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# CBT repackaged or a novel treatment? The Lightning Process compared with UK specialist medical care for paediatric Chronic Fatigue Syndrome

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## ABSTRACT

**Rationale:** UK specialist medical care (SMC) for paediatric Chronic Fatigue Syndrome (CFS/ME) includes behavioural approaches (Graded Exercise Therapy; Activity Management) and Cognitive Behavioural Therapy for fatigue (CBT-F). Treatment is suboptimal with a third of children not recovering after 6 months of SMC. Many families seek alternative treatments at personal cost, including the Lightning Process (LP). Evidence shows LP can improve patient outcomes, though this intervention is not widely known/understood.

**Objectives:** To describe LP in comparison with SMC approaches in order to identify distinct elements, inform clinicians about treatment options, and generate hypotheses around effectiveness.

**Methods:** Theoretical comparison including stakeholder consultation.

**Results:** While overlaps with SMC approaches were identified, and CBT-F in particular, distinct elements of LP were its focus on language style, neurophysiological rationale, affective/physiological change technique and mode of delivery.

**Conclusion:** This theoretical comparison identified distinct elements of LP which could be explored in future interventions or research aiming to improve clinical outcomes for children with CFS/ME, and informs clinicians about treatment options available for families.

## KEYWORDS

Fatigue syndrome; chronic; CFS/ME; complementary therapies; cognitive behavioral therapy; behavior therapy; therapeutics; adolescent; pediatrics

## Background

There is limited evidence of effective treatment for paediatric Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis (CFS/ME), compounded by the wide variety of possible causal factors of CFS/ME, and lack of clear evidence around these [1]. Cognitive Behavioural

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Therapy for Fatigue (CBT-F) and two behavioural treatments, Graded Exercise Therapy (GET) and Activity Management (AM), have been recommended by the National Institute for Health and Care Excellence (NICE) [2] and offered within UK specialist medical care (SMC). All these approaches provide treatment and advice to improve sleep and pain. All three approaches in paediatric settings are designed to support children to convert a 'boom-bust' pattern of activity to a more stable pattern of activity which can then be gradually increased. However, these behavioural treatments have only been trialed in adult populations [3]. While CBT-F has been shown to be effective for treating CFS/ME in young people [4–6], around a third do not recover after six months [5]. Though GET and AM have been recommended, there is little evidence of effectiveness in the paediatric population [7,8]. A review of the NICE guidance is currently underway (revised guidelines are due to be published in late 2021) [9]. There is a clear need to improve treatments for paediatric CFS/ME.

The Lightning Process® (LP) is a trademarked, commercially-available alternative intervention for multiple conditions, including CFS/ME [10–13] with around 1000 people accessing it each year globally (600 in the UK; two thirds for CFS/ME) [14], at personal cost. The SMILE (feasibility and full) Trial provided evidence of the effectiveness of LP in improving outcomes in paediatric CFS/ME treatment if given in addition to SMC [15–17]. The trial found that compared to those receiving SMC, young people receiving SMC + LP had:

- Improved physical function at 6 months: Short-Form Health Survey Physical Function Subscale (SF-36-PFS) adjusted difference in means 12.5 ([95% CI 4.5, 20.5],  $p = 0.003$ ), increasing to 15.1 (95% CI 5.8, 24.4,  $p = 0.002$ ) at 12 months.
- Reduced fatigue: Chalder Fatigue Scale (adjusted difference in means  $-4.7$  [95% CI  $-7.9$  to  $-1.6$ ],  $p = 0.003$ ) and reduced anxiety: Hospital Anxiety and Depression Scale (HADS) ( $-3.3$ , [95% CI:  $-5.6$ ,  $-1.0$ ],  $p = 0.005$ ) and Spence Children's Anxiety Scale ( $-8.7$ , [95% CI:  $-16.9$ ,  $-0.5$ ],  $p = 0.039$ ), at 6 months, continuing at 12 months.
- Reduced depression at 12 months: HADS adjusted difference in means ( $-1.7$  [95% CI  $-3.3$ ,  $-0.2$ ]  $p = 0.030$ ).
- Reduced pain scores at 6 and 12 months (though confidence intervals were wide).
- Improved school attendance at 12 months (adjusted difference in means 0.9 days of school per week [95% CI 0.2, 1.6]  $p = 0.018$ ).

The trial also reported evidence that combining SMC with LP was cost-effective and no serious adverse events attributable to treatment were reported within the trial. A recent systematic review of LP effectiveness for any condition [18] found all studies showed benefit from the intervention, commonly for a majority of participants, though concluded that more research is needed as beyond the SMILE Trial, the evidence is mainly comprised of surveys and anecdotal reports. Two qualitative studies have investigated patient experiences of LP for CFS/ME. Reme et al [19] interviewed young people (aged 14–26 years), who reported helpful aspects of the approach (e.g. theoretical rationale, practical exercises) and less helpful aspects (e.g. intensity, short duration). Sandaunet et al [20] interviewed adults, who reported mixed experiences of the intervention and one review focused on paediatric CFS/ME [21] including LP and healthcare practitioner

interviews, and reported that LP is positively regarded though intervention content is vaguely defined.

Before further trials of LP for paediatric CFS/ME are conducted, we need a better understanding of what the intervention involves and how it compares to current treatments employed in SMC. Understanding the ways interventions are similar as well as different can enable hypotheses to be generated about what is unique and potentially effective in any one approach [22]. It can also help to specify and operationalise what the intervention is and how it is differentiated from existing treatments for the purposes of testing in future intervention studies and for explaining to patients the range of treatment options.

LP draws from multiple disciplines and techniques, some with limited evidence base (e.g. Neurolinguistic Programming [NLP]), which has contributed to scepticism about the approach [23]. The designer of LP describes it as addressing dysregulated physical stress responses that can serve to maintain conditions such as CFS/ME, proposing that LP improves neurology, drawing parallels with literature on the physiological effects of psychological techniques such as mindfulness [24]. This remains theoretical at present due to a lack of evidence.

