National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on Chapter 4

Status	**SH organisation**	**Order no.**	**Document**	**Page No.**	**Line no.**	**Comments**	**Responses**
SH	25% ME Group	123	FULL	78	4.1.1.1	The range of therapies and management in this Guideline is very limited and narrow i.e. it only advocates CBT and GET. This will not be useful or helpful to medical professionals or patients. Patient reporting and research has shown that these therapies are unhelpful and even harmful for people who have ME; make patients worse! PACING, as advocated by the CMO Working Group (2002), should also be highlighted and recommended in this Guideline. This is also important as all the patient organisations, also advocate for this on the whole. In the 25% ME GROUP Survey in 2004. It was found that 70% of members had found PACING to be helpful, but only 5% had found GET helpful. http://www.25megroup.org/Group%20Leaflets/Group%20reports/March%202004%20Severe%20ME%20Analysis%20Report.doc Page 8. PACING is also part of a major funding research project funded by the MRC, but this is not highlighted in this Guideline either. It must be CLEARLY highlighted that patients have a right to refuse. Some or all elements of treatment and/or management where they feel that it could cause a problem to their condition, without the fear or threat of them being	Please see the revised recommendations, which include other strategies such as pacing and activity management. We have highlighted the right of people to withdraw from, or refuse treatment.

						penalised in any way i.e. withdrawal of medical support, benefits etc	
SH	25% ME Group	124	FULL	79	4.1.1.4	Patients should also have choice and equal control in the "review process", at all levels of the treatment and management of their condition.	Patient choice and involvement is key throughout the whole process of care.
SH	25% ME Group	125	FULL	79	5	*“ people with CFS should be able to access accurate information”* Indeed they should, but the Guideline fails to provide accurate information about ME/CFS and provides only “evidence” that has been shown to be biased and incorrect.	Noted.
SH	25% ME Group	126	FULL	82	11-12	*“people with CFS/ME should have the opportunity to make informed decision about their care”* Indeed so, but the Guideline pays lip-service only to this ideal, stating on page 181 that all adults and children with “CFS/ME” are to be offered CBT/GET.	Please see the revised recommendations.
SH	25% ME Group	127	FULL	83	9	The sentiment is appreciated and agreed with, but it must be said that "disease is also Generally detrimental to health and well-being". Although, we would agree with helping those 'who were able', to continue to be in education and work, it must be remembered that if the Guideline continues to advocate the use of CBT and GET for anyone with ME, then we feel this would be very unhelpful to the possible improvement or recovery of patients.	Please see the revised recommendations on management strategies.
SH	25% ME Group	128	FULL	83 - 84	27-29 & 1-5	This would not be possible if the person was severely affected and it would only be advisable to have home tuition at best	Please see also Chapter 7 on issues specific to people with severe CFS/ME.

						on a limited basis.	
SH	25% ME Group	129	FULL	84	8-16	http://www.25megroup.org/Group%20Leaflets/Group%20reports/March%202004%20Severe%20ME%20Analysis%20Report.doc This survey shows the difficulty in getting essential services for the severely affected, even the most basic!	Noted.
SH	25% ME Group	130	FULL	86	4.3.6.1	To read….'education, **training** and employment plans'	This has been added.
SH	25% ME Group	131	FULL	86	4.3.6.4	To read 'Assistance negotiating the healthcare, benefits, Social Services, and **education, training and employment** systems	We have made separate recommendations on work and education.
SH	Action for M.E.	19	FULL	78	4.1.1.1	Shared decision-making - this section was welcomed and recognised as best practice.	Noted.
SH	Action for M.E.	20	FULL	78	4.1.1.2	The term "appropriate skills and expertise" needs to be more fully defined throughout both the FULL and the NICE guidelines. Particular concern was expressed that, given the shortage of expertise in properly qualified CBT practitioners, qualifications and experience in this field would need to be clearly delineated. It has also been suggested that, if GET is used, it should be obligatory for multi-disciplinary teams to include a suitably trained practitioner.	Defining skills and competencies is outside the remit of this guideline, but appropriate professional organisations are expected to develop standard definitions.
SH	Action for M.E.	21	FULL	79 - 80		Research on the type of information required by patients, carers and healthcare professionals is extremely important to ensure that one of the key recommendations of the guidelines - shared decision-making - can be properly implemented.	Noted.
SH	Action for M.E.	22	FULL	81	4.2.6.	"Universally understood definitions…."	Noted.

