Primary Integrated Community Services Ltd

ME/CFS Service
Care and support plan.

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What is a care and support plan?

The National Institute for Health and Care Excellence (NICE, 2021) Clinical Guideline for the diagnosis and management of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) states that the ME/CFS specialist service supporting the person with ME/CFS, should provide them with a care and support plan.

The person with ME/CFS is in charge of the aims of the plan and a copy should be given to their GP, and people involved in caring for them with consent.

The information in this booklet is to support you and all those who care about you, including your GP, health and social care professionals, carers, and your family and friends who know you well. It will help everyone understand how ME/CFS affects you and what can help you as well as understanding what might make your symptoms worse.

You, or a person who knows you well, can start to complete this form before you meet with a health care practitioner from the ME/CFS service.

You don't have to fill in all the information before your initial appointment, but you might find it useful to read it through beforehand to help you think about what you need to tell us.

Consent

I, or my trusted representative, agree to the development of a care and support plan.

Name_____Signed_____Date __/__/____

I, or my appointed trusted representative, agree to the sharing of my care and support plan with individuals who I have given consent to be involved in my care, including my GP.

Name_____Signed_____Date __/__/____

Review date __/__/____

Patient overview

Full name: **I like to be called:**

People who support me with this condition:
Occupation / education: Full / part time
Home and family: social situation, dependents roles responsibilities etc.
Hobbies, leisure, interests:
Other information I would like you to know:
I would like to be contacted / receive information via ***- phone*** ***- email*** ***- post***

Medical history and support from services

History of ME/CFS
Other Medical Conditions:
Mental health information:
Medications:
Support I receive from Health and Social Care Services:

How the condition affects me

Common experiences & symptoms of ME/CFS	Have you experienced this symptom? YES/NO.	Rate the general impact of the symptom from 0 no impact at all; 10 significant impact.
Persistent, debilitating fatigue.		
Post-Exertional Malaise (PEM) Which is the worsening of symptoms following activity, which is disproportionate to the activity, has a prolonged recovery time that may last hours, days, weeks or longer, is often delayed in onset by hours or days.		
Unrefreshing sleep.		
Insomnia. Including difficulty getting to sleep and disturbed sleep.		
Hypersomnolence. Including prolonged night-time sleep and excessive daytime sleepiness and/or long daytime naps.		
Cognitive difficulties, sometimes described as “brain fog”. May include - poor concentration, memory problems, word-finding difficulties, difficulty in processing spoken and written language.		
Orthostatic intolerance. Symptoms which are worse when in an upright position i.e., when standing or sitting for prolonged periods.		
Headaches.		
Widespread muscular and/or joint pain.		

Common experience & symptoms of ME/CFS	**Have you experienced this symptom? YES/NO**	**Rate the general impact of the symptom from 0 no impact at all; 10 significant impact**
Sore throats, tender glands and/or flu-like malaise.		
Digestive disturbance. May include nausea, loss of appetite, bloating, irritable-bowel-type symptoms.		
Poor temperature control and/or changes in sweating.		
Sensitivity to light and noise.		
Sensitivity to some smells.		
Sensitivity to some medications.		
Sensitivity to some foods.		
Dizziness and balance problems.		
Unusual sensations – pins and needles, numbness.		
Feeling worried or concerned.		
Feeling low in mood.		
(Add further symptoms below as necessary)		

Symptom management

What makes my symptoms worse is:	What makes my symptoms better is:

Activities of daily living

Daily Living Activities	What challenges or difficulties you face when undertaking this activity	Support I need / adjustments I make
Preparing a cooked meal.		

Eating and drinking.		
Washing and bathing.		
Managing toilet needs / incontinence.		
Dressing and undressing.		
Communicating verbally.		
Reading and understanding written information.		
Socialising.		

Making household decisions.		
Mobility	**Challenges, difficulties and support I need**	
Physically moving around.		
Getting out of the house.		

Health and wellbeing

Health and wellbeing goals to manage this condition are:

Actions agreed with my healthcare practitioner today are:

Useful contacts

Names of people to contact on my behalf if you cannot reach me.

Name	Relationship	Contact details

Organisations involved in my care.

Contact name	Organisation	Contact details

Organisations I can contact if needed.

Organisation name	What they can help with	Contact details

Acknowledgements

BACME British Association of Clinicians in ME/CFS (November 2020) *ME/CFS Care and Support Plan Guidance.*