

National Institute for Health and Clinical Excellence
CFS/ME consultation draft
29 September – 24 November 2006
Comments on Chapter 7

Status	SH organisation	Order no.	Document	Page No.	Line no.	Comments	Responses
SH	25% ME Group	227	FULL	256-265		<p>Given the apparent understanding of severe ME/CFS outlined in this NICE section, it is a matter of concern that the severely affected should nevertheless be deemed “<i>able to access the same therapeutic options as those who are not severely affected</i>”, an oxymoron which seems to call into question the probity of the NICE Guideline Development Group members and their advisers, since the only two recommended management regimes (CBT/GET) have already been shown to be harmful and to convert moderately affected ME/CFS patients into being severely affected. How can this be ethical?</p> <p>It seems increasingly inescapable that, where ME/CFS is concerned, neither ethical considerations nor scientific evidence plays any part in the present Government’s policy-making.</p>	We have revised the recommendations, but the intent of this specific statement is to enable people with severe CFS/ME to access appropriate services, rather than be unable to access healthcare as has been reported.
SH	25% ME Group	228	FULL	256-257		<p>The most severely affected patients experience barriers to accessing all forms of care, variable responses to treatments and under-representation in research (DH2002A) and therefore it is not surprising that there is insufficient evidence to guide the specific management of severe ME.</p> <p>We would therefore call for relevant research in the area of the severely affected but would oppose research in the area of psychology alone (ie, the research needs to be biomedical to possibly find the underlying causes).</p>	This has been acknowledged in the research recommendations.
SH	25% ME Group	229	FULL	256	9	‘may be transient’ but also may be relentless. Why not tell the medical profession about the whole range of disability they might encounter	This has been revised.

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						– it is a disservice to the most ill patients to omit this.	
SH	25% ME Group	230	FULL	257	1 - 6	How can the severely affected possibly receive the same care? Invariably they cannot access the 'services'!	This has been revised.
SH	25% ME Group	231	FULL	257	1 + Gene ral	<p>'the same care' !!! They need far more practical care!</p> <p>There is no evidence for using the 2 main therapies for patients with severe ME or children and to use such approaches would be dangerous and open to abuse by therapists.; as is already happening!!</p> <p>This only goes to show that the people at NICE do not understand the true nature of the condition and the difficulties that many severely affected patients have to cope with on a daily basis. See following link: http://www.25megroup.org/Group%20Leaflets/Group%20reports/Understandingsevere%20me%20article%20(1).doc</p>	This has been revised.
SH	25% ME Group	232	FULL	258	7.3.1. 4	<p><i>' Elements of CBT and GET may be suitable for people with severe CFS/ME'</i></p> <p>I cannot understand why CBT and GET have been advocated at all for anyone, but especially why elements are being advocated for the severely affected. Has the information provided by the 25% severe ME Group to the Gibson Inquiry regarding GET and CBT and ME which was reported this year, been read or accepted? It shows that these are not appropriate and are positively damaging for people with severe ME. Why has this been disregarded?</p> <p>What about the earlier Research from the 25% Group or even AfME which reported similar findings ie. that they are both</p>	Please see the revised recommendations on management.

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						<p>dangerous and harmful to people with ME?</p> <p>Why have all ME charity research questionnaires and results that showed that GET and CBT (Even with trained professionals using these techniques?) actually do harm particularly to the severely affected, been ignored?</p>	
SH	25% ME Group	233	FULL	258	7.3.1.4	<p>Unacceptable and highly dangerous. Could seriously delay improvement or remission of the condition.</p> <p>It has no basis in evidence to implement these forms of therapeutic approaches and this has been reported in a previous section and can be seen in this document. http://www.25megroup.org/Group%20Leaflets/Group%20reports/March%202004%20Severe%20ME%20Analysis%20Report.doc and page 8</p> <p>Personal Experience</p> <p>I have been told that the proposals are of the type which involves graded exercise and CBT.</p> <p>My own personal experience of graded exercise was that any advice I was given along these lines were music to my ears and I dutifully followed all GET type advice in trusting hope that it would help me. The result on each occasion was an extreme relapse. The final GET type advice ever took was given during an appointment with Dr. [X] in [x] Hospital. After seeing Dr. [X], I followed his advice to the letter the following day and lost my mobility instantly along with any remaining vestiges of my dignity. I went from being able to struggle along with several hours of care per day or less, to requiring at least one person 24 hours per day heaving me on and</p>	<p>Please see the revised recommendations on management. We have also recommended the need for regular review and patient agreement</p>