					1	Further guidance on this is needed with an awareness of patient sensitivity.	
SH	Action for M.E.	23	FULL	81	4.2.6.5	A clear delineation of what “informed consent” should mean should be provided.	‘Informed consent’ is as for all conditions and healthcare professionals should be aware of the appropriate guidance on this.
SH	Action for M.E.	24	FULL	83	4.2.6.7	We would like the importance of a written record to be highlighted, as this can be very helpful. It is also one of the components of providing good clinical care in the GMC’s Good Medical Practice.	Noted and we have recommended that a summary of the consultation be provided in an appropriate format.
SH	Action for M.E.	25	FULL	83		The points raised re. loss of work or education are important, as long as undue pressure is not placed on the patient.	Noted.
SH	Action for M.E.	26	FULL	86	4.3.6.1	We support the intention of the guidelines to help get the patient to return to as normal a life as possible, which would need to be undertaken with great sensitivity.	Noted.
SH	Action for M.E.	27	FULL	86	4.3.6.4	We welcome the recommendation that assistance should be provided in negotiating the healthcare, benefits and social services systems.	Noted.
SH	Action for M.E.	28	FULL	86 - 87	4.3.6.4- 4.3.6.6	Hospitals should be made aware of some patients’ multiple chemical sensitivity and sensitivity to light etc. The guidelines need to note that hospital care may not be acceptable for all patients and domiciliary care should be available. However, in other cases respite care might be a real need and the guidelines should comment on this.	Any hospital care should be as appropriate for the individual.
SH	Association for Psychoanalytic Psychotherapy in the NHS (APP)	12	FULL	78	4.1.1.1	add to consider patient preference, experience and outcome of previous treatment(s) - "where a specific	We have noted the need to individualise management and to use different options

						psychological therapy [eg. CBT] has not worked or is not preferred, the patient should routinely be offered an alternative psychological therapy approach" - what is the reason this hasn't been added?	for each person.
SH	Association of Young People with ME	14	FULL	87 192 195 258	9 6.3.6.21 6.3.6.26 7.3.1.3	Please add • Telephone and email together when 'support' is mentioned	This has been added.
SH	BRAME Blue Ribbon for the Awareness of ME	68	FULL	77	9	4.1: As the NICE guideline for Patient Centred Care has not been added, how can we comment on whether or not it is appropriate for the needs of ME patients.	Noted, and revised. For information, the NICE Patient Centred Care text can also be found in the NICE version.
SH	BRAME Blue Ribbon for the Awareness of ME	69	FULL	78	4.1.1.1	4.1.1.1: Agree with introduction plus bulleted points 1, 5, 6 and 7. However we have concerns over points 2, 3 and 4. Patients should be equally involved in decision making at all stages. They should feel able to refuse any component of care, without detriment to further provision of care, benefit provision or insurance claims. They should be listened to, especially if previous experiences of treatment have been unhelpful or harmful.	This recommendation has been revised in light of this and other comments.
SH	BRAME Blue Ribbon for the Awareness of ME	70	FULL	78	4.1.1.1	Bullet 2 – We are concerned that, by only giving information on the therapies in this guideline, an unbalanced view will be conveyed to the patient, resulting in the patient only being offered CBT and GET, as they are the only 'evidence based' management strategies to appear in your guideline, especially as these are	Please see the detailed recommendations for all strategies recommended in this guideline.

						recommended elsewhere as the therapies of first choice for anyone who wants to return to normal life - which is the entire patient population. By only giving information about those in your guideline, this will mean that patients are unlikely to get the management technique which is most suitable to their illness.	
SH	BRAME Blue Ribbon for the Awareness of ME	71	FULL	78	4.1.1.1	Bullet 3 – Aetiology – you have given no real information on aetiology, and as the York Review showed that they looked at no research evidence on the aetiology and pathogenesis of this illness, it would be interesting to know what research evidence and discussion, if at all, took place within the GDG to discuss aetiology and pathogenesis.	Noted and please see Chapter 5 for a more detailed discussion of diagnosis and aetiology.
SH	BRAME Blue Ribbon for the Awareness of ME	72	FULL	78	4.1.1.1	Bullet 4 – With regard to returning to school/work it is good to be optimistic, but there also has to be a realistic view of living with ME/CFS and possible time scale of recovery – if at all – as it can also have a very negative impact as years go by, with no major improvement or possibly continued deterioration of heath. People with ME/CFS are desperate to be well and will often force themselves beyond their body's physical ability/limitations to achieve this goal or to fulfil the expectations of the therapy practitioners.	Noted.
SH	BRAME Blue Ribbon for the Awareness of ME	73	FULL	79	11	4.2.2.1: Agree with this statement as long as quality information and training is given by those who truly understand the reality and biomedical nature of ME/CFS.	Noted.
SH	BRAME Blue Ribbon for the Awareness of ME	74	FULL	82		4.2.6.7: People with severe ME/CFS, WILL have cognitive difficulties not 'may have'. There is also a paucity of information here/recommendations for the	We have revised this recommendation.

						severely affected which needs to be addressed.	
SH	BRAME Blue Ribbon for the Awareness of ME	75	FULL	83	3-8	DANGER – We have serious concerns about this statement, and the DoH's 'reference guide to consent for examination or treatment' for 'patients who do not have the capacity to make decisions', and that from April 2007 healthcare professionals will need to follow a code of practice accompanying the Mental Capacity Act 2005. There is evidence that some health care professionals erroneously take the stance that ME/CFS is a psychiatric/psychological condition. This has led to some children being taken into care and adults being forcibly, and wrongly, sectioned just because they have ME/CFS, much to the detriment of their health. Some SHAs have also acknowledged that if there are no ME/CFS services in their area, or they are not aware of local/regional ME/CFS services, their patients are automatically referred to Mental Health Services. Would this be acceptable for other chronic non-psychiatric illnesses? Our concerns are supported by our respondents, one of which said: "*Who will decide that a patient does not have the capacity to make a decision about his/her treatment? Will a refusal to accept CBT and GET be regarded, as has happened to frequently in the past, as indicating such a lack of capacity even when the patient has made an 'informed decision' concerning their 'individual needs and preferences'?"*	This is standard wording used in all NICE guidelines for all conditions.

