Appendix 4: Comparison of Guidance Documents

Key points/recommendations noted in major documents	Supported by	Note
Shared decision making with patient	UK	
CFS/ME symptoms[1] / diagnostic criteria	Various	Evidence to substantiate any case definition/set of criteria is weak. No studies providing basis of case definition[2]
Diagnosis: when symptoms have persisted for 4months (adult) / 3months (child) => 6months(adult)	UK Australia; Canada; Netherlands	Evidence on diagnostic testing is weak. NZGG: agreement on fatigue persistence with >6 months (adult) 3 months (child) being the most common duration given.
Diagnosis: re tests that should be done (n=13)	Various	NZGG indicates agreement for routine tests to include: full blood count; TSH; biochemistry profile and serum electrolysis & urinalysis. Additional tests include: Hep B&C; thyroid function test, and any others suggested by history or symptoms.
Conditions considered in differential diagnosis differs:		
14+ psychiatric disorders	Australia	Taken from NZGG (2004)

[1] Fatigue that is new onset; is persistent and/or recurrent; is unexplained by other conditions; has resulted in substantial reduction in activity level; is characterised by post-exertion malaise AND one or more of : difficulty with sleeping; muscle and/or joint pain without inflammation; headaches; painful lymph nodes without pathological enlargement; sore throat; cognitive dysfunction; symptoms exacerbated by physical exertion; general malaise of flu-like symptoms; dizziness and/or nausea; or palpitations.

[2] Mulrew, C.D., Ramirez, G., Cornell, J.E. & Allsup, K. (2001) 'Defining and managing chronic fatigue syndrome' *Evidence Rep Technology Assessment* Summer (42): 1-4

12+ psychiatric disorders	UK	
32 including psychiatric disorders	US	
8+ psychiatric disorders and substance abuse	Canada	
Specialist diagnostic testing for adolescents & children	US	
Advice on symptom management should not be delayed until diagnosis established	UK	
Information & training patients and carers. [info and support re illness, healthcare, and assistance re work/education]	UK SSLWG (p.8) NZGG: info to patients and carers part of shared management. AfME (p.14)	
Take account of severity, patient's age and previous treatments	UK	
Recognise patient's right to refuse/withdraw from treatment	UK	
Establish supportive/collaborative relationship with patient/carer/family	UK; Australia; Netherlands	
Care co-ordinated for each patient by named health professional	UK	
Diagnostic/therapeutic options to suit individual need	UK NZGG SSLWG	
Management:		
Diet [healthcare professionals should	UK	

provide general advice re importance of good diet but seek advice from dietician if patient wishes to undertake special diet]		
Drug treatment [of the three noted by NZGG NICE cite only tricyclic antidepressants]	UK NZGG: include tricyclic antidepressants; NSAIDS and other analgesics, and muscle relaxants.	NICE (UK) state that no research evidence supports people's experience of greater intolerance to drug treatments including more severe side effects. NZGG: common agreement that people with CFS/ME 'are often susceptible to medication side effects'.
Nausea [Should be managed conventionally]	UK	
Sleep [advise on sleep hygiene]	UK SSLWG NZGG	
Rest [rest periods part of management plan. Should be reviewed regularly]	UK	
Relaxation [help with pain; sleep problems and co-morbid stress/anxiety. Can be incorporated into rest periods]	UK	
Pacing	Canada Australia	Patient confidence in Pacing noted by : SSLWG(p.15) (UK); AfME (p.32) (UK) ; Gibson Enquiry (UK) ; and Netherlands The NICE Guidelines (UK) view is that people should be advised of

		insufficient research to support benefit/harm of pacing.
Equipment (e.g. wheelchair) recommended if maintains independence and QoL.	UK	
Education (liaise with education services re fitness for school/coll/uni)	UK	
Employment (liaise with employers re fitness for work)	UK	
Complementary therapies/medicines [insufficient evidence to support]	UK SSLWG (p.17)	Lack of empirical trials (SSLWG) US guidance suggests some benefits.
Referral to specialist [should be based on need – decision to refer should be made jointly – should be offered immediately to those with severe CFS/ME symptoms]	UK SSLWG (p.14) NZGG: referral may be necessary as part of diagnostic workup.	Evidence weak. GDG group consensus. NZGG: specialist in put may need to be multidisciplinary.
Referral to paediatrician for children	UK SSLWG (p.14) NZGG	
Specialist care (management & treatment):	UK SSLWG: level of specialist services required in Scotland	UK notes need to avoid referring to specialist management programmes delivered by practitioners with no experience of ME-CFS.
Individualised plan	UK SSLWG (p.11); AfME (p.18)	