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						off a bedpan. I have no respect for any doctor who retains the erroneous belief that Graded Exercise might help patients with ME, because it proves to me that he/she is not listening to enough of the patients, or following up this treatment.	
SH	25% ME Group	234	FULL	258	7.3.1.7	Guidance for both emergency and planned admissions to hospital need to be given. The experiences of those PWME who have been admitted need to be sought. Further to this the recent coroners report in to the tragic death of [X] from ME, and the concerns regarding her treatment raised by [X] should be taken in to account. The limited issues that I am aware of that need to be covered include; sensitivity to light, noise, chemicals and movement; and high sensitivity to anaesthetics and relapses following operations. Similarly guidance to dentists re. anaesthetics, adrenaline injections, preference for non amalgam fillings should be included.	We have stated that individual needs are to be considered .
SH	25% ME Group	235	FULL	262	7.6	There seems to be no detailed suggestions about pain management. Since pain is one of the main problems of the condition, this would be a major oversight. There should be advice on the pros and cons of various pain medications, muscle relaxants, and sleep medication. There should also be a duty for the healthcare provider to direct the patient to an appropriate pain clinic where necessary.	We have added and revised the recommendations on pain management.
SH	25% ME Group	236	FULL	263	4 - 5	Many severely affected people with ME/CFS would find the task of keeping a diary extremely difficult.	This section has been substantially revised.
SH	25% ME Group	237	FULL	263	9-17	A home visit from someone with counselling skills and a sympathetic ear and demeanour	This section has been substantially revised.

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						would be useful.	
SH	Action for M.E.	79	FULL	256	7	Many of the severely affected are physically unable to access services; so domiciliary visits become an essential requirement and should be noted as such.	Domiciliary visits are now included in the home support section in the chapter.
SH	Action for M.E.	80	FULL	258	7.3.1.3	Telephone support for the severely affected – 76.5% of respondents to our survey thought this was a useful resource for the severely affected.	Noted.
SH	Action for M.E.	81	FULL	259	7.4.1	'Access to DWP and other benefits may be an issue and this should be discussed and help provided if appropriate'. This is warmly welcomed but we would like to see it further emphasised – and perhaps related to the issue of a patient refusing a particular component of treatment.	We have recommended that healthcare professionals should be pro-active in this area.
SH	Action for M.E.	82	FULL	259	22-23	Regular home monitoring is welcome – human contact alone would be beneficial. In many cases, home visits from specialists would also be welcome.	Noted.
SH	Action for M.E.	83	FULL	260	7.4.3	These comments regarding the position of carers are welcomed. These do not appear in the FULL guidelines, which would be useful.	The section on carers is part of the full guideline.
SH	Action for M.E.	84	FULL	262		Is this note about the skin sensitivity of people with M.E. included in the NICEer guidelines? We have not been able to find it.	This section has been removed.
SH	Action for M.E.	85	FULL	262 – 263	27 –2	"At first it should aim to control pain..."needs to be highlighted in the NICEguidelines.	This section has been substantially revised.
SH	Association of Young People with ME	11	FULL	261	26	Please add <ul style="list-style-type: none"> • '.NICEstay in an appropriate hospital environment 	This section has been revised.
SH	Association of Young People with ME	12	FULL	261	11	Please change <ul style="list-style-type: none"> • 'need to be' ...to ...'must be' 	This section has been removed.

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SH	Association of Young People with ME	13	FULL	264	26	Please add <ul style="list-style-type: none"> ‘ ... on a 3-6 month cyclical programme’ 	We have noted that the timing of reviews should be appropriate for the individual.
SH	BRAME Blue Ribbon for the Awareness of ME	235	FULL	256-265	General	Severely Affected: We are pleased that people who are severely affected will not be made to do GET and CBT, however we are extremely concerned, that it is felt to be suitable to include elements – this is not appropriate.	The GDG considered the recommendations to be appropriate.
SH	BRAME Blue Ribbon for the Awareness of ME	236	FULL	256-265	General	Like ourselves many of our respondents felt that there is a lack of acknowledgement of the severe neurological and other symptoms experienced by the severely affected eg. Paralysis/paresis, blackouts, convulsions, loss of speech, muscle weakness without muscle wasting/deconditioning including the muscles relating to swallowing – making tube feeding a necessity for many. There is also only the briefest mention of the photophobia, hyperacuity and the inability to control body temperature.	We have acknowledged the range and severity of the symptoms.
SH	BRAME Blue Ribbon for the Awareness of ME	237	FULL	256-265	General	There is a lack of information about the need to be especially aware of the high number of co-morbid conditions associated with ME/CFS, in particular with the severely affected. There is a high number of people with ME/CFS who have undiagnosed/diagnosed co-morbid heart problems and doctors must be made particularly aware of this, especially given the high number of deaths from co-morbid heart conditions at an earlier than expected age. This is often missed, as with palpitations being experienced by many with ME/CFS, they are not investigated thoroughly. Women with ME/CFS are also more likely to	We have noted the need for comorbidities to be assessed.