SH	BRAME Blue Ribbon for the Awareness of ME	76	FULL	83	9-13	Whilst everyone has the goal of being well enough to return to education/work, this is not always possible. Patients do not choose to leave work/education, it is the overwhelming debilitation caused by their illness that leaves them with no choice, as they are unable to continue with any semblance of normal life. On the other hand, if they are mildly affected and able to achieve any part-time flexible work/education, some are forced out by non-understanding employers/educational establishments. There is also the risk of a serious relapse if people are encouraged to go back too soon, which could take them months/years to recover from. We also understand that the DWP is encouraging people back into work, and state that the longer people are absent from work, the less likely they are to return, and doctors are being paid bonuses for getting people back to work. However ME/CFS is an illness from which, even if people have good management advice in the early stages, and are mildly to moderately affected, may well still take many months to years before they are able to return, even part-time, to the workplace or education to resume their studies. This part-time process back into work, which may take some time, creates problems with claiming benefits, and some may never manage FULL-time employment, thus causing extra financial impact this has on the individual/family.	Noted.
SH	BRAME Blue Ribbon for the Awareness of ME	77	FULL	84	8	4.3.2.1 and 4.3.2.2: Felt that for evidence statements these were rather ambiguous eg ‘perceived specific support needs’.	These evidence statements were agreed by the GDG.

						Does this refer to medical, emotional or practical eg the need for carers, wheelchair or other aids, or something completely different?	
SH	BRAME Blue Ribbon for the Awareness of ME	78	FULL	86	1	4.3.6.4 – point 3 - Healthcare: People with ME/CFS need more help to access appropriate healthcare services, and to be referred to those health care professionals who truly understand the physical organic illness of ME. This may be through home visits, or may be out of area, and so funding may need to be allocated, to allow them to access the services. Benefits: The DWP are currently rewriting their Clinical Guidelines on ME/CFS for Disability Living Allowance, we now have to wait and see whether when they are adopted, they will improve the allocation of benefits to those people with ME/CFS. Through this consultation process we have been proposing for the DWP to accept the ME/CFS consultant's/GP's letter regarding their patient's current medical status to be acknowledged and accepted, as it is with other chronic health conditions, instead of the often disbelieving visiting doctor. We have also recommended that the DWP accept the ME consultant/GP rating of the patient on a functionality scale eg using the globally recognised Karnoffsky Scale, and also the CMO Report/NICEGuideline of level of severity of their ME/CFS, and the percentage of function they have compared to normal. Patients with ME/CFS have particular problems in being awarded benefits, often having to	We have made recommendations for healthcare professionals in the NHS. Recommendations for other sectors are outside the scope of this guideline.

						go to appeal, and the NICEGuideline needs to address these issues more rigorously and robustly in their evidence statements and recommendations. Social Services: Many patients with ME/CFS have great difficulty in accessing care through Social Services. They are often refused the help they need, especially for those who are struggling to cope on their own. Even to get a few hours a week to do shopping, cleaning or to provide a meal, would be enormously beneficial. For many severely affected this care need is essential, not only for the reasons already mentioned, but for all their personal and domestic needs. For some these carers may be their only contact with the outside world. Again this Guideline needs more robust and rigorous recommendations to help successFULLy access the services and support which should be provided by Social Services, for these more vulnerable individuals.	
SH	BRAME Blue Ribbon for the Awareness of ME	79	FULL	87		4.3.6.5: Why do the Guidelines always have to refer to psychology, when most people find learning coping strategies through counselling, especially person centred counselling, far more helpful, than seeing a psychologist and having behavioural therapies? Yet again patient evidence is being ignored! Also for heath economics it has to be more cost-effective to offer what patients find to be more helpful and effective.	We have listed only some of the services that may be accessed. The list is not intended to be exhaustive.
SH	BRAME Blue Ribbon for the Awareness of ME	80	FULL	87	6-11	The need for home visits should be emphasised here for those who are severely affected and bed/house bound by their illness. Most ME/CFS patients	Please see all recommendations specifically for people with severe CFS/ME.