	NZGG	
Aim at physical and emotional impact on symptoms	UK NZGG, SSLWG	
Patient should be well-informed	UK AfME (p.18) NZGG: info to patients and carers part of shared management	
Patient autonomy	AfME (p.18)	Implied but not emphasised
Goals setting by patient	AfME (p.18)	Implied but not emphasised
CBT (offered to those with mild-moderate) [patient should be in charge of aims of programme] [therapeutic goals should be agreed between patient and health professional]	UK SSLWG (p.15)	Further research required (SSLWG) Netherlands note limited benefit and modifications for some UK notes the need for specific ME-CFS experience by the professional offering CBT. This should be tailored to the patient's need and level of functioning. .
GET (offered to those with mild-moderate)	UK	Long term data is limited (SSLWG) Netherlands: CBT/GET considered together – non-commital on effectiveness of GET NZGG includes note that graded exercise programmes recently found to be harmful. UK notes the need for GET to be delivered by a therapist with experience in ME-CFS management. This should be tailored to the patient's need, circumstances and level of functioning.
Activity management	SSLWG (p.16) UK	UK specifies Activity Management as it is used within the NICE Guideline
Drug therapies		
Pain management: -start with lower doses -multiple non-pharmacological	 UK; SSLWG UK; US; Australia	

and/or psychological approaches may be helpful -lifestyle management with no mention of psychological approach -efficacy of alternative therapies cited	Canada US	
Setbacks/relapses -should be planned for -should be managed	SSLWG (p19) UK	
Review/ongoing management [should be regular and structured]	UK SSLWG	
Patients with severe CFS/ME: - require specialist management - requires community involvement/home visiting	 UK SSLWG (p.18)	
Self-monitoring/patient diaries to help management	Canada Australia	

Reference Note: documents cited in this table

Australia: Royal Australian College of Physicians (2002) *Chronic Fatigue Syndrome. Clinical Practice Guidelines*, Health Policy Unit, Royal Australian College of Physicians

South Australian Department of Human Services (2004) *Myalgic Encephalopathy (ME) /Chronic Fatigue Syndrome (CFS) Management Guidelines for General Practice*

AfME: Action for ME (2007) *Scotland M.E.? CFS Scoping Exercise Report*

Canada
Australia
UK Comparative document covering all four countries:

US New Zealand Guidelines Group (NZGG) (2004), Chronic Fatigue comparison matrix Available URL: http://www.nzgg.org.nz/guidelines/0084/040518_matrix.pdf [Accessed 13 May 2008]

Netherlands: Gezonheidsraad. Health Council of the Netherlands (2005) *Chronic Fatigue Syndrome. Advisory Report to the Minister of Health, Welfare & Sport*

NZGG: New Zealand Guidelines Group (NZGG) (2004), Chronic Fatigue comparison matrix Available URL: http://www.nzgg.org.nz/guidelines/0084/040518_matrix.pdf [Accessed 13 May 2008]

SSLWG: Scottish Short Life Working Group (SSLWG) (2002) *Chronic Fatigue syndrome / myalgic encephalomyetis (CFS/ME). Outline for Development of Services for CFS/ME in Scotland.Report of the Scottish Short Life Working Group*

UK: National Institute for Clinical Excellence (NICE) (2007), *Chronic fatigue syndrome / myalgic encephalomyelitis(or encephalopathy). Diagnosis and management of CFS/ME in adults and children. Quick Reference Guide*, NHS National Institute for Clinical Excellence; Turnbull, N., Shaw, E.J., Baker, R., Dunsdon, S., Costin, N., Kuntze, S. and Norman, R. (2007) *Chronic Fatigue syndrome / myalgic encephalomyelitis(or encephalopathy): diagnosis and management of chronic fatigue syndrome / myalgic encephalomyelitis(or encephalopathy) in adults and children* [Full guidelines]