We set out to describe and define LP in the context of established SMC for paediatric CFS/ME available in the UK National Health Service (NHS). Specifically, we aimed to identify similarities and differences between LP, CBT-F, and the behavioural treatments, GET and AM, with respect to the key elements of these interventions. The purpose was to identify possible avenues to explore in future research aiming to enhance NHS patient care as well as to inform clinicians about treatment options available for families.

## Methods

Two comparative tables of key components of LP, CBT-F and behavioural treatments for paediatric CFS/ME were populated by the lead author (EA), a researcher with a background in Health Psychology and intervention testing and development. The tables were based on key elements of the TIDieR template (the why/what/who/how/where/when) of interventions [25] to describe the mode of delivery, theoretical conceptualisation of the problem, key therapeutic content and rationale (theoretical mechanisms of effectiveness) of each intervention approach. We utilised published information which detailed the approaches. For LP details, information was gathered from LP books, websites and publications describing the approach [10–13,16]. This was supplemented by observations made by the lead author shadowing a three-day course (June 2018)<sup>1</sup> and discussions with LP practitioners – two of whom are co-authors (PP, FF). SMC details were drawn from NICE guidelines [2], Magenta Trial protocols for AM/GET [26], and PACE protocols [27,28] for further details (though PACE was designed for adults with CFS/ME). This was supplemented by observations made by the lead author shadowing SMC sessions at a specialist paediatric CFS/ME clinic in an NHS hospital (25/07/18 and 06/08/2018) and discussions with paediatric CFS/ME clinicians – three of whom are co-authors (JS, ML, EC).

These initial comparative tables, together with a written summary of LP, formed the basis of a stakeholder consultation to discuss and refine the differentiation of intervention approaches. This consultation process included email exchanges, individual discussions and a 1-hour group meeting (held on 14/02/2019) comprising of: LP designer (co-

author PP) and LP practitioner (co-author FF), medical clinical lead of a specialist paediatric CFS/ME NHS service (co-author EC), two clinical psychologists who deliver CBT within the NHS service (co-authors ML, JS) and three independent researchers (lead author EA, and co-authors RB, LB). In the group meeting, the lead author presented the initial tables and the LP practitioners and NHS clinicians discussed the key elements in more detail, advised on any changes to be made, and via discussion reached consensus on the elements that were similar and distinct between interventions based on their clinical expertise. The tables and descriptive comparisons presented in this paper were refined within and after this meeting in collaboration with these key stakeholders/co-authors to ensure the core elements of each treatment approach were captured.

## Results

### *Mode of delivery*

Differences in the mode of delivery of LP compared to SMC approaches are found in the format, practitioner background, intervention location and mode of access, as presented in [Table 1](#). Key differences are described below

SMC treatments, whether CBT-F, GET or AM, are typically delivered to patients individually, usually with the parent/carer present (family-focused therapy [29]) over 6–12 weekly/fortnightly sessions. LP is typically (though not exclusively) delivered as a group, often including different issues, not solely CFS/ME, and always delivered intensively over three consecutive days. SMC approaches frequently (but not always) include parental/carer involvement in treatment sessions whereas in LP, parents/carers take an observer role (though can ask questions).

SMC approaches are delivered by NHS clinicians such as Clinical Psychologists (mainly CBT), Occupational Therapists or Physiotherapists (mainly behavioural treatments) with specific additional training to work with paediatric CFS/ME. LP practitioners have mixed professional backgrounds, (e.g. management/education/marketing/coaching/law/communication and allied healthcare professions) and undergo months of LP-specific training (see [Table 1](#)). While not a requirement, many LP practitioners (anecdotally, two thirds) have recovered from CFS/ME or other problems using LP, and disclose this to clients (true for both SMILE Trial LP practitioners). While CBT training promotes self-reflection and practice [30,31], it is not usual practice for NHS therapists to disclose personal experiences of illness or treatments they deliver.

### *Intervention content*

Our comparison identified similarities and differences in intervention content— see [Table 2](#). The closest comparisons are drawn between LP and CBT-F, forming the larger part of these results. It is to be noted that CBT-F incorporates similar behavioural approaches as GET and AM (shown in [Table 2](#)), while additionally addressing cognitions.

### *Pre-course assessment: diagnostic suitability versus readiness for change<sup>2</sup>*

Criteria for being offered ongoing care after assessment differ between LP and SMC approaches; LP assessment focuses on psychological readiness to engage with the

