges report on CFS (1996). It gives an authoritative statement that CFS/ME is a genuine illness which imposes a substantial burden on the health of the UK population, and stresses that improvement of health and social care for people affected by the condition is an urgent challenge. Importantly, it states that CFS/ME can be clinically recognised for treatment purposes; lists the initial battery of tests that should be performed; and is clear that inaction by healthcare professionals due to ignorance or denial of the condition is not excusable. These, and many more, positive aspects of the report represent progress in terms of recognition of the illness and its consequences. However, for a variety of reasons, the report is inadequate.

Most importantly, the narrowness of the remit, concerned primarily with providing best practice guidance on the healthcare management of the illness, has ensured that the focus is on containment and coping, rather than on solving the clinical conundrum, namely, what actually causes the illness and what steps can be taken to elucidate the cause. The constraint of the remit has several important consequences, some of which are discussed below.

It has permitted the Working Group to side-step the central issue which energises every discussion about CFS/ME. This concerns the diagnostic construct 'CFS' which most probably includes heterogeneous patient groups (one of them with classically-defined ME), limiting the generalisability of any specific management strategy or therapeutic intervention. The question, "what's in a name?", has particular poignancy in the case of this illness: one increasingly plausible answer is "everything" since de facto misdiagnosis not only complicates the interpretation of clinical trial evidence, but obscures treatment options and, in the long run, influences management and practice for the worse. Given that there is a growing number of experts who consider that there is a strong case for unpacking the term 'CFS' and reclassifying and renaming in accordance with more specific clinical criteria, a opportunity for the Working Group to seriously address this issue has been lost.

As the Working Group was concerned with therapeutic management, it sought evidence from a systematic review of forty-four randomised clinical trials on a range of clinical interventions. Two clinical "therapeutic interventions" were identified, cognitive behavioural therapy and graded exercise therapy. By conventional standards of literature reviewing, formal evidence for the use of either in a general patient population is rudimentary, a fact indicated by the authors of the original review. The specific efficacy of neither is convincingly supported by the systematic review evidence, and nor is the pragmatic efficacy supported by survey reports from CFS/ME patients. As regards cognitive behavioural therapy, five interpretable trials were identified (three "positive" and two "negative"), a less than conclusive evidence base for an intervention which is also non-curative, expensive, beyond the resources of Health Authorities to fund given the scale of the problem, and has been found helpful by only a small minority of patients surveyed by patient organisations. For graded exercise therapy, only three positive clinical trials were identified, none with a fully comparable control group and all consisting of patients classified by the Oxford criteria which does not diagnose 'ME' or

'CFS (1994)' exclusively. Again, the true usefulness of this therapy to the general population of patients is unclear given that the effectiveness of such motivational interventions is by no means established; that deconditioning may not, in fact, be an important factor limiting the activities of many CFS/ME patients; and that around half of patients surveyed indicated that graded exercise therapy actually worsened their condition. The third recommended intervention, pacing, is intuitively sensible but hardly warrants the status of a separate therapy within a healthcare management program.

Despite part of the remit "to make recommendations for further research," the Working Group has dealt with the research findings in 639 words out of a total of some 34,600 in the main report. A large body of research literature on CFS/ME exists, however, and numerous biological abnormalities have been reported, although the aetiology of the illness remains elusive. By systematically assessing the significance of these, the Working Group may have been able to recommend a specific direction for future research. Instead, the message presented to the media, the public, and opinion formers is that the best that can be done is to manage symptoms, most prominently with psychological strategies. Interestingly, given the volume of published research evidence on pathophysiological mechanisms, the range of clinical signs and symptoms exhibited by CFS/ME patients, and a large body of professional opinion supporting a 'biomedical' model of the illness, it seems negligent that clinical opinion on the Working Group was proportionately over-represented by professionals who tend to subscribe to the use of biopsychosocial interventions for CFS/ME. Since four of their number resigned from the Key Group shortly before publication, after several years of participation, on the grounds that the report paid too little attention to biopsychosocial aspects of the illness, a question is raised about the role of the initial composition of the Working Group in colouring the final report.

At several points, the report mentions the problems of the most severely-ill patients. Yet, a database of information collected and analysed on behalf of severely-ill sufferers by The 25% ME Group, presented to the Working Group, was not used to full advantage in the final report, though other patient data was produced. MERGE's summary of this data shows that 25% of these patients described themselves as bedridden, and 57% had been either housebound or bedridden for more than six years, illustrating in numbers rather than words that morbidity in CFS/ME can be substantial, despite the opinion of many healthcare professionals to the contrary. The management strategies recommended by the Working Group are inappropriate for this group of sufferers whose care remains a neglected challenge.

