



ME/CFS Guide to Therapy

October 2020

Document History

Year	Format/changes
2014	Original Document – incorporated with the Symptom management Guide
2020	Original Document split into 2 separate documents: Guide to Therapy and Guide to Symptom Management Introductory section rewritten, CFS/ME changed to ME/CFS, weblinks updated.

Aim

This guide was developed through the British Association of CFS/ME (BACME), an organisation that represents health professionals working with people with this condition. It aims to provide information to support clinicians in their work with people with ME/CFS. It was developed by a group of experienced professionals both in a specially convened open workshop, held in 2014, and through circulation and consultation with the wider BACME membership, AYME (Association for Young people with ME) and service -users.

Originally one guide was produced to include both pharmacological and rehabilitative approaches. In October 2020, the single guide was divided into two to improve accessibility. These two sections are:

1. Guidance for therapists covering the provision of therapy for people with ME/CFS. This includes resources for use in therapy, as well as guidance on support and supervision. It represents pragmatic recommendations from experienced clinicians to guide practice when seeing adults with ME/CFS and is informed by clinical and research evidence. It does not replace specialist training in understanding and working with people with ME/CFS.
2. Symptom management guide. This provides information about symptoms experienced by people with ME/CFS, and if pharmacological therapy can ease these symptoms. Information on contra-indications and cautions to consider is also provided for these pharmacological treatments.

The term ME/CFS has been applied throughout this guide as it is the term which will be used by the next NICE Guideline. Other terminology may be used by some clinicians, therapists and service users.

Introduction to ME/CFS

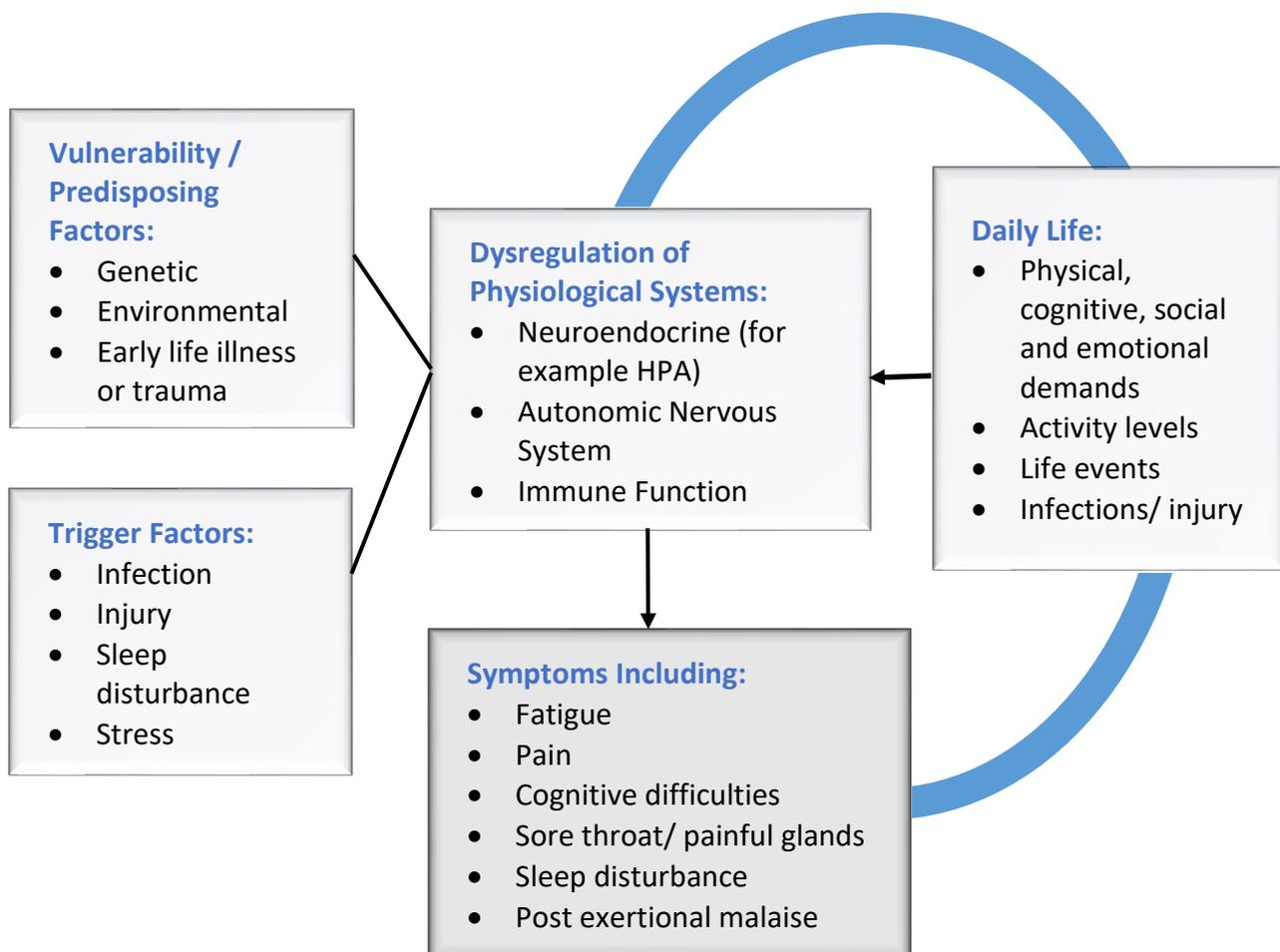
ME/CFS is a serious, complex, chronic multi system illness that can profoundly affect the lives of people who develop it. There is evolving evidence to indicate a dysregulation of multiple dynamic physiological systems in explaining the symptom picture seen in ME/CFS involving demonstrated changes in Immune System responses, Autonomic Nervous System function, Neuroendocrine pathways including the Hypothalamus-Pituitary-Adrenal axis along with cellular metabolic changes. ME/CFS is a clinically defined syndrome with a characteristic pattern of symptoms but no consistent abnormalities on physical examination or on imaging/laboratory evaluation. It is often called a “diagnosis of exclusion” but in practice the symptomatology is frequently consistent enough to allow a confident positive clinical diagnosis to be made. It is very important that the person has a detailed medical examination by a doctor to exclude any other treatable condition. The NICE guideline recommends that a number of investigations are carried out to exclude conditions that potentially could be confused with ME/CFS.

