EXTRACTS FROM: Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management of chronic fatigue syndrome /myalgic encephalomyelitis (or encephalopathy) in adults and children

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Chapter 7 People with severe CFS/ME [P303 - 313]

Section 7.2 Purpose and context of this chapter

The purpose of this chapter is to highlight where there are additional needs or additional caution is required specifically in the care of people with severe CFS/ME. However, this is not intended as a definitive guide to the specialist CFS/ME care needed for this patient group, and further reading is recommended. [50]

REF 50: Crowhurst G. Supporting people with severe myalgic encephalomyelitis. Nursing Standard 1921; (21); P38-43

Section 7.4.1 Support

A full functional assessment of the personal and domestic needs of the patient within the home should be completed (for example, people with severe CFS/ME are often sensitive to light, noise and chemicals, so may require quiet, dark surroundings with no or limited use of household products such as cleaning products or air fresheners), as well as an assessment of the carer's needs.

Section 7.6.3 Dietary interventions and supplements

People with severe CFS/ME may face many difficulties in achieving adequate and balanced dietary intake including:

- pain and fatigue making the physical process of eating difficult and possibly requiring help with feeding
- sensitivity to the smell or taste of food
- difficult or painful swallowing
- sore throat making eating difficult
- nausea affecting the ability to eat
- bowel symptoms affecting food choices
- food intolerances leading to a restricted diet
- disturbed sleep patterns causing meal patterns to be disrupted
- the need for carers to help with all aspects of food purchase and preparation.