As regards social care, the Working Group set out to consider how the NHS might best provide care for sufferers. Yet, the NHS is only one agency among many providing care, and the responsibilities of other agencies involved in both care planning and direct service provision could have been usefully identified. Overall, the comforting statements from the Working Group about the services CFS/ME sufferers should receive in the community are little more than aspirations: without the full support and practical backing of local social work departments, sufferers will struggle to see their needs met either fully or appropriately.

Importantly, the report does not describe how or when change is to occur. The Working Party had no executive power and brought no additional funding to stimulate change. Even in its advisory role, it does not evaluate the cost implications of its recommendations, call for directives to be issued to the various health agencies or professional bodies, or propose any mechanism for checking that changes will be made. Crucially, it gives no indication that the illness will be looked at again, in the medium to long term, to assess whether real, meaningful change has come about.

In summary, while the Working Group's report may go some way towards improving recognition of the illness, MERGE considers that it has avoided serious consideration of the important issues surrounding the diagnosis and treatment of ME/CFS; that it has given undue emphasis to management strategies of limited applicability; that practical recommendations for social care provision are lacking; and that, consequently, an opportunity to effect real change has been lost.

Appendix 2

Following publication of the Working Group's report to the CMO, there was some debate about the future direction of research into CFS/ME in the UK. In particular, great reliance was placed on the "research" evidence documented in the National Research Register.

During a debate in the House of Lords on the Working Group's report on CFS/ME (16th April 2002), mention was again made of the role of the National Research Register in informing policy in this area. Accordingly, MERGE has included the executive summary of its document, Research into ME/CFS in the United Kingdom: Can the National Research Register inform future policy, in this Appendix. Electronic copies of the full document (50 pages, with 39 pages of tables) are available from merge@pkavs.org.uk.

Research into ME/CFS in the United Kingdom: Can the National Research Register inform future policy?

An analysis by MERGE, February 2002 – Dr NC Abbot and Dr VA Spence

Executive Summary

There is presently a debate in the United Kingdom about future direction of public policy regarding research into Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). Energising the debate is an apparent increase in the scale of the problem nationally and, recently, publication of a report by an independent working group to the Chief Medical Officer of England. However, policy must be guided by good data and great reliance has been placed on the UK National Research Register (NRR) of completed and ongoing medical studies as a resource for informing debate. This register is a database of ongoing and recently completed research projects funded by, or of interest to, the United Kingdom's National Health Service. This analysis of the information on ME/CFS contained within the NRR was designed to answer a specific question: given the interest in the development of a research policy for ME/CFS in the medium to long term, is the information contained in the NRR records robust and accurate enough to inform policy-makers?

The total raw number of studies on ME/CFS retrieved from the NRR was 28 ongoing and 133 completed studies (partial records are presented in a 35-page Appendix to this report). From each, the following key data were extracted: Title; End date; Contact person; Principal research question; Sample group description; Funding source and amount. Each record was assigned to an ad hoc "research category" (of interest to researchers), and a "clinical category" (of more interest to the public and policy-makers) on the basis of the professional and/or departmental affiliation of the "contact person".

Of the 161 NRR reports retrieved, 10 appeared not to involve ME/CFS patients directly, and 12 appeared to be duplicates of existing reports. Thus, only 139 (23 ongoing and 116 completed) could be classed as "relevant" reports - representing 0.17% of the 80,000 on the entire NRR database. Eighteen reports (5 ongoing and 13 completed) concerned research in Scotland. Many reports were incomplete: 35% and 31% of ongoing and completed study records, respectively, had missing descriptions of the proposed sample group; 22% and 28%, respectively, had missing details of sources of funding; and the amount of funding received was not stated in more than a half of all entries. In addition, some records had very similar content, despite a difference in "end dates" which varied by up to 18 months, raising the possibility that some records describe extensions of an existing project rather than separate discrete investigations.

When classified by clinical category, 41% of reports had "contact persons" whose professional association was with "psychiatry, psychological medicine or mental health". The second and third largest categories were neurology, neurosciences or neurophysiology (13%) and general medicine/medical care research (12%), respectively. When classified by research category, investigations with some scientific rationale and some

relevance to the pathophysiology of the illness constituted the largest group of records (43%), but many of these were smaller exploratory studies (evidenced by relatively small sample sizes) that are unlikely to have given a definitive answer to the initial research question. The main other categories contained clinical trials or other investigations of essentially biopsychosocial interventions (17%), followed by surveys pertaining to biopsychosocial interventions (14%), and surveys of welfare or social aspects (9%).