Continued monitoring of the patient is important in relation to any new symptoms, which may or may not be part of the illness profile.

Once a diagnosis has been made, patients should be considered for further evaluation to see if they would benefit from support from a specialist ME/CFS clinician.

A pragmatic model of the condition is shown in Figure 1.

Figure 1: A Pragmatic Model for ME/CFS



Purpose

This guide emphasises a person-centred collaborative approach that can be delivered in an interdisciplinary way. It is specifically focused on the therapeutic rehabilitation pathway and does not cover diagnostic issues. These foundations can be built upon by individual clinicians with profession specific skills and interventions.

The manual aims to reference both research evidence and clinical expertise but is primarily about the pragmatic implementation of these ideas in practice.

We hope that therapists may find this helpful to appraise and refresh their practice and access new resources, whatever their background and training.

Approach

The therapy should be built around the relationship with the person with ME/CFS. Therefore, this should not be seen as a one size fits all model, but an on-going, non-judgmental conversation and dialogue. Therapy is a collaborative process of both the therapist and person with ME/CFS sharing knowledge, agreeing realistic goals and reflecting upon experience. It is recognised that each therapist using this manual will also have an individual and professional perspective which can enhance the core approach described.

There is a large range of complementary resources, contributed by ME/CFS therapists, available from the BACME website.

Overview of the therapy

This section has two parts, within which there are numerous subsections to cover each area. The guide is written with each part of the therapy process in a different colour.

As the remit of the guide is active therapy it does not cover diagnosis and causation. It is a pragmatic framework for understanding the condition and therefore the rationale for the rehabilitation approach is included. This also forms part of the dialogue with the person with ME/CFS when forging a therapeutic alliance. Guidance on managing co-morbidities, identifying red flags and dealing with symptoms that cannot be addressed within therapy is outside the remit of this document.