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						<p>experience co-morbid/exacerbated menstrual problems.</p> <p>Given the sensitivity to medication/treatment, alongside the compromised bodies, of the severely affected makes any treatment a real difficulty. Decisions on the way these co-morbid conditions should be managed should be made in partnership with the patient, making an informed choice.</p>	
SH	BRAME Blue Ribbon for the Awareness of ME	238	FULL	256	9	<p>For the severely affected, severe or very severe symptoms, are not transient. They can be continuous and relentless, especially where pain is concerned, or may be transient in their level of severity, but not transient in appearance. However the moderately or mildly affected will experience a more severe set of symptoms during a relapse, this may be temporary or may persist for a longer period of time.</p>	This has been revised.
SH	BRAME Blue Ribbon for the Awareness of ME	239	FULL	256	13-16	<p>Whilst we acknowledge that some people may progress to the point of being able to be classed as mildly or moderately affected, the guidelines should put in here, as the CMO report acknowledges on a number of occasions, that the prognosis for the severely affected is poor, and are less likely to make an improvement, especially those who have been severely affected for more than five years.</p>	We have noted that only some people have significant improvement.
SH	BRAME Blue Ribbon for the Awareness of ME	240	FULL	256	21-25	<p>You say that you will not address access to care, but there is a real problem with ME and ME/CFS, because of the disbelief of medical professionals/social services/DWP.</p> <p>There is real difficulty for the severely affected in trying to get care and help, in order to live even a basic existence. We know of severely affected people who have not had a hot meal</p>	We have recommended the need to recognise the reality of CFS/ME and the aim of the guidelines is to improve care and access to care.

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					<p>in weeks because even if they are able to afford it, they are unable to get the care they desperately need, they are too ill to shop or prepare food themselves, and are denied care by non-understanding care services, often because the doctors/nurses do not appreciate the severity of the illness, nor believe that it is physical.</p> <p>This is also true of the severely affected who are constantly denied benefits, we know of many people who have been denied benefits repeatedly, despite the fact that they are unable to do anything for themselves. They are left in the position where, without money, they cannot feed themselves or keep warm. The 25% Group's survey has shown that 59% of severely affected sufferers are turned down for benefits first time, with 85% successful on appeal – some of this is down to the decision makers, but often it is down to the visiting doctor not believing in ME/CFS. Something must be done to ensure that the severely affected are assured that their basic human requirements of care, food and heat will be provided – something that starts with the medical establishment agreeing that ME/CFS is a chronic neurological illness that seriously incapacitates its sufferers, and by disseminating that opinion.</p> <p>One of our respondents, who is in his 40s, long-term severely affected, bed/housebound, in constant unrelenting pain and doubly incontinent has had difficulty getting benefits, difficulty getting care and just feels that he has nowhere left to turn and says that "<i>he is in constant pain, has no life, no dignity, no privacy and no-one understands unless they have experienced it themselves.</i>"</p>	
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						Please see the end of this proforma for more comments from those affected by ME/CFS.	
SH	BRAME Blue Ribbon for the Awareness of ME	241	FULL	257 258	1-6 / 7.3.1. 1	We agree that all sufferers should be able to access care and services no matter what the severity of their illness – however extra special provisions must be made for the severely affected because they cannot access them, especially without assistance. More home visits and provision of services within the patients' home should be introduced.	We have recommended the need for a different delivery of care – including home visits etc.
SH	BRAME Blue Ribbon for the Awareness of ME	242	FULL	258	7.3.1. 2	They 'will' have cognitive difficulties, not 'may'.	The wording was considered to be appropriate.
SH	BRAME Blue Ribbon for the Awareness of ME	243	FULL	258	7.3.1. 4	It is extremely dangerous to recommend that elements of CBT and GET should be used on the severely affected. CBT and GET should not be used for the patient population, and certainly not for the severely affected. Nor should there be the use of 'elements' of CBT and GET – these are not suitable for adults or children who are severely affected. There is no research into the effects of GET/CBT in the severely affected, so to even make a suggestion that this is appropriate is extremely harmful – too many severely affected people are already being forced into GET and CBT already – not exercise programmes, GET programmes, and the evidence is that they are being made worse. The only evidence available for this group is the patient evidence which shows that 95% of patients found GET unhelpful, with 82% being made worse, CBT was found unhelpful by 93%. To recommend these management processes is flying in the face of evidence from the patients, and to recommend these would seem to indicate a	Please see the revised recommendations on management. We have also recommended the need for regular review and patient agreement.

