

This table offers an overview of how the PPSS service is delivered and illustrates how it is aligned to the recommendations of NICE NG206

NICE Recommendations NG206	Persistent Physical Symptoms Service provision and process
<p>The NICE guidance lists core staff, in addition to medical staff (these are provided within Primary care, Secondary or tertiary services in line with commissioning) to include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.</p>	<p>The core staffing in PPSS includes:</p> <ul style="list-style-type: none"> • Occupational therapists • Physiotherapists • Psychological therapists and Practitioner psychologists • Living well coaches to support patients with their care plan and goals <p>We can also access other specialist team members including Neuropsychologists and refer within the Trust to:</p> <ul style="list-style-type: none"> • Dietetics • Tier 2 and Tier three weight management • Complex Pain MDT • Other medical and surgical colleagues
<p>Assessment The NICE guidance for CFS/ME states that patients must be offered a person-centred approach to care and assessment . NICE recommends that a holistic assessment is completed and a Person centred care plan is created. The assessment should include all aspects of functioning physical, social and psychological</p>	<p>Once patients are referred to PPSS, they are offered an assessment with a member of the MDT, these assessments are offered:</p> <ul style="list-style-type: none"> • Face to face • By telephone • By video <p>As preferred by the patient.</p> <p>This holistic assessment in PPSS includes:</p> <ul style="list-style-type: none"> - We enquire about: the patient’s most important concerns, whether they have any accessibility difficulties, their hopes and goals for the future - We explore the patients story / history of what they have been through in relation to their CFS/ME, their physical symptoms, whether they are living with other Long term conditions, the impact of the CFS/ME on their Quality of life and emotional health, psychological health and cognition, their social and family context, their level of functioning across a range of domains (past and present functioning) - We explore what has been tried before, what’s worked well and what the struggles have been - We discuss the therapy options within PPSS, including referral on to other services to work alongside us, to help the patient choose which pathway of care is best matched to their needs

<p>NICE recommends that the person and their family or carers (as appropriate) a copy of their care and support plan and share a copy with their GP</p>	<p>In PPSS once this assessment is completed, which may be completed over more than one appointment to support the management of fatigue, then a comprehensive Person centred care plan is agreed and shared with the patient, GP and other health care professionals agreed with the patient.</p> <p>The care plan will then lead to a plan to address the patients needs and goals, the service offers input via one to one sessions, in a group and can be delivered Face to face, or by telephone or video calls; as required by the patient. We adapt care flexibly to the person's needs (e.g. the location, modality, timing, length and frequency of appointments)</p> <p>If a patient is discharged at assessment, we document why they have been discharged, the patient safety plan because of discharge and whether any onwards referrals are required. Patients are always informed they can be rereferred at any time.</p>
<p>NICE recommends that the agree a personalised care and support plan with the person with ME/CFS and their family or carers (as appropriate) informed by their holistic assessment. Include the following, depending on the person's needs</p>	<p>See above</p>
<ul style="list-style-type: none"> • information and support needs (see the section on information and support), 	<ul style="list-style-type: none"> • in PPSS information is offered in written format, video and audio material. This information is tailored to the individual patient
<ul style="list-style-type: none"> • support for activities of daily living (see the section on access to care and support and recommendation 1.6.8 on accessing social care) 	<ul style="list-style-type: none"> • In PPSS patients are supported by the Physiotherapists and Occupational therapists in this area
<ul style="list-style-type: none"> • mobility and daily living aids and adaptations to increase or maintain independence (see the recommendations on aids and adaptations) 	<ul style="list-style-type: none"> • Physiotherapists and Occupational therapists offer assessment, aids and referral to Adult social care for review of housing and adaptations
<ul style="list-style-type: none"> - education, training or employment support needs (see the section on supporting people with ME/CFS in work, education and training) 	<ul style="list-style-type: none"> • PPSS liaise with Employers, Job centres and Occupational Health services as required and with patient consent. PPSS liaise / write assessment letters to the patient and GP which patients can chose to submit as evidence with regards to reasonable adjustments in work/education