**Table 1.** Comparison of mode of delivery.

|                   | Name of intervention/treatment                                | LP<br>Lightning Process                                                                                                                                                                                                                                                     | CBT-F<br>Cognitive Behavioural Therapy for Fatigue                                                                                                                                                       | GET<br>Graded Exercise Therapy                                                                                                                                                                              | AM<br>Activity Management |
|-------------------|---------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------|
| Who provided      | <b>Practitioner characteristics</b>                           | LP and NLP-specific training (LP language, coaching, NLP, solution therapy, anatomy/physiology, group management skills). Varied professional backgrounds. Many (but not all) practitioners have overcome illness using LP in past and then trained to deliver it to others | Usually Clinical Psychologist/mental health professional trained in CBT (post-graduate Doctorate/equivalent) plus specific experience and training in applying CBT-F to patients with CFS/ME             | Usually allied health professional (e.g. occupational therapists or physiotherapists) or medical professional with professional training and specific experience in working with young patients with CFS/ME |                           |
| What              | <b>Physical or informational materials used</b>               | LP audio/book (pre-course)<br>Handouts (during course, including information for friends/family)<br>Graduation CD (post course)                                                                                                                                             | Activity diaries<br>Some written CBT material may be provided or generated within sessions                                                                                                               | Activity diaries<br>Information leaflets e.g. about sleep, activity                                                                                                                                         |                           |
| How               | <b>Mode of delivery</b> (group/individual/face-to-face/other) | One-to-one via telephone (pre and post-course)<br>Group course – one practitioner usually with 3–4 attendees<br>Parents may attend also (mainly as observers rather than participating)                                                                                     | Usually face-to-face – one therapist to one patient plus parent/carer (often directly participating)<br>Online delivery of treatments is available for individuals and families within some NHS services | Usually face-to-face – one therapist to one patient plus parent/carer (often directly participating)<br>Online delivery of treatments is available for individuals and families within some NHS services    |                           |
| Where             | <b>Location and access</b>                                    | Usually non-clinical setting<br>Usually accessed by self-referral (online form) and client payment for the course.                                                                                                                                                          | Usually NHS clinic<br>Usually accessed by GP referral with no payment required by the patient                                                                                                            | Usually NHS clinic<br>Usually accessed by GP referral with no payment required by the patient                                                                                                               |                           |
| When and how much | <b>Duration, intensity and frequency</b>                      | Telephone assessment and coaching (pre-course): usually 2 phone calls<br>Main course: 4 hours/day on 3× consecutive days plus:<br>3 hours post-course available as phone calls (e.g. 3 × 1h calls/more frequent, shorter calls)                                             | ≥6× weekly/fortnightly 1-hour sessions with follow-ups as clinically necessary                                                                                                                           | ≥6× weekly/fortnightly 1-hour sessions with follow-ups as clinically necessary                                                                                                                              |                           |
| Tailoring         | <b>Tailoring</b>                                              | Follows a standard taught course with individually tailored elements                                                                                                                                                                                                        | Individually tailored, with some standard elements                                                                                                                                                       | Mainly following a standard course with individually tailored elements                                                                                                                                      |                           |



**Table 2.** Comparison of intervention content.

|                                                                                                                                                                                                         | LP<br>Lightning Process                                                                                                                                                                                                                                                                                                                                       | CBT-F<br>Cognitive Behavioural Therapy for CFS/ME                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | GET<br>Graded Exercise Therapy                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | AM<br>Activity Management                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Why</b><br><b>Conceptualising the problem</b><br><i>NB: All approaches recognise multiple (biopsychosocial) triggers for CFS/ME and focus on conceptualising maintenance factors to be addressed</i> | <p>Illness model of:<br/>Neurological/physiological stress response</p> <p>Specifically:<br/>• Elevated state of alertness and persisting activation of the sympathetic nervous system<br/>• Some recognition that secondary mental focusing may also reinforce unhelpful neurological pathways</p>                                                           | <p>Illness model of:<br/>(1) Boom and bust pattern of activity (doing too much on 'good' days when have energy, leading to payback where able to do far less) leading to (2) Sleep dysregulation exacerbates fatigue<br/>(2) Symptom focus and fear avoidance.<br/>(3) Sleep dysregulation exacerbates fatigue</p> <p>Specifically:<br/>• Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement<br/>• Fatigue and muscle pain lead to activity avoidance<br/>• Resting more = deconditioning (can exacerbate symptoms)<br/>• Sleeping more/less reduces sleep quality and contributes to fatigue. Common for patients to nap during the day, further affecting quality of night-time sleep.<br/>• Combined with cognitive elements e.g. increased focus on symptoms = fear of activity (might exacerbate symptoms). Fears that symptoms = severe illness = further reductions in activity.</p> | <p>Illness model of:<br/>1) Boom and bust pattern of activity based around all types of activity (including physical, cognitive, emotional)<br/>2) Sleep dysregulation exacerbates fatigue</p> <p>Specifically:<br/>• Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement<br/>• Sleeping more/less reduces sleep quality and contributes to fatigue. Common for patients to nap during the day, further affecting quality of night-time sleep.</p> | <p>Illness model of:<br/>(1) Boom and bust pattern of activity based around all types of activity (including physical, cognitive, emotional)<br/>(2) Sleep dysregulation exacerbates fatigue</p> <p>Specifically:<br/>• Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement<br/>• Sleeping more/less reduces sleep quality and contributes to fatigue. Common for patients to nap during the day, further affecting quality of night-time sleep.</p> |
| <b>Basic model of illness maintenance/problem</b>                                                                                                                                                       | Primarily physiology (implicit behavioural and cognitive maintenance elements; though the LP would not use these terms)                                                                                                                                                                                                                                       | Physiology + Behaviour + Cognition                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Physiology + Behaviour                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Physiology + Behaviour                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| <b>Goal of intervention</b>                                                                                                                                                                             | <ul style="list-style-type: none"> <li>• Explicitly described as restoring neurophysiological functioning</li> <li>• Equip client with affective state management techniques</li> <li>• Implicit goals are to switch to positive mental focus and belief that wellness can be achieved (akin to self-efficacy) by stopping 'physiological spirals'</li> </ul> | <ul style="list-style-type: none"> <li>• Equip patient with behavioural and cognitive techniques</li> <li>• Activity regulation – break boom and bust cycle (achieve manageable activities and increase to normal levels and pattern).</li> <li>• Regulate sleep pattern</li> <li>• Cognitive shift away from illness fears limiting activity</li> </ul>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                | <ul style="list-style-type: none"> <li>• Equip patient with behavioural techniques</li> <li>• Activity regulation – break boom and bust cycle of physical activity/exercise attendance, extra-curricular activity, physical activity etc. (achieve manageable activities and re-increase to normal levels and pattern). Regulate sleep pattern</li> </ul>                                                                                                                                                                                     | <ul style="list-style-type: none"> <li>• Equip patient with behavioural techniques</li> <li>• Activity regulation – break boom and bust cycle of a range of activities e.g. school attendance, extra-curricular activity, physical activity etc. (achieve manageable activities and re-increase to normal levels and pattern).</li> <li>• Regulate sleep pattern</li> </ul>                                                                                                                                                                     |