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						lack of common sense.	
SH	BRAME Blue Ribbon for the Awareness of ME	244	FULL	258	7.3.1.4	Why is there no mention of pacing/energy management, or person-centred counselling which the severely affected find helpful?	Please see the revised recommendations. No evidence on the use of counselling was identified.
SH	BRAME Blue Ribbon for the Awareness of ME	245	FULL	258	7.3.1.4	This recommendation should include symptom management which on p263 is described as “the most useful form of management” and yet is not included in the recommendations.	Please see the revised recommendations.
SH	BRAME Blue Ribbon for the Awareness of ME	246	FULL	258	7.3.1.6	Psychology should be removed and replaced with person-centred counselling.	The wording is considered to be appropriate as this describes the service.
SH	BRAME Blue Ribbon for the Awareness of ME	247	FULL	2582 59	7.3.1.7	Advice needs to be given on hospital admittance for someone who is severely affected with ME and ME/CFS. A single room, with thick curtains/blackout blinds, a low light, away from noise and with chemical use kept to a minimum are necessities. It may be that the sufferer will need their own bed sheets/pillows due to reactions. Some people even need special mattresses due to their heightened physical and/or chemical sensitivity. Advice is also needed for doctors and nurses on skin sensitivity, sleep dysfunction/reversal, heightened sensitivity to pharmacological/non-pharmacological management, use of oxygen and anaesthetics.	We have stated that individual needs are to be considered.
SH	BRAME Blue Ribbon for the Awareness of ME	248	FULL	259	18	Not ‘may’ severely exacerbate symptoms, but ‘is likely to’.	This section has been revised substantially.
SH	BRAME Blue Ribbon for the	249	FULL	260	13	Again ‘will’ have cognitive problems not ‘may’.	This has been removed.

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	Awareness of ME						
SH	BRAME Blue Ribbon for the Awareness of ME	250	FULL	260	7.4.3	There needs to be something added here about the loss of social interaction and rites of passage by the severely affected child/young person. Understanding needs to be given about this loss, and encouragement, when physically able, for friends to keep in touch and visit/call – this is vital.	As noted before, this is not intended as a text book, but a clinical guideline – again, this would be the same as for any serious, chronic illness in childhood/adolescence.
SH	BRAME Blue Ribbon for the Awareness of ME	251	FULL	260	7.4.3	One of our respondents said of this section: <i>“This paragraph on Carers shows more understanding of their position than the complete NICE guidelines does for the sufferers of ME. What an opportunity lost.”</i>	Noted. The full guideline will be published alongside the NICE version (which is simply a list of the recommendations).
SH	BRAME Blue Ribbon for the Awareness of ME	252	FULL	260	22-23	We are pleased that you acknowledge that the carer’s health can be affected by caring for someone severely affected, but more information is needed here. Carers are often met with cynicism by doctors, who put down all symptoms a carer goes to the doctor with as being due to the ‘stress’ of caring, even though they may have rarely seen a doctor for themselves over the years, just because a person is a carer, does not stop them being able to get ill or develop a chronic condition themselves – too many carers are just told to take anti-depressants and their symptoms are never investigated, leading to serious conditions never being identified. This is especially relevant for those carers who have been caring for a number of years/decades and are aging themselves.	Although this is an important point, these issues are not specific to carers of people with CFS/ME therefore it was not considered appropriate to provide detailed information here, but to point to relevant guidance (ie the NSF).
SH	BRAME Blue Ribbon for the Awareness of ME	253	FULL	260	25-27	Something needs to be added about the financial implications, the compounding impact of which can leave families living below the poverty line, unable to pay for food and heating, especially when the child	We have noted the need for healthcare practitioners to be proactive about supporting carers, but

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						becomes an adult and much financial/care assistance stops.	benefits and financial support are not the remit of a clinical guideline.
SH	BRAME Blue Ribbon for the Awareness of ME	254	FULL	260	27-29	Carers do not only face difficulty claiming benefits and accessing services themselves. They also have to deal with helping the person they are caring for to claim benefits/access services/deal with medical professionals. It is usually the carer, because the severely affected person is too ill to do it themselves, who has to battle for basic rights on the person's behalf, and this can be a soul-destroying experience, especially given the scepticism and disbelief they have to encounter and fight against.	We have noted the need for healthcare practitioners to be proactive about supporting carers and general resources for carers, but benefits and financial support are not the remit of a clinical guideline.
SH	BRAME Blue Ribbon for the Awareness of ME	255	FULL	261	26-27	Again there needs to be understanding and acknowledgement of the special needs of the severely affected. As with recommendations comments: Advice needs to be given on hospital admittance for someone who is severely affected. A single room, with thick curtains/blackout blinds, a low light, away from noise and with chemical use kept to a minimum are essential. It may be that the sufferer will need their own bed sheets/pillows due to reaction; some people even need special mattresses due to their heightened physical and/or chemical sensitivity. Advice is also needed for doctors and nurses on skin sensitivity, sleep dysfunction/reversal, heightened sensitivity to pharmacological/non-pharmacological management, usage of oxygen and anaesthetics.	Each patient should be assessed individually and care provided and adapted as appropriate.
SH	BRAME Blue Ribbon for the	256	FULL	263	4-5	More than one of our respondents stated, and we agree, that keeping a daily diary is	This section has been substantially revised.