						find that GPs refuse to do home visits, and it is virtually impossible to get a consultant to do a home visit. Whilst it is good to offer follow-up contact on the phone, and it should be offered, it needs to be understood that very often the severely affected are so unwell that they are barely able to say a few words with their carer, let alone have a consultation over the phone, (even the moderately affected may have trouble with answering phone calls). They have severely impaired cognitive function and trying to listen to what has been said, to understand it, and then think of a response, can often be almost impossible, and after 2 or 3 questions the brain would almost feel like it is closing down – especially if the conversation is not face to face.	
SH	Cambridgeshire Neurological Alliance	31	FULL	82	All 4.2.6.7	"As they may have cognitive difficulties, adults and children with severe symptoms may find it useful to have a summary record of every consultation for them to ref to" By definition of "severe" CFS/ME, the person affected by severe CFS/ME will no doubt have cognitive difficulties"	We have revised this recommendation.
SH	CFS/ME Clinical Network Coordinating Centre	4	FULL	77		Principle of multi-agency working and noting the role/contact of other agencies in the care of CFS/ME as a principle	Noted.
SH	College of Occupational Therapists	33	FULL	78	4.1.1.1	How can we provide information on the aetiology when this is still unclear?	Noted and please see Chapter 5 for a more detailed discussion of diagnosis and aetiology.
SH	College of Occupational	34	FULL	78	4.1.1.	Should this identify that healthcare professionals should have the appropriate	The wording is considered to be appropriate as it would be

	Therapists				2	'knowledge, skills and attitude regarding the condition', as particularly the attitude of the professional seems to be a key factor in individuals' experiences of care.	very difficult to define and measure attitude.
SH	College of Occupational Therapists	35	FULL	82	4.2.6.6	Occupational Therapy and Condition Management Services should be added to the list.	This list is not intended to be exhaustive.
SH	College of Occupational Therapists	38	FULL	83 183 144	17 6.3.6.8 21	The use of equipment needs careful consideration with CFS/ME as it is a potentially complex issue. On the one hand we are working with a long-term condition and are seeking to maintain/increase independence as early as possible, minimising the impact of symptoms on activity levels/ lifestyle, so equipment can help with this. On the other hand, unless the issue and use of equipment is integrated into a planned rehabilitation programme, it can counteract the proactive interventions such as CBT and GET/GAT which are advocated elsewhere in the document. Reference is made here to the fact that equipment may be used on a NICEterm basis and/or monitored which is a more helpful statement that the previous references **Suggestion:** Would it be possible to mention that there can be both benefits and detrimental effects to using equipment and that it is important that a person is able to make an informed choice. Therefore, provision of equipment should be supported by an appropriate professional, e.g *Occupational Therapist* or *Physiotherapist* who can ensure it is being used within the	Noted and we have recommended the use of equipment only if appropriate, and that the benefits and risks of any intervention should be considered and discussed.

						context of a rehabilitation programme for CFS/ME and monitor the changing needs of the individual.	
SH	College of Occupational Therapists	39	FULL	83	18-23	Occupational Therapists are trained and specialised in vocational rehabilitation and return to work. An individual's roles and activities in relation to productivity will be a core component of occupational therapy intervention. The document implies that if Occupational Health departments are unavailable then the intervention of a health care professional is a second choice is unhelpful and inaccurate. OTs are very experienced in working with OH departments and other agencies mentioned in this section, and can perform work assessments and provide advice to assist an individual with returning to work.	Occupational Health, Occupational Therapists and other members of the clinical team all have skills that will help to inform an appropriate rehabilitation plan,. However, Occupational Health has additional skills and local knowledge of the workplace that will enhance the likelihood of successful implementation of the plan. Therefore the GDG considered the wording to be appropriate.
SH	College of Occupational Therapists	40	FULL	87	4.3.6.4	Work and education would normally be described as activities related to productivity. **Suggestion;** Is the point supposed to be referring to both 'social and productivity activities, such as work and education.'	This has been revised.
SH	Department of Health, Peninsula Medical School	19	FULL	78	1	Box. Here and elsewhere. This section is really important and valuable.	Noted.
SH	Department of Health, Peninsula Medical School	20	FULL	87	6-11	It would be helpful to mention other ways in which these patients can be supported, such as tailored domiciliary health and social care input; and, for those with some external mobility, support through local GP practices and community hospitals.	Please see all recommendations specifically for people with severe CFS/ME.
SH	Invest in ME	84	FULL	78	1 onwa	*- 4.1 Recommendations* *4.1.1.1* Shared decision-making between	Noted. Shared decision making –

					rds	an adult or child and healthcare professionals should take place during diagnosis and all phases of care. To facilitate shared decision-making the healthcare professional should: • acknowledge the reality and impact of the condition and the symptoms. • provide information about the range of therapies and management strategies as detailed in this guideline. • provide information on the aetiology, nature, course and approaches towards CFS/ME, including the use of any therapy (such as benefits, risks, likely side effects), and returning to work or education. IiME Comment: This is a laudable aim. However, significant research is required to identify the aetiology, nature and course of ME, let alone any biomedical approaches in the treatment of ME Therapies have yet to be established that are safe for application with severe ME sufferers, given the evidence of physical neurological damage from SPECT brain scans and post-mortem examinations of inflammation to the dorsal root ganglia. Shared decision-making needs to be changed to patient empowerment. • offer information about access to self-help groups and support groups for adults and children, families and carers. (see www.nhsdirect.nhs.uk, and also the NHS Expert Patient Programme www.expertpatients.nhs.uk/)	this is a common term and was considered appropriate by the Guideline Development Group. www.nhsdirect.nhs.uk – this has been revised and the ‘Understanding NICE Guidance’ document will include details of relevant charities and patient support groups.