Part 1 – Phases of Therapy

In the next section the guide focuses on phases of therapy as people will have different requirements at different stages of their condition. This is not intended to be a fixed process but reflects the development of therapy in relation to the individual's needs. Evidence based therapies emphasize a therapeutic relationship that has the potential to enable a graded increase in activity and a process to explore barriers to this increase. From this evidence we felt there were 4 phases to successful ME/CFS therapy. Active verbs have been suggested to describe these phases:

■ Engaging

■ Regulating

■ Increasing

■ Sustaining

There is an expectation that there is a continual assessment and review process throughout each phase. There is no presumption of timescale for each phase, as each individual will differ. Some will need to consolidate strategies at each phase and may not require direct contact with a therapist during this time. This is not a linear process; for example, a person

may have a relapse and find it beneficial to focus again on regulating. It is useful for both therapist and patient to understand that this is a dynamic process, not a procedure.

Part 2 – Delivering Therapy

In this section broader issues related to the delivery and adaptation of therapy are discussed. This includes delivery modalities, team working and dealing with difficulties that may occur within the therapy process. On-going supervision is an essential component of delivering therapy from an individual and team perspective.

Part 1 – Phases of Therapy

This part of the guide will give a detailed view of the components of therapy. It progresses from working with people to engage them in the approach to establishing their needs, reducing fluctuation and supporting improvement.

Therapy is designed to work with all the above processes described in the pragmatic model. The aim of a rehabilitation plan is to regulate bodily systems and to begin to desensitise a heightened level of sensory processing inside the body by doing a small amount (a baseline) of activity and achieving a better balance of rest in all areas of activity in daily life. Having achieved this, the challenge is to then gently build up activity over time thereby re-educating the body and increasing tolerance for activities.

The figure below is designed to show the relationship of the phases and potential journey through therapy for the person with ME/CFS. Individuals will need to be assessed as to the phase they are in. The person may already be within a particular phase, such as they may have regulated and are ready to increase. People may transition through stages at different rates and have different needs depending on the severity of their condition.

Aims of each phase of therapy:

Engaging:

To engage the person in a relationship (with the therapist) that facilitates collaborative working towards the person's goals. The person is supported, through the by the therapist's expertise and knowledge base, to develop self-management skills and make changes that fit with their goals.

Regulating:

To reduce the variation (boom and crash pattern) through stabilising daily routines, including physiological cycles such as sleep, eating and moving. This provides a sense of control and enables the person to have a foundation for improvement. For some people this may help achieve their goals or for some the goal may be to achieve regulation and stay at this level.

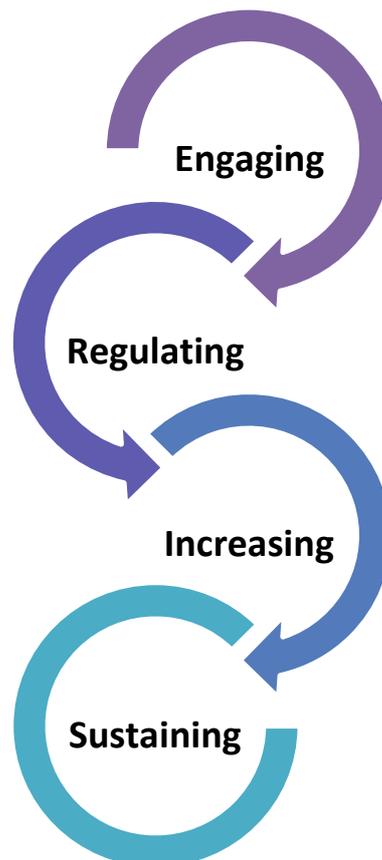
Increasing:

To gradually build the level of activity in the areas that fit with the person's goals. This might entail increases in frequency, intensity, quality and/or duration. This is a consolidating, gently incremental approach that supports sustainable change. It is always guided by the person's goals and their feedback.