(Continued)

Table 2. Continued.

|                                                                                                                                    | LP                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | CBT-F                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       | GET                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | AM                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                                                                                                                                    | Lightning Process                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Cognitive Behavioural Therapy for CFS/ME                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                    | Graded Exercise Therapy                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                  | Activity Management                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         |
| What <b>Main ingredients of intervention</b> (below):                                                                              | <ul style="list-style-type: none"> <li>• Explanation of illness maintenance model (as above) + explanation of brain neuroplasticity and the concept of excellence (can be taught)</li> <li>• Language and focus shift:                             <ul style="list-style-type: none"> <li>– Switch from passive to active language in relating to illness</li> <li>– Positive filtering</li> <li>– Stop symptoms focus – switch to positive focus</li> </ul> </li> <li>• Technique rehearsal (with kinetic elements – standing in different positions for each step) the ‘mat work’:                             <ul style="list-style-type: none"> <li>– Self-monitoring of thoughts</li> <li>– Thought stopping (with arm and body posture change)</li> <li>– Compassionate self-affirmation, and self-coaching</li> <li>– Visualisation for affective/physiological state change</li> </ul> </li> <li>• Goal setting (positive, solution-focused) – taking immediate action to show change using technique; reflecting on previous goal success (in group)</li> </ul> | <ul style="list-style-type: none"> <li>• Explanation of illness maintenance model (as above)</li> <li>• Behavioural treatment (primary focus):                             <ul style="list-style-type: none"> <li>– establish a stable baseline of general activities, with a graduated return to normal activity – breaking ‘boom and bust’ cycle. Bed and wake time anchoring to establish more normal routine. Cutting out daytime sleeping</li> </ul> </li> <li>• Cognitive treatment:                             <ul style="list-style-type: none"> <li>– Assessment of illness beliefs and coping strategies, collaborative challenging of unhelpful beliefs about symptoms and activity (as they come up).</li> <li>– Goal setting and reflection on previous goals (successes, challenges) with practitioner; collaborative problem-solving</li> </ul> </li> </ul> | <ul style="list-style-type: none"> <li>• Explanation of illness maintenance model (as above)</li> <li>• Behavioural treatment:                             <ul style="list-style-type: none"> <li>– Establishing manageable baseline of <b>physical</b> activities (only) – usually begins with reduction of activities</li> <li>– Planned incremental increases in physical activity – on basis of physiological tolerance</li> </ul> </li> <li>• Bed and wake time anchoring to establish more normal routine. Cutting out daytime sleeping</li> </ul> | <ul style="list-style-type: none"> <li>• Explanation of illness maintenance model (as above)</li> <li>• Behavioural treatment:                             <ul style="list-style-type: none"> <li>– Establishing manageable baseline of <b>all</b> activities, including cognitive and physical, social and emotional – usually begins with reduction of activities</li> <li>– Planned incremental increases in activity on basis of tolerance</li> </ul> </li> <li>• Bed and wake time anchoring to establish more normal routine. Cutting out daytime sleeping</li> </ul> |
| Monitor & stabilise activity (usually starts with activity reduction) then increase incrementally<br>Planned increases in activity | N                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Y                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           | Y                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Y                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
| Specific encouragement of aerobic exercise                                                                                         | Y – immediate increase based on client’s ability to experience physiological change and expanded sense of what is achievable<br>N                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | Y – gradual                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Y – gradual                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                              | Y – gradual                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 |
| Direct challenge of unhelpful illness beliefs<br><b>Implicit/explicit mechanisms of effectiveness</b>                              | Y (beliefs questioned and discussed)<br>Language and focus shift leads to neurological change which brings improved physiology enabling increase in activity                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | N<br>Changing patterns of thoughts and behaviours that maintain fatigue leads to change in fatigue                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          | Type of physical activity negotiated with patient: gentle, manageable aerobic.<br>N                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | N<br>Changing patterns of behaviours that maintain fatigue leads to change in fatigue                                                                                                                                                                                                                                                                                                                                                                                                                                                                                       |



training and its concepts, while SMC assessment focuses on diagnosis. LP clients are encouraged to engage with LP materials (audio/book) before completing an online form and pre-course telephone call which includes assessment of their psychological readiness to engage, belief that change is possible using the LP and belief in capability to recover. For example, questions see Parker p. 122 [10]. Telephone coaching is provided to support clients to become psychologically ready to proceed to the course at the facilitator's discretion. By contrast, SMC approaches begin with CFS/ME diagnostic assessment including whether a different primary diagnosis (such as mood/pain) may need treating via referral to another service prior to beginning CFS/ME treatment. In SMC approaches, if no other primary diagnoses are identified at assessment, treatment is offered without explicitly assessing psychological readiness: patients can accept treatment or not. In contrast to SMC approaches, LP may be offered to those with different/multiple diagnoses as it does not exclusively apply to CFS/ME.