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	Awareness of ME					extremely difficult, if not impossible for the severely affected.	
SH	BRAME Blue Ribbon for the Awareness of ME	257	FULL	263	16-17	Last sentence should read “As travel is likely to exacerbate symptoms, people with severe ME/CFS will need support and care within the home.”	This section has been substantially revised.
SH	BRAME Blue Ribbon for the Awareness of ME	258	FULL	263	20-21	This is a vitally important statement and should be a recommendation rather than CBT and GET.	Noted and this is a recommendation for all people with CFS/ME.
SH	BRAME Blue Ribbon for the Awareness of ME	259	FULL	263	24	This is not totally correct – yes, some gain weight due to being bed-bound, however there is a distinctive swing in weight with ME with the classic 2-3 stone weight gain or loss, explanation for which has not yet been found but probably due to gastro-intestinal dysfunction/mitochondrial dysfunction. Weight gain often occurs despite a lack of appetite and an intolerance to food.	The reasons for changes in weight is unknown. The important thing is for healthcare professionals to respond to changes appropriately.
SH	BRAME Blue Ribbon for the Awareness of ME	260	FULL	264	1-11	There should be a mention about the poor uptake of vitamins and nutrients within the gastro-intestinal tract, which often leads to deficiencies. This is another reason why regular monitoring of the blood levels is so vital – to pick up deficiencies so that they can be managed to prevent further complications. This section is vitally important especially given the death of [x] who died from “[x] caused by CFS”; due to her being unable to eat or even sip water.	We have noted the need for healthcare professionals to be aware of the potential for nutrient deficiencies.
SH	BRAME Blue Ribbon for the Awareness of ME	261	FULL	264	27-29	There needs to be more information, using the research on heart conditions, cancer, and the co-morbid conditions, which people with ME have died at an earlier than expected age, to create a series of red-flags for further investigations – the paper by Jason et al (2006) on deaths of people with ME is a good	We have noted the need to be aware of co-morbidities and investigate as appropriate.

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						starting point.	
SH	CFS/ME Clinical Network Coordinating Centre	6	FULL	259	22/23	Make explicit reference to telecare here as possible support solution for this group of patients	Noted and revised.
SH	College of Occupational Therapists	80	FULL	259	Severely affected	It would be helpful to make reference to the need for co-ordinating care for the severely affected. In this client group we have to work more closely with other services, such as the GP and Social Services. This liaison role can be very time consuming but is important in making sure the individual has a comprehensive package of care.	We have noted the need for a key worker to co-ordinate care.
SH	College of Occupational Therapists	81	FULL	260	1	The term “aids” – is no longer used in equipment provision; we would suggest the word is deleted.	Noted. This has been changed.
SH	College of Occupational Therapists	82	FULL	260	3	Who or what is “they”? We would suggest, “Equipment and adaptations can be useful..”	Noted. This has been changed.
SH	College of Occupational Therapists	83	FULL	263	4	In the severely affected they are often unable to keep a diary as they are too unwell. It could be suggested “or a carer” to show that others may be able to do this task for them.	This section has been substantially revised.
SH	Invest in ME	196	FULL	256	7	7 People who are Severely Affected It is therefore common for this group of people to experience isolation, loneliness and barriers when accessing all forms of care IIME COMMENT: This is not only severe pwme. Also moderately affected children can be affected by isolation. Home tuition is often necessary but schools seem unable to handle this and often forget about the child studying from home. They frequently offer no help to involve the child in school activities (via post, email, telephone or visits by colleagues).	The section on education and home tutoring has been reworded.

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						NICE do nothing to address this.	
SH	Invest in ME	197	FULL	258	1	<p>7.3.1.1 Adults and children who are severely affected should be able to access the same diagnostic and therapeutic options as those who are not severely affected, as appropriate.</p> <p>IIME COMMENT: The only options given are CBT and GET.</p> <p>7.3.1.3 Adults and children who are severely affected should be offered an individually tailored programme based on activity management which may be delivered at home (and/or by telephone if appropriate).</p> <p>IIME COMMENT: <i>[Programme ... which may be delivered ... by telephone if appropriate]</i> Should any medical intervention programme be delivered by telephone? This is insulting to the severely affected patients.</p> <p>Some need to be given just care – no management possible. These people may be in an active phase of the illness and need rest.</p> <p>7.3.1.7 <i>[Hospital Admission]</i> What would be the purpose of hospital admission apart from easing the provision of access by the patient to the doctors in the clinic. If the severity of ME is causing access problems, perhaps home visits should be considered more seriously and the provision of training for the District Nursing staff to provide enhanced support?</p> <p>7.3.1.4 Activity management should be the core therapeutic strategy but elements of CBT and GET may be suitable for some adults and children.</p>	<p>Please see the revised recommendations.</p> <p>We have recommended that the delivery of the intervention may be by telephone if appropriate. This is a common delivery method in many types of intervention.</p> <p>Hospital admission is only recommended if appropriate to help the patient.</p> <p>We have clarified the use of CBT/GET in people with severe</p>