Sustaining:

To continue improvement towards the person's goals and an improved quality of life, whilst accommodating the demands of daily life over time.

Figure 2: The Phases of ME/CFS Therapy



The table on the next page outlines the phases of therapy, the relationship to the therapy thematic content and the possible (not exhaustive) tools and resources for each phase. It is important that each person is assessed and the program is individually tailored. Therapists should select tools that are within their own professional competencies and therapeutic style. It is not intended that every option is given to every patient. Throughout the therapy journey barriers to change or progress need to be addressed; these will also be discussed more fully in Part 2.

Table 1: CFS/ ME Therapy Phases, Themes, Tools & Resources Summary

Phase	Therapy Themes	Illustrative Tools & Resources
<p>Engaging</p>	<p>Subsections:</p> <ul style="list-style-type: none"> ▶ Assessment for therapy and agreeing a formulation, should include <ul style="list-style-type: none"> ■ Information on background and onset ■ Symptoms (historical and current/other conditions) ■ Impact on routines, habits, patterns and lifestyle ■ Physiological wellbeing (diet, sleep, relaxation, exercise) ■ Cognitive function (memory, concentration, attention) ■ Emotional wellbeing (mood, anxiety) ■ Social Environment (family, friends, finance, work, study) ■ Current self-management strategies (what makes it worse or improves it) ■ Hopes and beliefs related to condition (what the patient thinks is wrong) and therapy. ▶ Establishing a therapeutic alliance. Therapeutic strategies that enable the above include: <ul style="list-style-type: none"> ■ Listening, actively hearing the story ■ Validating: empathising and demonstrating belief ■ Communication; verbal & non-verbal, using their words ■ Shared understanding of the individual’s experience ■ Developing a common understanding and formulation around their illness ■ Explaining the rationale for therapy and information on the model ■ Collaboration and co-creation of their individual plan ■ Agreeing their readiness for change & approach, is this the right time and allowing people to opt in/out ■ Consideration and identification of the barriers they experience ▶ Engaging in the model and their pathway to recovery. 	<ul style="list-style-type: none"> • Conversation • Assessment framework, standardised assessment forms. • Standardised assessment & outcome measures – minimum data set (MDS) • Team model of illness & therapy, metaphors, diagrams and text information • Model of change • Mutually agreed plan to progress • Copies of letters/summary outlining the assessment • Professional individual, peer and team supervision • Contact with/narratives from other people who have participated in rehabilitation, e.g. through groups, DVDs, podcast, volunteers. <div data-bbox="1007 1417 1410 1832" style="background-color: #4b0082; color: white; padding: 10px; margin-top: 20px;"> <p>Collaborative goals and action plans: Set priorities & targets that are realistic with achievable steps towards the goal. In this stage this would mean overall goals for therapy.</p> </div>

	<ul style="list-style-type: none"> ■ Providing information on the therapy model ■ Exploring how this model will benefit the individual ■ Agreeing the model for delivery of therapy that best meets their needs 	
Phase	Therapy Themes	Illustrative Tools & Resources
Regulating	<p>Subsections:</p> <ul style="list-style-type: none"> ▶ Patterns to support physiological homeostasis. <ul style="list-style-type: none"> ■ Sleep/ diurnal rhythms ■ Nutrition ■ Activity – consistency and tempo ■ Movement, exercise & posture ▶ Balance of daily life, reducing variation <ul style="list-style-type: none"> ■ Duty versus pleasure/ fun ■ Work, study, home and social life ■ Establishing patterns of planned activity and rest ▶ Quality sleep, rest & activity <ul style="list-style-type: none"> ■ Enhancing parasympathetic activation – relaxation, sensory approaches, mindfulness ■ Exploring understanding about sleep, activity and rest ■ Doing differently and reducing impact ▶ Beliefs, sense of control & self-efficacy <ul style="list-style-type: none"> ■ Exploring beliefs around self, illness and exertion. Understanding acute v chronic models of health ■ Expectations, priorities & choices ■ Addressing factors that increase low mood or anxiety ■ Increasing self-compassion with permission to stop or ■ How to communicate and be assertive about own needs ▶ Dealing with physical and social environments & relationships, including liaising with other services, such as care agencies ▶ Establishing a starting point (baseline) as a basis for increasing 	<ul style="list-style-type: none"> • Education and information • Diaries; sleep, daily activity, diet, thoughts (regular planning &/or recording) • Specific measures and outcomes, e.g. sleep, balance, posture, mood, activity • Posture & Movement strength, stamina, suppleness and stability/ pedometers/ actimeters, mobile apps, equipment to optimise ability • Relaxation training; CDs, websites, apps, podcasts • Sensory interventions • Metaphors • Case examples • Illustrative diagrams • Reflective enquiry • Support from other people/agencies to meet daily needs. <div style="background-color: #663399; color: white; padding: 10px; margin-top: 10px;"> <p>Collaborative goals and action plans: Establish plans to stabilise variable patterns in daily life – e.g. setting goals for sleep, rest, activity, socialising, diet, etc. that can be implemented consistently.</p> </div>