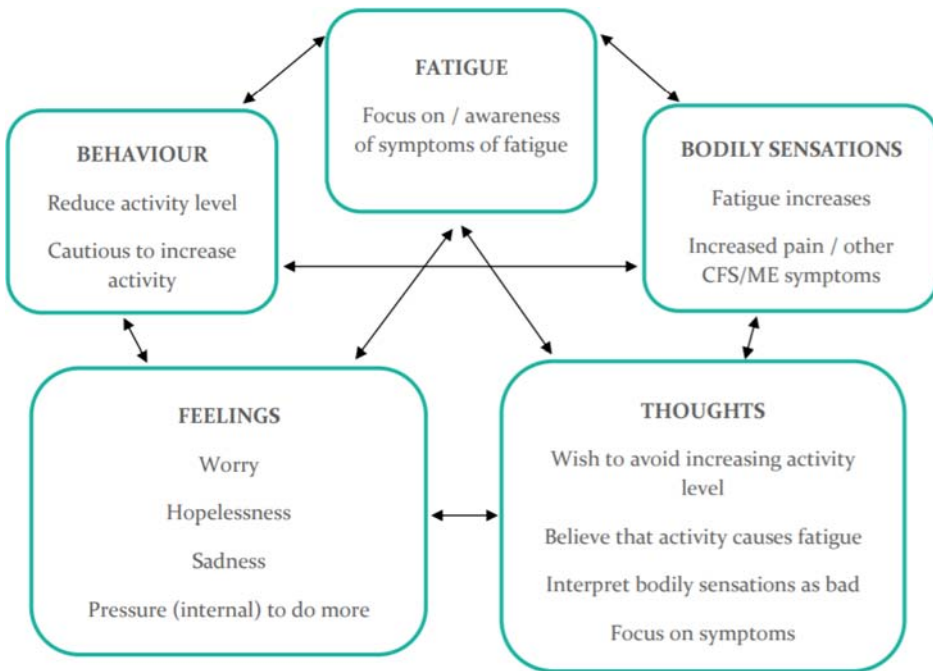
### ***Conceptualising CFS/ME: physiology, behaviour, cognitions and neurology***

Both LP and all SMC approaches socialise the patient/client to the intervention including some illness explanation and treatment (or 'training') rationale. While all recognise that CFS/ME has multifactorial aetiology, often triggered by a physiological event (e.g. acute infectious illness) in combination with other biopsychosocial triggers or predisposing factors (e.g. stressful life events, genetic predisposition) [3,24], the factors involved in the *maintenance* of CFS/ME are central to interventions, and explanations focus on these.

CFS/ME maintenance is conceptualised as a combination of physical and behavioural factors in all SMC approaches (GET, AM and CBT-F), with CBT-F adding cognitive factors to these (Table 2). Examples of CFS/ME-maintaining *physical* factors in SMC approaches are sleep deregulation and circadian dysrhythmia [32]. Behavioural conceptualisations focus on 'boom-and-bust' activity patterns of patients doing too much (physical activity in the GET model, or all types of activity in AM) when feeling well, suffering payback (exacerbated symptoms) which can lead to continued reduction in activity and ongoing symptoms. Behavioural patterns associated with poor sleep such as irregular waking/bedtimes, and daytime resting/napping are presented as part of the problem, as ongoing fatigue is related to circadian dysrhythmia and compromised sleep quality. This explanation establishes the rationale for behavioural interventions to regulate activity levels and sleep.

CBT-F additionally focuses on cognitive aspects of maintaining cycles, for example boom-and-bust patterns and over-focusing on symptoms can lead to fears that any activity will cause harm or exacerbate illness [33,34]. Socialisation to CBT-F involves explanations of the link between thoughts, behaviour, emotions and physical symptoms, often presenting an illustrative diagram individualised around the patient's presentation, such as shown in Figure 1 – taken from a clinical manual recently developed by two of the authors (ML, JS) [35]. This establishes the basis of the CBT-F approach in addressing cognitions and behaviour to help break maintaining cycles of CFS/ME.

Contrastingly, LP maintains entirely neurophysiological and biological explanations, conceptualising CFS/ME maintenance as sustained arousal of the autonomic system (or heightened physical stress response), described as the 'Physical Emergency Response' (PER) [24]. The rationale centres on neurological rewiring to enable enhanced physiology



**Figure 1.** CBT-F illustrated formulation of CFS/ME maintenance.

and reduce the PER. Socialising to the model includes taught explanations (using illustrative examples, metaphors and anecdotes) of brain–body connections and neuroplasticity (e.g. placebo effects) which establish concepts of the brain’s power and adaptability, and expectations for achieving rapid change via brain training.

### ***Behavioural goals: gradual sleep and activity regulation versus immediate change***

The LP and all SMC interventions include behavioural goal setting and progress checking, with key differences in focus and timing. All SMC approaches focus primarily on sleep regulation and activity management [36]. Sleep regulation involves advice and goal setting to normalise sleep amounts, stop daytime napping and set consistent waking/bedtimes to restore circadian rhythms. Behavioural approaches aim to break ‘boom-and-bust’ patterns, beginning with assessment and monitoring of current activity levels (AM and CBT-F focus on *all* types of activity; GET solely on *physical* activity), and establishing manageable daily baseline activity levels, usually involving activity *reduction* (to a level maintainable on ‘bad’ days). Once baseline activity level is established and maintained, the practitioner helps patients implement planned incremental increases over many weeks, aiming to regain normal functioning at a safe and individualised pace. Longer-term goals usually focus on increasing school attendance and resuming social/leisure activities. Fully normal activity may not be achieved by the end treatment, though treatment aims to equip patients with tools for continued improvement, and CFS/ME relapse prevention.

The specific CFS/ME behavioural elements (addressing sleep, monitoring/regulating activity) of SMC approaches do not feature in LP, though client-led behavioural goal

setting does. Each LP course day ends with clients being asked to set behavioural goals to demonstrate change since starting the LP. Goals usually focus on achievable activity increase (e.g. shopping, walking, eating meals). By contrast to SMC approaches, goals within LP are immediate, to be completed on the same day (after the 4-hour group session) to report back the following day. This fits the intensive (three-day) format, as well as the rationale of immediate neurological change. Clients are encouraged to use brain training state management (the ‘mat work’, see below) to achieve an appropriate physiological/emotional state for goal achievement.

### ***Thoughts and beliefs: cognitive restructuring versus changing neurology***

Both LP and CBT-F address thoughts (while behavioural approaches do not), and apply comparable techniques, though using different terminology.