						IiME Comment: As commented before this site cannot be trusted currently. Also a list of ME charities and support groups could be given. • be aware that all adults and children with CFS/ME have the right to refuse any component of a care plan without detriment to the provision of other aspects of care. IiME Comment: Also knowledge of current biomedical research which is underway and what biomedical research is being funded by the Medical Research Council We welcome the statement that patients are in charge of decisions being made about their care. We welcome the statement that healthcare staff need to acknowledge the reality and impact of the condition and the symptoms. We would like to have seen this emphasised yet again in the overall recommendations This would be an improvement if evidence-based logic could support the acknowledgement and replace the conventional medical professional training that states that ME is a psychological problem that can be treated with CBT/GET. Also, the medical professionals should be trained that the psychosocial model is not correctly applied for people with ME, since they do not have a psychological illness as the root-cause of ME, accepting that ME can cause long-term depression and sensitivities to external suggestions.	

SH	Invest in ME	85	FULL	78	1	*4.1.1.2* Healthcare professionals who are responsible for the care of an adult or child with CFS/ME should have the appropriate skills and expertise in the condition. IiME Comment: What are appropriate skills? This is meaningless unless these skills are described. Psychiatric skills would not be relevant for a responsibility for pwme.	Defining skills and competencies is outside the remit of this guideline, but appropriate professional organisations are expected to develop standard definitions.
SH	Invest in ME	86	FULL	79	1	*4.1.1.4* As part of the transition process, diagnosis and management should be reviewed. Throughout the transition process there should be clarity about who is the lead clinician to ensure that there is continuity of care. IiME Comment: We welcome the review of diagnosis and management. We feel that clarity about lead clinician should also be affected/decided by the patient/carer.	Noted. The choice of lead clinician would be agreed through negotiation and would be based on many factors, including patient preference/need.
SH	Invest in ME	87	FULL	79	2 - 8	*4.2 Information* IiME Comment: We agree. Accurate information is mandatory. Does this extend to the proper basis for defining the illness? Terminology, the name used by the WHO, the policy of the government/MRC on funding for research, the ratio of funding given to biomedical research compared with non-biomedical research etc.	Noted and please see Chapter 5 for a more detailed discussion on case definitions.
SH	Invest in ME	88	FULL	79	11	*4.2.2 Evidence Statements* *4.2.2.2* There is no evidence as to whether this need for information is	These were agreed by the Guideline Development Group and we are not able to change these – and the

						specific to CFS/ME or on the content and appropriate mode of delivery of the information (3/4). IiME Comment: There is much evidence that this is specific to ME. The testimonies of ME patients in this document illustrate how poorly informed many healthcare practitioners are about ME. We do not understand this.	information in the guidelines is expected to help improve levels of knowledge for healthcare professionals.
SH	Invest in ME	89	FULL	80	9	*4.2.4 Health Economics Evidence Summary* No studies were found that addressed the clinical question. IiME Comment: Isn't this significant?	Depending on the question asked, there are often areas where evidence is limited, or even lacking.
SH	Invest in ME	90	FULL	80	11	The GDG decided that clinical scenarios would not contribute to decision making. IiME Comment: Why? We do not understand this.	The clinical scenarios were based on two factors: age and severity. Scenarios based on these to ascertain which information and support should be offered and how to deliver this were not considered to be useful in the decision making.
SH	Invest in ME	91	FULL	81	1 onwards	*- 4.2.6 Recommendations* *4.2.6.1* Consistent and universally understood definitions of treatments and medical terminology should be applied throughout CFS/ME care (such as those in this guideline. See glossary). IiME Comment: Why not start with the WHO standard definition and name? Definitions of symptoms and treatments are not universally understood or agreed and some differ significantly from those included in this guideline. Moreover, notable biomedical researchers challenge	Please see Chapter 5 for a more detailed discussion on case definitions.

						the basis of the diagnosis and treatment included in this proposed guideline.	
SH	Invest in ME	92	FULL	81		4.2.6.5 Where adults and children with CFS/ME are able to continue at, or return to work or school, the healthcare professional should ensure that, with the patient's informed consent, employers, occupational health or education institutions have information on the condition and the agreed management plan. IiME Comment: "*agreed management plan*" shouldn't this be the "agreed treatment plan"?	We have used the term 'management plan' throughout the guideline.
SH	Invest in ME	93	FULL	82		*4.2.6.6* Healthcare professionals should be proactive in advising about fitness for work and education, and recommend adjustments or adaptations to work or studies to enable rehabilitation of adults and children with CFS/ME. This includes liaising (with the person's consent) with employers, education providers and support services for example: • occupational health services • disability services through Jobcentre Plus (http://www.jobcentreplus.gov.uk/JCP/Customers/Helpfordisabledpeople/index.html) • Connexions for schools • disability advisers in universities and colleges. IiME Comment: Why not also DLA – the government needs to be informed.	This is a guideline for healthcare professionals working in the NHS, however information in this guideline will be relevant to other sectors.