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						<p>IIME COMMENT: Wrong. Some severely affected can't cope with any management strategies. This is far too Generalized and can therefore be misinterpreted by busy GPs or by those with bias toward the condition. This is quite a NICE-sighted analysis.</p> <p>7.3.1.6 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. (4.3.6.5)</p> <p>IIME COMMENT: [<i>Access ... to community services ...</i>] The list seems to be missing clinicians, medical doctors and treatment facilities such as clinics and hospitals, was this by design? The balance seems to indicate a bias towards the psychological end of the spectrum of possible specialist supporting care. Perhaps this should be considered careFULLY.</p> <p>We also feel that ME patients may need access to legal advice to prepare for litigation if/when NICEproposed therapies prove harmful to the health of the patient.</p>	<p>CFS/ME.</p> <p>We have recommended that all people with CFS/ME need to access healthcare services as appropriate, but that people with severe CFS/ME may have additional needs.</p>
SH	Invest in ME	198	FULL	260	17	<p>7.4.3 Carers</p> <p>One of the main difficulties for carers, which may have an impact on their health, is that people with severe CFS/ME find it very difficult to sleep. This means that for the carer, sleep is fragmented and restricted as during the night the carer is often caring for the person with CFS/ME. As a result the primary carer can also feel isolated whilst having</p>	<p>Although this is an important point, these issues are not specific to carers of people with CFS/ME therefore it was not considered appropriate to provide detailed information here, but to point to relevant guidance (ie</p>

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						<p>given up their job they may experience a loss of their individuality and professional status. Carers may also face difficulties in claiming benefits and access to services whilst the widespread disbelief in the condition can compound the situation.</p> <p>liME Comment: perhaps this could also comment on the intransigence of the medical community to accept neurological ME as a real illness, lack of help from schools for children with ME, and the lack of education of medical staff regarding the research which has been made which proves ME as a neurological, multi-system illness.</p>	the NSF).
SH	Invest in ME	199	FULL	261	1	<p>Family life may also be affected as people with severe CFS/ME are often sensitive to sounds and smell.</p> <p>liME Comment: Family life <u>IS</u> affected – there is no <i>may</i>.</p> <p>This is not only the case for severe ME – so-called ‘mild’ or ‘moderate’ ME can severely affect a family.</p>	Although this is an important point, these issues are not specific to carers of people with CFS/ME therefore it was not considered appropriate to provide detailed information here, but to point to relevant guidance (ie the NSF).
SH	Invest in ME	200	FULL	262	21	<p>7.6 Additional information related to Chapter 6 - Management</p> <p>Because of the complexity of the illness, they usually are excluded from recruitment into research trials and consequently there is a poor understanding and a lack of agreement over the management of severely affected people. .</p> <p>liME Comment: This doesn't stop cancer patients being included despite that being a complex illness. Perhaps it is easier to get the desired result by excluding severely affected</p>	We are not able to comment on the reasons for excluding this patient population

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						ME patients?	
SH	Invest in ME	201	FULL	263	12	For children, the management plan should also include educational arrangements which recognise individual needs. liME Comment: How is this achieved. Schools are not compliant in giving children with ME the correct service and often parents have to battle to get the school to act or be pro-active.	This section has been substantially revised.
SH	Invest in ME	202	FULL	263	16	As the group is often excluded from research there is a lack of evidence and agreement over the management of severely affected patients. liME Comment: Shouldn't NICE make a recommendation that severely affected ME patients are included in research trials on ME.	The research recommendations do include this.
SH	Invest in ME	203	FULL	263	11	7.6.1 Self Management Strategies People with severe symptoms may be more susceptible to the cumulative effect, with their bodies being able to neither undertake nor sustain. liME Comment: Yet GET is advised earlier even for severely affected patients.	This section has been substantially revised.
SH	Invest in ME	204	FULL	263	13	In devising a programme the healthcare professional should understand, that to sit up or for some severely affected people to lift their head is an achievement and having a conversation is a good day. As travel may exacerbate symptoms, people with severe CFS/ME may also need support with the rehabilitation or care within the home. liME Comment: And yet these guidelines are recommending GET!!!	This section has been substantially revised.
SH	Invest in ME	205	FULL	264	21	There may be a need for use of prescribable supplements or where there are severe	The recommendation