<ul style="list-style-type: none"> self-management strategies, including energy management (see the recommendations on energy management) 	<ul style="list-style-type: none"> PPSS has not offered input based on GET, the care focuses on energy management, pacing and rest. Our Living Well Programme (LWP) has specific sections on energy management including how to balance rest and activity, as described in the Guidance, We do not encourage people to push past their envelope of energy.
<ul style="list-style-type: none"> physical functioning and mobility (see the recommendations on physical functioning and mobility) 	<ul style="list-style-type: none"> - In PPSS the patients are supported by Physiotherapists and Occupational therapists, to oversee their baseline activity, any increase in activity is determined by the patient, without pushing them outside the limits of their energy. - Any increases in activity are individually tailored and developed with the AHPs in response to patient request and their personal goals
<ul style="list-style-type: none"> managing ME/CFS and symptom management, including medicines management (see recommendations 1.12.1 to 1.12.26 on managing symptoms) 	<p>PPSS liaises with other medical professionals involved with the patient, to ensure that medication is reviewed and new symptoms assessed; this is facilitated by a shared patient electronic record</p>
<ul style="list-style-type: none"> guidance on managing flare-ups and relapses (see the section on managing flare-ups in symptoms and relapses) 	<ul style="list-style-type: none"> PPSS as part of the input we help patients develop strategies for managing flares and relapses
<ul style="list-style-type: none"> details of the health and social care professionals involved in the person's care, and who to contact (see recommendation 1.10.3). 	<ul style="list-style-type: none"> This is included in the care plan documents
<p>Adaptations</p>	
<ul style="list-style-type: none"> taking into account physical accessibility, such as how far the person has to travel, whether there is suitable transport and parking, and where rooms are for appointments taking into account sensitivities to light, sound, touch, pain, temperature extremes or smells providing care flexibly to the person's needs, such as by online or phone consultations or making home visits. 	<p>The service offers all patients appointments:</p> <ul style="list-style-type: none"> that are flexible in format, face to face flexible in location are accessible in respect of public transport, parking

<p>Service providers should be proactive and flexible in delivering services to people with severe or very severe ME/CFS, who may have particular difficulty accessing services and articulating their needs. This could include home visits, online or phone consultations, supplying written communication, and supporting their applications for aids and appliances.</p>	<p>We do offer domiciliary assessment for patients who are housebound and if appropriate we offer remote input. If patients need more intense input then the option for inpatient care is discussed with the appropriate medical team and we would provide our assessment as part of the referral for such a process.</p>
<p>Pain Be aware that pain is a symptom commonly associated with ME/CFS. 1.12.13 Investigate and manage the person's pain according to best practice, referring to specialist pain services if appropriate. 1.12.14 Refer to the following for advice on treating neuropathic pain or headaches:</p>	<p>As PPSS is an integrated pathway with Persistent pain services, all staff in the MDT have the skills to manage presentations of chronic pain and work closely with our Complex Pain MDT. We offer care aligned to NICE 59 and NICE 193</p>
<p>1.10 Multidisciplinary care Provide care for people with ME/CFS using a coordinated multidisciplinary approach. Based on the person's needs, include access to health and social care professionals with expertise in the following as a minimum, with additional expertise depending on symptoms:</p> <ul style="list-style-type: none"> • Medical (external to this pathway) • self-management strategies, including energy management • symptom management, including prescribing and medicines management • managing flare-ups and relapses • activities of daily living, including dental health 	<p>In PPSS all patients are offered a comprehensive treatment, rehabilitation and therapy package covering these areas of the NICE guidance, this is based on:</p> <ul style="list-style-type: none"> • holistic assessment • patient goals • This intervention is offered: <ul style="list-style-type: none"> ○ Face to face ○ In groups ○ Remotely by telephone, video as per patient preference <p>The focus of the intervention is to help people live a valued life, alongside having a long term health condition, with a focus on their goals</p> <ul style="list-style-type: none"> • There is a comprehensive written patient manual that patients have and covers each area in detail, supported by videos and the service website <ul style="list-style-type: none"> ○ This includes many areas including: <ul style="list-style-type: none"> • Self management • Personal goals • mobility and other physical activity <ul style="list-style-type: none"> • energy management • pacing • rest and relaxation (both quality and duration) • ability to undertake activities of daily living, hobbies , with support if required