Cognitive elements of CBT-F address illness beliefs and coping strategies, collaboratively challenging unhelpful beliefs about symptoms and activity as they arise (e.g. reframing achiness after physical activity as normal; challenging global beliefs such as inability to recover; enhancing self-efficacy with respect to coping skills). The CBT illustration as shown in [Figure 1](#) maps out relationships between thoughts, feelings, behaviour and physiology as part of an individualised formulation of the patient’s problem to show patients they can be active agents of change and break maintenance cycles of fatigue by responding differently. An element of CBT-F is to address unhelpful cognitions (e.g. symptom-focusing) by designing and conducting behavioural experiments and practising redirecting attention (e.g. to positive activities), and family members may be encouraged to help [5]. This is designed to enable the patient to experience the benefits of focusing on activities and move away from planning activity levels based on subjective experience of current symptoms.

Similar elements are found in LP, which involves teaching the ‘structure of excellence’ in which the practitioner introduces the idea of ‘recipes for success’, teachable patterns to consistently produce results every time (illustrative examples include footballers’ penalty shooting and a practical exercise in which the group learns to spell a difficult word [37]). LP introduces the concept of ‘Excellence of Limited Function’ (ELF), describing unhealthy patterns of thinking and behaviour as ‘genius’ (e.g. a client can be a genius at discounting positives or focusing on symptoms). Clients are taught that changing recipes can change patterns to become excellent at what they want. This element includes explanations of differences between *facts* and *opinions*, how different people respond in different ways, the power of positivity and practical demonstrations of optical illusions and perception filtering. Through these means, clients are encouraged to see the benefits of filtering for positives and shifting away from symptom- and problem-focusing.

LP maintains physiological explanations throughout treatment, including for the use of the ostensibly behavioural and cognitive techniques described above. While CBT describes work on patient thoughts as ‘reframing’ or ‘cognitive restructuring’ [38], LP characterises such techniques as ‘changing neurology’.

### ***How to talk: symptoms and problems versus ‘dūing’ active, positive language***

A key difference arises in language use, with the LP placing special emphasis on language, where SMC approaches do not.

In LP, clients are coached to use positive descriptive language and focus on positive experiences (e.g. 'I feel excited'; 'It was awesome'), rather than negative reflections on present/past ill health (e.g. 'I felt awful all the time'), drawing on the neurological shift rationale. LP practitioners coach clients to use 'congruent' vocal tone and body language (e.g. talk in upbeat, confident tone, stand tall and smile), particularly when reflecting on achievements since starting LP when reporting back on behavioural goals. During coaching for positivity, expression of negative elements is deliberately discouraged. Negative reports are addressed separately in terms such as clients feeling 'stuck'. Similarly, the LP intervention is termed 'training' rather than 'treatment', and young people are 'clients' not 'patients', aiming to distance from an illness model and foster an active approach. This is different from SMC approaches where practitioners routinely ask about symptoms, negative emotions and negative impacts of CFS/ME as well as positive progress made, with little/no emphasis on communication style and language choice.

LP goes further and teaches the linguistic concept of 'dû' and passive versus active language [12]. Clients are taught to change passive statements using the term, so for example 'I have anxiety' becomes, 'I'm dûing anxiety'; 'I'm tired because ...' becomes 'I'm dûing tired' aiming to transform problem feelings into active verbs. It is designed to sound odd to disrupt habitual thinking, reminding clients of their agency in creating solutions. CBT would term this 'cognitive restructuring', though would tend to foster patient agency by examining unhelpful thought processes and conducting behavioural experiments rather than changing language per se.

By contrast to LP, SMC practitioners encourage discussion of illness, symptoms and impacts, exploring how to address these (using techniques described above). SMC approaches to goal setting and reporting may account for framing effects in encouraging patients to identify desired achievements in a positive way (e.g. CBT therapists may use Socratic questioning to help patients reframe aims and/or progress made from negative to positive, especially with negatively focused patients) but positive language focus/coaching, is not core to SMC treatments for paediatric CFS/ME. LP places much greater emphasis on this throughout all communication, including positive symptom checking (e.g. 'how *energetic* are you feeling?'), which contrasts with SMC assessment (e.g. 'how *tired* are you feeling?') and future planning ('how to excel in all situations') rather than SMC approaches' 'relapse prevention'.

### ***In the moment: cognitive control versus emotional/physical state management***

LP clients are taught a kinetic technique involving self-monitoring, thought stopping and self-coaching with visualisation which SMC approaches do not. This main LP technique (called 'the mat work') is presented as brain training to be rehearsed in all situations where the client notices thoughts, conversation or feelings going in a direction that is not 'life enhancing' (termed 'the pit'). The rationale is to change neurophysiology via compassionate self-coaching into the most helpful state (e.g. calm/energetic/focused) for their situation. The desired state focuses on how the client wants to feel (physically/emotionally) at the moment. The 'mat work' is taught via physical and verbal demonstration, with clients going through stages in front of the group, standing on prescribed positions on a special mat for each stage – see [Figure 2](#). At least initially, most verbal self-coaching aspects are scripted, which clients learn by rote. There are spaces for individualised elements within the technique (e.g. affirmations for the self-coach to say).

| LP: The 'mat work'                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                        | 'STOPP' (CBT in a nutshell)                                                                                                                                                                                                                                                                                                                                                                                                                                                                                |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Self-monitoring of thoughts/conversations (recognising 'the pit')</li> <li>• Thought stopping: Actively saying "stop!" with taught (arms/body) stop motion</li> <li>• Active choice (between 'the pit' and the 'life I love'); verbalising this</li> <li>• Verbal compassionate self-affirmation ("well done, you are a powerful genius...")</li> <li>• Verbal self-coaching: "What do you want?" (i.e. what state do you want to be in) and "How will you achieve this?"</li> <li>• Visualisation state change, aiming to reduce 'PER' and access helpful affective/physical state, drawing on (client-identified) role model, previous experience, or metaphor/simile (e.g. an animal). Visualisation may include the desired state as a colour filling the person up. The client rates achievement of desired state on 0-10 scale.</li> </ul> | <ul style="list-style-type: none"> <li>• Stop – say this to self and pause for a moment</li> <li>• Take a breath – calms the physical reaction (emotion/adrenalin); focusing on the breath reduces focus on distress and enables more rational thinking</li> <li>• Observe – thoughts and focus, sensations, what reacting to</li> <li>• Pull back – gain perspective. Consider other possible views of the situation</li> <li>• Practise what works/Proceed – choose the best course of action</li> </ul> |