	▶ Dealing with Barriers, what are destabilising factors? Collaborative problem solving	
Phase	Therapy Themes	Illustrative Tools & Resources
Increasing	<p>Subsections</p> <ul style="list-style-type: none"> ▶ Reviewing and refreshing the starting point (baseline) ▶ Intention and desired destination <ul style="list-style-type: none"> ■ Dealing with expectations / standards and priorities ■ Setting realistic goals in line with core values ▶ Collaborative grading <ul style="list-style-type: none"> ■ Analysis (all components of activity; physical, mental, emotional, cognitive, social) ■ Re-introduction of activity and/or exercise ■ Agreed phased, incremental increases to physical, cognitive and/or social activities ▶ Doing differently <ul style="list-style-type: none"> ■ Real world analysis (contextualising); environment, social, physical, work, study, home life, exercise ■ Setting up Experiments that enable positive risk taking, with support needed and rewards ■ Reflective Review – looking at shared understanding, awareness, meaning, progress, and barriers ■ Recognising change/achievements ■ Making sense of arising symptoms & experiences (normalising) ■ Modifying (talking through, closing loops) ■ Solution finding ■ Communicating changes to others/assertion ▶ Dealing with variation, priorities & choices ▶ Consolidation, ensuring an increase can be sustained before moving forward ▶ Dealing with Barriers, discussing what represents progress or is inhibiting it and exploring solutions 	<ul style="list-style-type: none"> • Diaries; sleep, daily activity, diet, thoughts • Experiments • Monitoring or recording for experiments. • Problem solving • Managing obstacles • Experiential learning in and out of sessions. • Metaphors & case examples • Verbal and written goal sheets can include confidence and importance scales. • SMART goals • Priorities review • Setback management • Reflection on changes and progress towards goals <div style="border: 1px solid black; background-color: #4b0082; color: white; padding: 10px; margin-top: 10px;"> <p>Collaborative goals and action plans: Setting specific, measurable action plans or incremental goals that increase frequency, intensity, quality or duration of defined activities that is sustainable</p> </div>

Phase	Therapy Themes	Illustrative Tools & Resources
Sustaining	<p>Subsections</p> <ul style="list-style-type: none"> ▶ Preparing for end of therapy <ul style="list-style-type: none"> ■ Recognising resources; internal, external ■ Relapse planning ▶ Self-management of grading <ul style="list-style-type: none"> ■ Sense of mastery/ balance ■ Re-integration into life settings ▶ Planning the future <ul style="list-style-type: none"> ■ Keeping it going; work, study, home life, social ■ Problems solving barriers • Reviewing conceptualisation of being well/normal energy 	<ul style="list-style-type: none"> • Networks • Relapse plans <div style="background-color: #4a4a8a; color: white; padding: 10px; margin-top: 10px;"> <p>Collaborative goals and action plans: Setting longer term goals for maintaining well-being that reduce the risk of relapse and sustain long term improvement.</p> </div>

Part 2 – Delivering Therapy

1. Modes of delivery

Therapy can be delivered through individual or group formats; many people benefit from a combination of both.