						Insurance companies should also be informed of the real nature of this illness and be advised not to attempt to enforce therapies or 'treatments' which are not in the interests of the patient.	
SH	Invest in ME	94	FULL	82	11	*- 4.3 Support* People with CFS/ME should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. IiME Comment: Does this include whether to be sectioned or not by police/psychiatrists? Will NICEcomment that ME patients should not be allowed to be sectioned if they refuse to take CBT/GET?	Please see Chapter 7 for a discussion of sectioning. Nowhere do we recommend the use of sectioning if treatment is refused.
SH	Invest in ME	95	FULL	83	9 onwards	Loss of employment or education is Generally detrimental to health and well-being. Moreover, the longer that a person is off work due to illness or disability, the less likely they are to return to employment. Therefore, it is very important that work and education are addressed early in the care pathway for CFS/ME, and are reviewed regularly as part of the ongoing management programme. IiME Comment: Not at the risk of impairing the patient's health. The stress inflicted on patients by insurance companies who force a patient to accept unhelpful therapies and the attitude of DLA personnel needs to change. First one should start by making DLA informed of what ME is	This is a guideline for healthcare professionals working in the NHS, however information in this guideline will be relevant to other sectors. We have also noted throughout the need to tailor interventions appropriately.

SH	Invest in ME	96	FULL	83	14 onwards	Occupational health services are best placed to facilitate rehabilitation back to work. IiME Comment: Only if they understand fully what a neurological illness like ME is.	Noted.
SH	Invest in ME	97	FULL	83	27 onwards	"In the case of children and adolescents, there is a need to work with the family and the education provider (school, college, or university) to provide support. There needs to be close liaison between health, social care and education so there is a common understanding of goals and objectives. Therefore, the view of the GDG was that a key worker, responsible for co-ordinating care was needed. There may need to be a flexible approach with home tuition and use of equipment that allows a gradual reintegration into schools. It is important for the child that their peers understand and they are being supported rather than stigmatised. " IiME Comment: What about education of schools? Schools should have access to the research regarding the biological nature of ME.	We have noted the need for communication and information sharing with the schools.
SH	Invest in ME	98	FULL	83	1 onwards	"Unless specifically excluded by the patient, carers and relatives should have the opportunity to be involved in decisions about the patient's care and treatment. " IiME Comment: Does this include whether to be sectioned or not by police/psychiatrists?	Sectioning is outside the scope of this guideline, but please see Chapter 7 for discussion on the use of sectioning.
SH	Invest in ME	99	FULL	83	3 onwards	"If patients do not have the capacity to make decisions, healthcare professionals should follow the Department of Health guidelines – 'Reference guide to consent for examination or treatment' (available	This is standard wording used in all NICE guidelines for all conditions. The paragraph also states that healthcare professionals need to follow

						from www.dh.gov.uk). " IiME Comment: Where has this been analysed by stakeholders? Who determines if these guidelines are valid? How does this statement stand with the statement made on Page 82 lines from 11? How does this stand in relation to the code of practice accompanying the Mental Capacity Act 2005 which needs to be followed by healthcare professionals from April 2007 (That individuals must retain the right to make what might be seen as eccentric or unwise decisions)?	the code of practice relating to the Mental Capacity Act.
SH	Invest in ME	100	FULL	86	1 onwards	*4.3.6* *4.3.6.1* A documented, individualised management plan should be developed with the adult or child with CFS/ME, and the carer, where appropriate to include: • relevant symptoms and history • plans for care • information and support needs • education or employment plans • details of the healthcare professionals involved in care and their contact details. IiME Comment: "*individualised management plan should be developed*" - shouldn't this be an "individualised treatment and care plan should be developed"? Shouldn't the subsequent text also refer to "treatment and care" rather than "management"? Information from ME support groups – details of organizations should be included.	The GDG considered 'management' to be the appropriate term. Details of selected organisations can be found in the Understanding NICE Guidance.

						4.3.6.2 A designated healthcare professional should be identified who is responsible for coordinating care for each adult or child with CFS/ME. IiME Comment: Who designates – what type of healthcare professional. It is pointless having a psychiatrist designated as responsible for coordination of care for a patient with a neurological illness such as ME. It must be somebody who knows the biological background to ME *4.3.6.3* Healthcare professionals should aim to establish a supportive and collaborative relationship with the adult or child with CFS/ME, family, and carers to facilitate their effective management. IiME Comment: Agree – with patient/carer at centre and in charge of decisions about the patient *4.3.6.4* Support that should be considered for any adult or child with, or suspected to have, CFS/ME are: • information concerning the illness (see information recommendations) • acceptance and understanding • assistance negotiating the healthcare, benefits and social services systems • availability of care regardless of ability to travel to services • assistance with social activities including work and education. IiME Comment: Assistance dealing with insurance companies who do not listen to the patient should be added.	The designated healthcare professional will be as appropriate for the individual. Noted. The guidelines are developed for health care practitioners and are relevant to the NHS. The reference to social activities has been revised.