**Figure 2.** Comparison of 'in the moment' techniques: the LP's 'mat work' and the CBT 'STOPP'.

As a comparison, a technique described as 'CBT in a nutshell' (an online resource for use by clinicians and patients) [39] parallels this exercise, based on the acronym 'STOPP'– see Figure 2. While there are key similarities between these techniques (e.g. concise real-time techniques, aiming to break response patterns based on thought/reaction monitoring and a self-referential 'stop'), there are key differences. CBT-F and the STOPP encourage analysis of cognitions aiming for outcomes of (cognitively) decided actions. The LP discourages engagement with cognitions, aiming instead for physiological/emotional shift using visualisation, which is not a core component of CBT-F (though can be included as part of a suite of CBT techniques) [40]. The kinetic elements and language emphasis are unique to the LP technique.

## Discussion

While notable similarities were found between LP and SMC approaches, CBT-F in particular, we have shown key differences including how the interventions are delivered, and distinct elements of LP content, namely; positive language coaching, neurophysiological rationale, and explicit focus on emotional/physical (rather than cognitive) shift.

## Findings in the context of literature

That overlaps exist between LP and SMC approaches is not unexpected. Comparisons of many talk-based treatments/interventions have shown trans-therapeutic elements to account for variance in post-treatment outcomes for different conditions, for example; fostering positive expectations of treatment, therapeutic alliance, empathy and collaborative goal agreement [41,42]. The importance of the therapeutic relationship has been well documented, for example, a task force presentation of meta-analyses concluded that the

therapeutic relationship is fundamental to the outcome of all talking therapies, independently of the specific treatment type and the method itself [43]. Looking specifically at CFS/ME treatment, a Dutch study has shown the patient-rated therapeutic relationship to explain 25% variance in post-treatment fatigue after CBT treatment for adults with CFS/ME [44]. Interestingly, key elements of the therapeutic relationship measure used in this study included *expectations of recovery* and *task agreement*, with the authors commenting that task agreement is likely related to the perceived credibility of the rationale of CBT for CFS, which we discuss further below.

### **Intervention delivery**

While not all LP practitioners have recovered from CFS/ME (or other conditions) using LP, the two thirds who have tend to disclose this. In doing so, they are role-modelling success from following LP, which according to Social Cognitive Theory (SCT) [45] powerfully influences behaviour, an element absent from SMC approaches. This aspect may also tap into key aspects of successful therapeutic interventions: building trust in the therapist and increasing engagement and belief in the intervention.

While LP describes the group delivery as enhancing learning and neurological shift from an increased volume of learning/observing the processes (i.e. repeated for each member of the group in turn), it will also add further SCT behavioural motivation in role-modelling of success by group members. There is evidence of patients' positive experiences of group delivery that fits these ideas [19], with young people reporting that the group aspect fostered learning from each other and enhanced engagement and commitment. Interestingly, group-delivered CBT-F has not been found to be effective in adults [46,47], though young people with CFS/ME have a desire to connect with peers with similar experiences [48]. Inevitably the therapeutic relationship, key to treatment success, is somewhat limited in a brief group format compared to longer-term one-to-one approaches. Patient preference will be paramount. While a group format may have a role in enhancing some treatment effects or commitment for those who engage with this, it may be prohibitive for some young people suffering CFS/ME who are more comfortable with a one-to-one relationship.

### **Intervention Content**

By comparison with the SMC focus on diagnosis in assessing treatment suitability, LP assessment of readiness may enhance client engagement in the intervention from the start. This relates to the Transtheoretical model [49] concept of the need to match clients' state of readiness to engage with appropriate interventions. As described by Miller [50] in discussing the effectiveness of Motivational Interviewing interventions, taking action (e.g. making change plans) before a client is psychologically ready can be counterproductive. It is worth noting in this context that the current reality for paediatric CFS/ME in the UK is that families often struggle to gain a diagnosis and treatment access, had varied primary care assessments and/or prior treatment, often meaning pushing through multiple barriers to reach SMC [51,52]. While not a measure of 'readiness to change' per se, families may have had to exceed a threshold of determination and motivation to reach specialist treatment, though this may be more indicative of parent, rather than patient, motivation.

The LP's consistent physical/neurological explanatory framework for intervention content, even for largely behavioural (e.g. goals) and cognitive (e.g. challenging beliefs) elements, may enhance acceptance and engagement from some clients compared with the (behavioural/cognitive) treatment rationale in SMC approaches. CFS/ME is a stigmatising condition for which any psychological explanations can be problematic [53]. Qualitative studies showed both adults and children found the LP theoretical rationale and CFS/ME explanation helpful [19,20], and quantitative evidence indicates that a biological rationale for CFS/ME treatment can enhance patient engagement and outcomes [32]. In a review of evidence of common factors in therapy, Wampold [54] states that the *expectation* of a successful outcome from treatment is essential to treatment engagement – and the self-efficacy and mastery beliefs required to implement changes – and that patients' belief in the therapeutic rationale provided is critical to this expectation pathway. Where many CFS/ME patients attribute symptoms to a physical cause [55], there are good reasons to suggest a physical justification for (and throughout) treatment may be beneficial to patients.