<ul style="list-style-type: none"> • psychological, emotional and social wellbeing, including family and sexual relationships • diet and nutrition • mobility, avoiding falls and problems from loss of dexterity, including access to aids and rehabilitation services • social care and support 	<ul style="list-style-type: none"> • psychological, emotional and social demands, including family and sexual relationships • sleep quality and duration, including sleep hygiene • cognitive activity • In terms of activity levels the advice is aligned to the NICE guidance and personalised to the patient • During the programme patients are asked for: <ul style="list-style-type: none"> ○ Feedback ○ Review of goals • During their care in the pathway they can be receive care from: <ul style="list-style-type: none"> ○ Occupational therapists ○ Physiotherapist ○ Practitioner psychologists ○ Living well coaches ○ <i>Tailored to the patients needs and new goals identified</i> • support access to third sector organisations, eg CAB • support referral to other agencies eg Adult social care • support interactions with work, training and Job centre services in line with patient goals and permissions • actively seek review by the patients medical team as required, or refer to other services eg Specialist MSK • access to Specialist pain services, which are part of the same service for review
<p>Psychological care Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain:</p> <ul style="list-style-type: none"> • its principles, including that it may help them manage their symptoms but it is not curative (see box 5) and • any potential benefits and risks. 	<p>In PPSS all our staff have enhanced psychological skills. Psychological therapy is offered to patients and is designed to help manage the distress of the impact of their condition on their life and is to enhance the ability to live a valued life , it is NOT and never has been considered a cure The Practitioner psychologists are all registered and trained in a range of Psychological therapies, in line with NICE (for example, Chronic Pain NG193, CFS/ME NG206, Depression in LTC CG91) for the following conditions:</p> <ul style="list-style-type: none"> • Anxiety • Depression • PTSD and Trauma • Health Psychology <p>The therapy offered includes:</p> <ul style="list-style-type: none"> • Cognitive Behavioural therapy • Acceptance and Commitment therapy, in line with NICE for Chronic pain • Compassion focused therapy

	<ul style="list-style-type: none"> • EMDR for trauma <p>The therapy model is agreed with the patient, through a process of formulation and understanding of their presentation, goals and needs. The service assesses and monitors all patients risk and acts appropriately with other services to manage this, Patients with complex and enduring mental health difficulties are supported to access Mental health care and we offer care in collaboration with these teams All our staff have regular clinical supervision for the therapy model from suitably qualified supervisors.</p>
<p>Managing coexisting conditions</p> <p>Be aware that other conditions may coexist with ME/CFS and should be investigated and managed according to best practice.</p>	<p>As PPSS is an integrated pathway with other Persistent symptoms, eg IBS, Fibromyalgia and Pain, and our Health psychology wider service, which offers care for other Long term conditions, including diabetes, cardiology, respiratory, Long COVID, functional disorders, stroke, MS and cancers – we can refer patients for appropriate care seamlessly in line with the appropriate NICE guidance We liaise with medical and nursing staff in these pathways</p>
<p>If a flare-up or relapse cannot be managed using the person's self-management strategies outlined in their care and support plan or they are worried about new symptoms or a change in symptoms, advise the person to contact their named contact in primary care or the ME/CFS specialist team.</p>	<p>Patients are discharged from the service with their personal plan for relapse prevention and keeping well.</p> <p>However patient can be re-referred, if more than 3 months has elapsed since their last contact, then we encourage this to be through the primary care team to ensure no new conditions have developed; as there is a risk that patients symptoms are automatically seen to be part of their CFS/ME leading to the risk of misdiagnosis.</p>