- ▶ **Individual** – examples of different models of delivery - face to face, telephone, email, tele media and home based (primarily for those severely affected).
- ▶ **Group** – examples of different models of delivery - one-off sessions or timed, specific closed group programmes, for example 4 – 10 sessions. Groups can be educational or based on a specific therapeutic model. The number of group members may make a difference to therapeutic benefit.

There needs to be a rationale for the choice, mode and technology used for each person which meets their needs. Factors that may influence the choice of mode:

- Accessibility and transport.
- Level of current activity and phase of therapy.
- Power of common experience through groups.
- Tolerance for engaging in therapy.
- A tool to increasing activity, e.g. through increased socialisation/regular attendance.
- Ability to engage in a group process.
- Available time or fit with current daily schedule.
- Content/purpose of sessions.

If using tele media the evidence suggests that least 2 individual sessions have most benefit before remote contact.

2. ME/CFS team

This guide can be delivered by any health care professional with a specialist interest, training and supervision in ME/CFS. As the scope of the guide is wide, then each professional needs to be aware of their own service specification as well as their own skills and style.

An interdisciplinary approach is often favoured by patients as they don't have to meet with as many health professionals. We felt that it was helpful to distinguish interdisciplinary working from generic work, each member aware of core skills from own profession and additional skills from ME/CFS therapy training and experience. Members of team can include: physiotherapist; psychologist; occupational therapist; medic; nurse; dietician; counsellor.

3. Supervision and support

In the development of the guide it was felt that training professionals in the delivery of ME/CFS therapy was only a beginning. In order to embed good practice and a flexible needs-led service, then supervision from another ME/CFS therapist would be essential to maximise learning for the therapist and the service user. We suggest the establishment of a network of supervisors from different professions who are experienced in ME/CFS and the contents of this guide, who can offer individual and team supervision either in person or via Skype. Peer supervision within teams can also help embed good practice and deepen understanding, particularly when different presentations of ME/CFS need different approaches.

Other supervision considerations could include:

- A different profession to supervise could be useful to develop skills and understanding.
- Shadowing other therapists could be a key to training.
- Keeping up to date with developments in the field (such as BACME).
- Local peer groups; national networks- yahoo group, email etc.
- Lone workers or very small teams would need to consider how to manage complexity of cases and may want to consider having informal networks for supportive supervision either from colleagues or therapists in other teams.
- Due to the complex nature of the condition, therapist self-care and care of team members needs to be addressed by all members of the team. Small teams and lone workers may find networking with other adjacent teams useful.

4. Employment and education issues

Employment issues can be complex but are an important aspect of rehabilitation that can be addressed throughout therapy. Awareness of appropriate legislation and sources of support locally will increase the effectiveness of work in this area. Therapists would need to be aware of the scope of their service and may find the most effective thing to do is sign post to organisations such as Citizens Advice Bureau, Unions and

Access to work. ME/CFS therapists can be help by focusing on baselines of activity and applying the same principles of stabilising and then gradually increasing work. Advocating for longer phased returns could be of required.

Action for ME and North Bristol NHS Trust developed useful resources:

<https://www.nbt.nhs.uk/our-services/a-z-services/bristol-chronic-fatigue-syndromeme-service/see-me-employment-support>

For education see <https://www.actionforme.org.uk/support-others/for-teachers-and-schools/higher-and-further-education/>

Examples of interventions could include:

- Primary focus- implementing changes that the individual can make themselves at home and work. Maintenance of relationship with manager. Small adjustments in workplace- short rests, managing home life so work is easier. Health and safety legislation re IT usage which recommends breaks and task switching.
- More complex intervention possibly in liaison with Occupational Health and possibly unions: Equality Act (2010) <https://www.gov.uk/guidance/equality-act-2010-guidance> which includes: disclosure; Reasonable adjustments (E.g. reduced hours, breaks, sick leave management, and position of desk). Access to work can help with transport, practical support in the work place such as equipment etc. <https://www.gov.uk/access-to-work>