						"assistance with social activities including work and education" - is this within the normal purview of support provided by the General medical practitioner to patients with biomedical conditions? Could this be a further indication that the NICEGuideline is following the psychosocial model in preference to the biomedical physical illness model?	
SH	Invest in ME	101	FULL	87	1 onwards	4.3.6.5 Adults and children who are severely affected may need to access, at various times, community services such as nursing, physiotherapy, psychology and occupational therapy (ref NSF long term conditions) –The input of various professionals should be coordinated by a named professional and those involved in care need to be trained in the management of CFS/ME. IiME Comment: Why psychology for a neurological illness? why not a neurologist? Why not continued medical examinations by a qualified physician?	We have listed only some of the additional services that may be accessed… the list is not intended to be exhaustive.
SH	Invest in ME	102	FULL	87	2 onwards	4.3.7 Deriving Recommendations The view of the GDG was that support should be provided to assist the person in maintaining as much of their normal life as possible. The emphasis should be on self management with goals and objectives important to the individual. IiME Comment: We feel the document would need to stress here that goals and objectives need to be balanced with the prime objective of avoiding a relapse or deterioration in the state of the patient.	Please see the revised recommendations on the choice of interventions.

						The GDG discussed the very severely affected who were frequently isolated at home away from services and support. IiME Comment: Even so-called mildly/moderately affected patients can be isolated – it is not just severely-affected who are isolated at home. The view of the GDG was that all patients should have access to appropriate service and care regardless of their ability to attend hospitals or clinics. Sometimes, there could be follow-up contact by telephone. The point was made that small improvements in quality of life were very important.	Noted.
SH	Royal College of Nursing	26	FULL	78	4.1.1.1	Include parents alongside ‘child’ in shared decision-making.	This has been revised, but the involvement of the carers and relatives, as appropriate, is noted in the Patient Centred Care section of the NICE version.
SH	Royal College of Nursing	27	FULL	81	4.2.6.4	These guidelines should be followed where appropriate – i.e. where medical needs exist.	Noted.
SH	Royal College of Nursing	28	FULL	82	4.2.6.6	Add home tutoring to list.	This has been added.
SH	Royal College of Nursing	29	FULL	83	3	The provision of equipment is not always necessary for a young person to return to school. Many young people do not need extra equipment, or adaptations to be made to the school environment. A graded return to school seems to be what is required.	Noted and we have recommended the use of equipment only when appropriate.
SH	Royal College of Nursing	30	FULL	87	4.3.6.6	An admission may be appropriate and the best way to deliver care for a severely affected patient requiring intensive	Noted.

						rehabilitation, care and support.	
SH	Royal College of Nursing	31	FULL	87	10	Include telephone and e-mail as both allow care and support to be delivered to patient with no travel.	This has been added.
SH	Sheffield South West Primary Care Trust	2	FULL	82		Recommendations (4.2.6.6) Making recommendations for fitness for work and education. Need to be clear if this is recommending that specialist services for CFS/ME should be completing application forms in support of client's application for Disability Living Allowance. Is it also recommending that specialist CFS/ME services should respond to requests for reports from client's employer's occupational health department and/or insurance company with respect to application for retirement on ill health grounds?	We have recommended that healthcare professionals be proactive in supporting and helping patients, in the ways appropriate to the needs of the individual.
SH	St Bartholomew's Hospital Chronic Fatigue Services	40	FULL	78	4.1.1.1	We fully endorse shared decision making and the importance of acknowledging the reality and impact of the condition.	Noted.
SH	St Bartholomew's Hospital Chronic Fatigue Services	41	FULL	87	4.3.6.6	Hospital care: This section should also mention the alternative of domiciliary care and treatment, which is a cheaper and a more patient centred care setting.	Noted and this is now in the recommendations.
SH	St Bartholomew's Hospital Chronic Fatigue Services	42	FULL	87-195		There seems to be a lot more information on GET than CBT. As both have been found to be effective, it may be important not to emphasise one approach over another.	Please see the revised recommendations on interventions.
SH	Stockport PCT	10	FULL	79	7 – 8	Currently our service provides only minimal support for carers, with the exception of providing access to the Master Class.	Noted.