Given that the amount of funding received was not stated in more than a half of all entries, no definitive conclusions can be drawn from the information on source or amount of funding. However, the clinical category "psychiatry, psychological medicine or mental health" is the most successful in attracting research funding. Overall, however, few public resources (NHS or Research Council) have been directed towards researching this illness.

In conclusion, the NRR records tend to be incomplete; to contain inadequate descriptions of the research proposed; and to have no cross-reference to the results emanating from the research. The records relating to ME/CFS reveal that comparatively little research has been done given the scale of the problem in the UK and that few public resources have been directed towards research, particularly into the pathophysiological basis of the illness. Much of the research undertaken has been led by investigators with a professional or departmental affiliation to Psychiatry, Psychological Medicine and Mental Health, and none of the 139 studies were conducted on the most severely-ill patients.

Given the recent recommendations of the Chief Medical Officer of England that government investment in research on ME/CFS should be comprehensive and include a range of studies designed to "elucidate its aetiology and pathogenesis, clarify its epidemiology and natural history; characterise its spectrum and/or subgroups; and assess a wide range of potential therapeutic interventions including symptom control measures", *we conclude that the NRR is not robust enough, as an information source or as a research resource, to inform the direction of future policy.*

ME Research Group for Education and support (Charity No 1080201)

WHAT IS MERGE

The charity was founded by Dr Vance Spence and Mr Robert McRae, both people with ME forced to retire early from their professions. With patrons Roger Jefcoate CBE and The Countess of Mar, and six trustees, MERGE obtained charitable status in 2000.

Since its foundation, significant progress has been made in establishing the charity:

- Permanent office set up at The Gateway in Perth
- Initial funding provided for the formation of the Cross Party Group on ME at the Scottish Parliament
- Scientific Advisory Panel brought together to review the scientific merit of research applications
- A strong team of medical research and social care professionals recruited
- A number of research projects and reviews completed

In the second year of the 5-year plan and beyond, the team aims to:

- Fund and commission further biomedical research
- Launch the MERGE website
- Inaugurate and administer the Friends of MERGE Scheme
- Consolidate MERGE's funding position
- Develop direct practical social care support

MERGE *RESEARCH*

As a medical research charity, our aim is to "commission and fund research into the causes of ME, its treatment, prevalence and social consequences". Projects to date include:

- Chronic inflammation and apoptosis in patients with ME, OP poisoning and Gulf War Syndrome
- Prolonged action of acetylcholine vasodilation in blood vessels of ME patients
- Collation and systematic review of a historical archive of literature on ME
- Investigation of oxidative stress pathways in ME
- Analysis of urinary proteins, IAG and caseomorphine in ME

MERGE *INFORMATION*

MERGE also aims to influence the medical and social care research agendas, and provide education - in its broadest sense - to healthcare professionals and the public. To date, the organisation has completed three major professional documents:

- *Unhelpful Counsel?*, a detailed response to the Chief Medical Officer's report
- *Research into ME/CFS in the United Kingdom: Can the National Research Register inform future policy?* - an analysis of ME research funding
- *Who Cares? A submission on the development of care pathways*, produced at the invitation of the Scottish Executive's Short-Life Action Group on ME.

All the above documents are available and will be accessible from the MERGE website.

MERGE *SOCIAL CARE*

MERGE recently received funding from the Disability Aid Foundation to establish the post of Development Officer (Support Services). Still in the early stages of implementation, the service is intended to assist MERGE in progressing the social care policy agenda and in helping people with ME to access social work services. Work is currently underway to publish on our web-site:

- The legal framework for social work services
- The agencies involved in complaints procedures
- A database of local authority social work provision with contact details

MERGE *TEAM*

At 2002, the active MERGE team comprises Dr Vance Spence (Chair); Mr Robert McRae (Treasurer); Dr Gordon Parish (Consultant/Adviser); Mrs Betty McRae (Administrator); Dr Neil Abbot (Director of Operations); Mr William Dockery (Development Officer: Support Services); Dr David Newton (Communications Officer & Research Fellow); Dr Gwen Kennedy (MERGE Research Fellow), and a core group of trusted volunteers.