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Appendix 3: The Three Tier Service for ME-CFS.

(Adapted from: Short Life Working Group (2002). Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (CFS/ME) Outline for Development of Services for CFS/ME in Scotland: Report of the Scottish Short Life Working Group. Scottish Executive, December 2002.

Tier 1 People in the Community	
Description of Need	Ways in which Services May Respond
To provide increased information on ME-CFS ¹ in the community and to develop sources of information and support to sufferers and their carers.	Estimates from this report would confirm view that ME-CFS is a relatively common clinical condition and as such should be considered with a higher degree of priority than at present. NHS Boards in Scotland should develop a comprehensive needs assessment of patients with ME-CFS. In three NHS Board areas, some local survey work has been conducted.
Need for increased knowledge and understanding of the complex pattern of illness suffered by those with ME-CFS. Need for development of information at local level. Need for development of local guidelines for patients, carers and health professionals.	A strong theme highlighted in the Independent Working Party Report was a belief from patients that their views and concerns were not being listened to and understood. In Scotland opportunities to explore development of information on ME-CFS should be examined further. In this context, the important role that Voluntary Sector support groups may be able to offer needs to be recognised and supported and in particular the opportunities offered by web based information systems and care guidelines should be developed further.
At present, there is a lack of information, training of health and other professionals.	Workforce development and training should be coordinated through regional workforce centres and NHS Education to address the need for improved education and skills of medical /other professional students. A regularly updated directory of available local and national services could be developed for patients and professionals.

¹ ME-CFS has replaced the original CFS/ME to reflect the convention used in this health care needs assessment.

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Tier 2 Local Services – Community Health Partnership Level	
Description of Need	Ways in which Services May Respond
<p>A Scottish general group practice, with a notional list size of 10,000 can expect to care for some 20-40 patients with ME-CFS</p> <p>For a CHP of 150,000 residents, an estimated 300 to 600 patients are likely to be affected.</p> <p>Around 50% of these patients may require specific input from services with up to 25% likely to be severely affected.</p>	<p>At Community Health (and Care) Partnership² level there is a need to stimulate development of local community based services. This could be encompassed within the current approaches to long-term, conditions management³.</p> <p>The use of chronic disease registers should be part of the approach to identification of patients with ME-CFS, organizing support, and assisting in the organisation of care and access to care. The care needs are:</p> <ul style="list-style-type: none"> • initial assessment and investigation⁴; • diagnosis – criteria and confirmation; • options for proactive and reactive treatment/care – self care with low intensity support, care management by generalist, intensive care management with specialist advice; • patient education/information; • follow up/monitoring, disease registers, review/recall systems; • indicators for onward referral; and need for support services and complementary services.

² “Community Health (and Care) Partnership” replaces the term “Local Health Care Co-operative” used in the original version.

³ “Long term conditions management” replaces the term “chronic disease management” used in the original version.

⁴ The inclusion of the term “investigation” has been included in response to a comment from the Scrutiny Panel.

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Tier 3 Specialist Services – Specialist Expertise specific to ME-CFS	
Description of Need	Ways in which Services May Respond
<p>Local higher tier specialist services that can:</p> <ul style="list-style-type: none"> • begin to offer a range of services and importantly be the major support service to local community based services; • develop diagnostic expertise; • develop expertise in the management of difficult problems; • develop expertise in rehabilitation services; • have a role in the monitoring of the services; and • have links to research, training and audit of services 	<p>The majority of provision will be for development of local secondary care services. This would include outpatient consultation, diagnosis and clinical investigation and development of the main medical components for management. Links should be made with partner agencies for other aspects of the management/care.</p> <p>Identification of a lead clinician or other specialist to champion the development of local services is seen as an important component of success.</p> <p>As these local specialist services begin to emerge, aim should be towards the development of a clinical and service network to address areas such as:</p> <ul style="list-style-type: none"> • development of approaches to treatment; • managed clinical networks; • research and information network; and • management of more complex cases.
<p>Children & Young People</p>	<p>A different care pathway to the adult services needs to be established for children and young people, involving paediatric services at an early stage and other statutory and non-statutory agencies such as Education and Local Authorities.</p>
<p>Severely Affected & Housebound</p>	<p>A care pathway involving the community teams from health and social services needs to be developed, including rehabilitation and the access to appropriate equipment from the community pool for the severely affected. Protocols and facilities for respite care need to be developed.</p>