SH	Stockport PCT	11	FULL	81	4.2.6.2	In terms of accuracy of information I am unsure as how we can provide information on the duration of the illness.	Noted, and we have given guidance on the communication of prognosis.
SH	Stockport PCT	12	FULL	82	4.2.6.7	Is this a separate record of each specific consultation? Alternatively, could the patient have access to their case notes? If so, this would result in two separate notes, with one of the sets being in clinical terms and the second set being "jargon free".	We have revised this recommendation, but the summary should be appropriate for the individual.
SH	Stockport PCT	13	FULL	83	5 – 7	If recommended to follow Mental Capacity Act 2005, perhaps some training would be required in how this will affect practice as a mental health professional.	All healthcare professionals should be aware of this act and its implications.
SH	Stockport PCT	14	FULL	83	15	These issues are already covered within the context of the group management programme.	Noted.
SH	Stockport PCT	15	FULL	87	4.3.6.5	Access to this service is predominantly from G.P. referrals, who I believe maintain medico legal responsibility. Thus, it would be logical to have the G.P. trained in the management of CFS/ME.	Noted and we have recommended the need for healthcare professionals to have appropriate skills and competencies.
SH	Stockport PCT	16	FULL	87	6 – 9	Following this recommendation might result in an increase of domiciliary visits on an already stretched service.	Noted, and this issue has been raised with the Implementation team.
SH	The Association for Family Therapy	3	FULL	83	27	Family and systemic psychotherapists, whether based in child and adolescent mental health services or elsewhere, would be well qualified to provide a co-ordinating role as well as specific support to the family	Noted, and we have not specified which healthcare professional should undertake this role to allow for flexibility and local circumstances.
SH	The Association for Family Therapy	4	FULL	84	21	In addition to social workers, improved links could be developed between child and adolescent mental health professionals in order to develop a greater understanding of a child/young	Noted.

						persons mental health needs	
SH	The Association for Family Therapy	5	FULL	87	4.3.6.5	Again, Family and systemic psychotherapists whether based in child and adolescent mental health services or elsewhere, would be well qualified to provide a co-ordinating role as well as specific support to the family	Noted, and we have not specified which healthcare professional should undertake this role to allow for flexibility and local circumstances.
SH	The Chartered Society of Physiotherapy	7	FULL	81	1 (4261)	Agree with statement but this is not actioned in the document	Noted and we have tried to address this.
SH	The Chartered Society of Physiotherapy	8	FULL	87	5	Agree that emphasis on self management is vital	Noted.
SH	Welsh Association of ME & CFS Support	47	FULL	79	3 – 8	It is good that the need for good information has been acknowledged, but much of the information in this guideline is not backed by 'evidence' and is controversial	Noted.
SH	Welsh Association of ME & CFS Support	48	FULL	81		4.2.6.4. This guidance does not apply to Wales therefore this section needs rewriting	Noted and revised.
SH	Welsh Association of ME & CFS Support	49	FULL	81		4.2.6.5. This section could lead to inappropriate goals being set by non medical people thereby causing relapse.	This recommends that information should be shared if appropriate, not that 'non-healthcare' professionals should agree goals.
SH	Welsh Association of ME & CFS Support	50	FULL	82		4.2.6.6. Some people will not be able to be rehabilitated due to the fluctuating nature of their condition and this needs to be made clear.	Noted. Please see the recommendation on prognosis.
SH	Welsh Association of ME & CFS Support	51	FULL	82		4.2.6.6. Not applicable in Wales	Noted and revised.
SH	Welsh Association of ME & CFS Support	52	FULL	82		4.2.6.7. Good idea	Noted.
SH	Welsh Association of ME &	53	FULL	83	1 – 2	Only with the patients consent. Patients,	We have noted the need for

	CFS Support					including children should be made aware of the 'Consent to Treatment' protocols which apply to different areas of the UK	consent (however achieved) throughout.
SH	Welsh Association of ME & CFS Support	54	FULL	83	4	Reference needs to be made to the different legislation in Wales	This is standard wording used in all NICE guidelines for all conditions, and we have raised this with NICE.
SH	Welsh Association of ME & CFS Support	55	FULL	83	7	There is a very real danger that professionals will use this act to enforce treatment on patients by using this act inapprotiately.	All healthcare professionals should be aware of this act and its implications.
SH	Welsh Association of ME & CFS Support	56	FULL	83	18	E-learning needs to be added	We have noted that a flexible approach, as appropriate to the individual, should be adopted.
SH	Welsh Association of ME & CFS Support	57	FULL	84	3	E-learning needs to be included here	We have noted that a flexible approach, as appropriate to the individual, should be adopted.
SH	Welsh Association of ME & CFS Support	58	FULL	84	17 - 21	Guidance needs to be given on the legislation applicable to Wales in education.	Noted and revised.
SH	Welsh Association of ME & CFS Support	59	FULL	86		4.3.6.4. put appropriate between the words 'of' and 'care'	This recommendation has been revised.
SH	Welsh Association of ME & CFS Support	60	FULL	87		4.3.6.6. Admission to hospital should only be done with the child or adults permission. Admission to hospital has been misinterpreted by some and patients should not be coerced into any course of action against their will.	Noted and the rights of the patient have been stressed throughout.
SH	Welsh Association of ME & CFS Support	61	FULL	87	10	This is not approriate for all severely affected patient. Therefore contact via a parent/carer should be recognised.	We have noted only that this may be an option for communication.