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						problems, tube feeding may be required. . liME Comment: Yet earlier in these guidelines supplements were not recommended – it becomes totally confusing which recommendation is meant to be used. Imagine how GPs must react!	has been reworded.
SH	LocalME	87	FULL	257	1-6	How can the severely affected possibly receive the same care? Invariably they cannot access the 'services'!	This has been revised.
SH	LocalME	88	FULL	260	7.4.3.	This paragraph on carers shows more understanding of their position than the complete NICE guidelines does for the sufferers of ME. What an opportunity lost.	Noted. The full guideline will be published alongside the NICE version (which is simply a list of the recommendations).
SH	LocalME	89	FULL	263	4-5	Many severely affected people with CFS/ME would find the task of keeping a diary extremely difficult.	This section has been substantially revised.
SH	LocalME	90	FULL	263	9-17	A home visit from someone with counselling skills and a sympathetic demeanour would be useful if a PWME was also suffering with depression, anxiety or any other mental health complaint.	This section has been substantially revised.
SH	North Glamorgan NHS Trust - Merthyr Tydfil		FULL	257	1 - 6	How can the severely affected possibly receive the same care? Invariably they cannot access the 'services'!	This has been revised.
SH	North Staffordshire Combined Healthcare NHS Trust	1	FULL	260	7.4.3.	This paragraph on carers shows more understanding of their position than the complete NICE guidelines does for the sufferers of ME. What an opportunity lost.	Noted. The full guideline will be published alongside the NICE version (which is simply a list of the recommendations).
SH	North Staffordshire Combined Healthcare NHS	2	FULL	263	4 - 5	Many severely affected people with CFS/ME would find the task of keeping a diary extremely difficult.	This section has been substantially revised.

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SH	North Staffordshire Combined Healthcare NHS Trust	3	FULL	263	9 -17	A home visit from someone with counselling skills and a sympathetic demeanour would be useful if a PWME was also suffering with depression, anxiety or any other mental health complaint.	This section has been substantially revised.
SH	Royal College of General Practitioners Wales	5	FULL	262	14	After FULL-stop add: These conditions must include those that the patient or carer are most worried about because an effective therapeutic relationship is unlikely to be established without open acknowledgement of their concerns.	We have noted throughout the need for proper consultation and communication with the patient/carer.
SH	Royal College of Nursing	39	FULL	262	27	Pain is not always the predominate symptom with severe CFS/ME. The first aim of a management plan is to stabilise symptoms by introducing structure with a rest (and relaxation)/ activity programme and with the use of medication for symptom control (if tolerated) – this may involve reducing activity periods and increasing rest periods initially.	This section has been substantially revised.
SH	Royal College of Nursing	40	FULL	263	21,22	Again there is not enough evidence to support the statement regarding those with CFS/ME have an increased sensitivity to drugs.	Noted, but patient experience supports this – please see the revised recommendation.
SH	St Bartholomew's Hospital Chronic Fatigue Services	90	FULL	258	1 +	The guideline has left out what we would regard as the most important intervention in the severely disabled. That is a thorough biopsychosocial assessment. It is unsurprising that severely disabled people, whatever their diagnosis, are more likely than the less disabled, to suffer from co-morbid conditions, such as sleep and mood disorders, and have social problems as a consequence of their disability. Perhaps even more importantly than this, we sometimes find that the most severely disabled do not suffer from CFS/ME at all, but	We have revised the recommendations on assessment and management and recommend that healthcare professionals be alert for co-morbid conditions and mis-diagnosis..

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						<p>suffer under a misdiagnosis. No wonder they are disabled. So accurate diagnosis is the sine qua non to the effective management of such patients. The appropriate interventions follow from such an assessment, which may involve more than one member of the MDT, but which must include a consultant medical practitioner's opinion.</p> <p>The guidance for severely affected patients is all about activity management and mentions CBT and GET almost in passing ("may be suitable for some patients"). It is curious that the guidelines support an intervention for which there is little evidence beyond common sense, while being cautious about interventions for which at least there is replicated evidence in patients suffering from the same illness, albeit with less disability. When one then considers the positive results from the open studies of helping patients with severe disability with CBT and GET adapted for their disability (all referenced above), the guidance as it stands seems even more idiosyncratic. And then you stress the "great care" required in providing any helpful intervention for such patients. It is enough to put off any self-respecting GMC/RCN fearing healthcare professional in trying to help patients with CFS/ME. Is this really what you wish to convey?</p>	<p>The guideline development group did discuss this issue at length and the recommendation has been revised to indicate that it should draw on the principles of CBT and GET.</p>
SH	St Bartholomew's Hospital Chronic Fatigue Services	91	FULL	260	13	<p>Why should anyone with concentration difficulties find it easier to use audiovisual technology, which by your implication does not involve reading, more than reading itself (from either a book or computer screen)? Would it not be more effective to negotiate a simple graded programme of reading to help such a patient improve their reading ability, along with helping to improve their cognitive</p>	<p>Noted and removed – we consider that the text on including cognitive activities addresses these points.</p>

