

ME-CFS Service - Astley Ainslie Hospital

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Patient Information Leaflet

This is a Lothian-wide service for patients who have been given, and accepted, a diagnosis of ME-CFS or Post-Viral Fatigue Syndrome. It is staffed by specialist physiotherapy and applied psychology staff.

The ME/CFS service aims to provide holistic patient-centred advice to people over 16 years old. The causes of ME/CFS and post-Viral Fatigue Syndrome are still largely unknown and there is no single recognised 'cure'. ME/CFS can have significant physical, emotional and social consequences. The ME/CFS service offers multi-disciplinary advice and support to help manage symptoms and the effects this condition can have on an individual's life. This is a rehabilitation service and work done together may include:

- Understanding ME-CFS
- Engaging in activity monitoring and learning how to pace activity
- Identifying energisers and drainers
- Initiating good sleep practices
- Learning relaxation and stress management techniques
- Developing strategies to manage mood
- Improving communication
- Relapse planning.

Patients interested in taking part in the programme will be asked to complete a series of questionnaires. These are used for ongoing monitoring and evaluation. Patients will also be asked to complete questionnaires prior to their first appointment.

Care Pathway

An initial assessment will be conducted with a specialist clinician who will seek to understand your current difficulties and your hopes/goals of your work with the service. The assessment will include taking an account of symptoms and reviewing fatigue, sleep, activities, mood, and overall current functioning.

In discussion with the clinician, and, if there is mutual agreement at this stage to proceed, a programme designed for your needs will be developed. This will involve the use of self-management strategies. Work with the service will include looking at specific individual goals in keeping with your needs and hopes and will be reviewed regularly. Referral to other relevant therapies may be discussed if necessary. You may be offered one-to-one sessions or invited to attend an ME/CFS group. These sessions may be conducted at the Astley Ainslie Hospital or by telephone/video call if appropriate. The number of sessions will be agreed with your clinician.