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						capacity through improving sleep and mood? What might be effective advice is to encourage the use of voice-activated software in someone who finds typing using a keyboard physical tiring, and needs to meet a deadline in their job or studies.	
SH	St Bartholomew's Hospital Chronic Fatigue Services	92	FULL	261	3 +	<p>A patient with increased sensitivity to the smell of various chemicals may be suffering from multiple chemical sensitivity, but you would be making a dubious assumption to state this is part of or even characteristic of severely disabling CFS/ME. MCS is a potentially remediable condition through a graded exposure programme on the basis that the underlying pathophysiology is a conditioned response. It should not be considered as a part of CFS/ME. (See: Staudenmayer H, Binkley KE, Leznoff A, Phillips S. Idiopathic environmental intolerance: Part 2: A causation analysis applying Bradford Hill's criteria to the psychogenic theory. Toxicological Reviews 2003;22:247-61.</p> <p>Bornschein S, Hausteiner C, Zilker T, Forstl H, Van den Bergh O, Devriese S, Winters W, Veulemans H, Nemery B, Eelen P, Van de Woestijne KP. Acquiring symptoms in response to odors: a learning perspective on multiple chemical sensitivity. Annals of the New York Academy of Sciences 2001;933:278-90.</p> <p>Otto T, Giardino ND. Pavlovian conditioning of emotional responses to olfactory and contextual stimuli: a potential model for the development and expression of chemical intolerance. Annals of the New York Academy of Sciences 2001;933:291-309.)</p>	This section has been removed.

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SH	St Bartholomew's Hospital Chronic Fatigue Services	93	FULL	262	3 and Generally in this section	The use of adverbs detracts from this section, particularly when you suggest that the pain a patient feels is incredible.	This section has been removed.
SH	St Bartholomew's Hospital Chronic Fatigue Services	94	FULL	262	12 & 18	The symptoms of severe CFS/ME are no more "varied and complex" than those with less severe disability. As you imply, such patients are more likely to have comorbid or even alternative diagnoses, to which the guideline should alert healthcare practitioners.	Such references have been removed.
SH	St Bartholomew's Hospital Chronic Fatigue Services	95	FULL	263	20	"For severely affected people, symptom management is regarded as the most useful form of management." What evidence is there to support this rather pessimistic statement? We have already mentioned the several open studies (see above) that suggest active rehabilitation is the most useful form of management. We suggest you change this to support active rehabilitation as the most useful strategy.	This section has been substantially revised.
SH	St Bartholomew's Hospital Chronic Fatigue Services	96	FULL	264	1 +	We have already mentioned above the importance of making an accurate diagnosis in the presence of sustained loss of weight. We suggest this is more important than symptomatic approaches to inability to sustain or gain weight.	This has been reworded in the chapter.
SH	The Association for Family Therapy	9	FULL	259	12	The NSF document appropriately emphasises the importance of excellent liaison between paediatricians/specialist CFS services and child and adolescent mental health services in order to properly meet the needs of children and adolescents with CFS/ME. Further attention needs to be paid in educating CAMHs professionals about the condition and	Noted.

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						enhancing communication across disciplines.	
SH	The Association for Family Therapy	10	FULL	260	6	<p>Family life is profoundly affected by the illness of a family member. Particular attention should be paid to the needs of siblings of children and young people with severe illness.</p> <p>Family therapists and others trained in family systemic therapy work to support children and their families in ways that respect and support close relationships. They help families mobilise their resources and encourage family members and others in close relationship (including other support professionals) to find constructive ways to help each other. This is of benefit to the identified patient and those upon whom they may depend for their care and support.</p>	<p>Noted and this would be the same as in any condition.</p> <p>We have recommended the need to assess the impact on the family and carers.</p>
SH	Welsh Association of ME & CFS Support	165	FULL	256	3	The Welsh equivalent needs to be placed here.	This has been revised.
SH	Welsh Association of ME & CFS Support	166	FULL	258		7.3.1.4 There is no evidence for the use of CBT and GET for the severely affected.	Please see the revised recommendations.
SH	Welsh Association of ME & CFS Support	167	FULL	260	12	The Welsh equivalent needs to be placed here.	Noted and added.
SH	Welsh Association of ME & CFS Support	168	FULL	260	16	E-learning needs to be included	We have noted virtual learning above.
SH	Welsh Association of ME & CFS Support	169	FULL	262	17	What if no specialist services? A list of additional symptoms experience by the severely affected would be useful.	<p>The guideline aims to influence service provision, such as specialised services if they are not currently available.</p> <p>A list of additional symptoms was not</p>

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							added as there is such as variety – please see also the section on diagnosis.
SH	Welsh Association of ME & CFS Support	170	FULL	263	3	Remembering some children/yp may not be able to access education	This section has been substantially revised.
SH	West Midlands Consortium	77	FULL	257	1-6	How can the severely affected possibly receive the same care? Invariably they cannot access the 'services'!	This has been revised.
SH	West Midlands Consortium	78	FULL	260	7.4.3.	This paragraph on Carers shows more understanding of their position than the complete NICE guidelines does for the sufferers of ME. What an opportunity lost.	Noted. The full guideline will be published alongside the NICE version (which is simply a list of the recommendations).
SH	West Midlands Consortium	79	FULL	263	4 - 5	Many severely affected people with CFS/ME would find the task of keeping a diary extremely difficult.	This section has been substantially revised.
SH	West Midlands Consortium	80	FULL	263	9-17	A home visit from someone with counselling skills and a sympathetic demeanour would be useful.	This section has been substantially revised.