We identified the LP focus on language style as distinct from SMC approaches. Parallels can be drawn with narrative therapy, which encourages patients to move on from limiting self-descriptions and choose a story of who they want to be [56], and solution-focused therapy, which directly encourages positive filtering and focusing on strengths and solutions [57]. Hansen and Zech [58] provide a compelling argument for the importance of clinician language and directing of patient attention in influencing clinical outcomes, describing evidence of nocebo (poorer outcomes from clinicians' negative suggestions) and placebo effects of clinicians' verbal communication across a range of medical interventions. While positive filtering/focus is a core component of both positive psychology and solution-focused therapy which have influenced CBT and behavioural approaches [59], it is not core to SMC treatments for CFS/ME. While CBT-F often includes shifting patient attention away from symptoms (to break negative cycles), language style is not addressed. There is evidence that shifting focus away from symptoms in CFS/ME treatment mediates fatigue outcomes [60,61]. Corresponding shifts in language (away from illness narratives) could serve to enhance such attentional shift effects.

There is limited, though mixed, evidence of perceived benefits from those who have taken LP of both the 'non-ill' language and the immediate behavioural changes (as opposed to the more gradual change in SMC approaches) encouraged by the approach. Some found these aspects helpful, and others interpreted it as denying illness limitations and feeling blamed for not recovering [19]. LP encourages immediate activity-based goals to be selected by clients and enacted on the same day, whereas SMC approaches encourage gradual change always starting with sleep regulation and usually activity reduction. These differences are likely to impact task/goal agreement, which as we have stated, is a core transtheoretical feature of successful therapy, and worth exploring further with respect to CFS/ME outcomes.

Reme et al [19] also provided evidence that young people with CFS/ME experience the main LP simple practical technique (the 'mat work') as helpful. While LP has elements that address cognitions, the main technique explicitly targets affective/physiological shift while bypassing cognitions in a way that does not feature in SMC approaches to paediatric CFS/ME, using visualisation, compassionate self-coaching and kinetic elements drawing on somatic learning approaches [62], towards this aim. Compassion-focused therapies such as acceptance and commitment therapy (ACT) similarly foster self-

soothing of emotions and avoidance of engaging with cognitions [63,64] and ACT has also shown promise in treating CFS/ME. A recent study showed a 3.5-week ACT programme reduced fatigue and increased quality of life in CFS/ME patients [65], though the mechanism of action remains unclear.

### ***Strengths and limitations***

This paper is the first to explore key similarities and differences between the Lightning Process and NHS Specialist Medical Care approaches for treating paediatric CFS/ME and its strength lies in illuminating core features of the LP approach in the context of established NHS therapies. We selected a recommended intervention reporting template (the TIDieR template) [25] to structure our presentation of the key intervention elements to enable clear comparisons. We recognise that interpretation and selection of intervention elements to report in a paper such as this can be influenced by author backgrounds (a limitation of any such paper). In consideration of this, consultation with practicing specialist NHS paediatric CFS/ME clinicians and LP practitioners (and their inclusion as co-authors) ensured a balanced approach across the interventions of interest and clinical expertise represented. We acknowledge that including the designer of the LP (PP) may have influenced the presentation of LP compared to SMC approaches as designers of GET, AM or CBT were not involved. However, LP is less understood than CBT and behavioural treatments with far less literature, and we chose to include PP to enable a full check of understanding to strengthen the presented comparison. A limitation is that SMC clinicians came from one South West UK service which may have limited the discussion on generalised SMC approaches, though the service is the largest in the UK and follows national treatment guidelines.

The SMILE Trial, which inspired this further exploration of LP, gave impressive results of LP improving outcomes for young people with CFS/ME. However, a limitation of the trial is that patient and parent preference influenced families' willingness to consider participation [17,66], and the trial was relatively small, so the results may not be applicable to all. Those who had LP had SMC simultaneously, and the LP has not been tested in a trial as a standalone treatment. SMILE Trial participants reported conflicting activity advice between SMC (e.g. initial activity reduction then very gradual increase) and LP (e.g. immediately start returning to normal such as attending school), and had to navigate these themselves. Therefore more research is needed before LP should be recommended within the NHS.

It is vital to address the issue of suboptimal treatment in paediatric (and all) CFS/ME treatment. There will never be a one size fits all for treatments, and inevitably patient preference will factor into what is acceptable and what works for whom. While no approach is perfect, continued efforts need to explore every potential for improving treatment, building on existing treatments, uncovering mechanisms of effectiveness as well as exploring other (e.g. novel pharmacological) therapies. CFS/ME is chronically underfunded and more research and treatment is needed.

### ***Research recommendations.***

We recommend the following areas for future research: (i) Conducting a large-scale clinical trial comparing LP alone against CBT-F for treating paediatric CFS/ME and including



measures of candidate mechanisms of intervention effects (e.g. therapeutic alliance, readiness to change, treatment engagement/belief in the model, attention shift, goal agreement); (ii) Conducting trials to test adding distinct elements of LP to SMC approaches to explore effectiveness (e.g. training SMC therapists in LP language style; provision of physiological rationale for all treatment elements; compassionate self-coaching and visualisation for shifting affect/physical state); (iii) Exploring in detail interactions between practitioners and young people within interventions, with a particular focus on the LP language coaching and how this might impact recovery from CFS/ME. A conversation analysis of audio-recordings of LP sessions is underway.

## Conclusion

We have helped define LP in the context of NHS treatment for paediatric CFS/ME, highlighting key similarities and differences between approaches. Particular parallels were found between LP and CBT-F approaches, though we have presented key differences in rationale, content and delivery that indicate that LP brings new avenues to explore with an aim of enhancing patient care.

## Notes

1. It is to be noted that as is usual for the LP intervention, the course was not exclusively for CFS/ME and the group included adults as well as teenagers.
2. Included here rather than in mode of delivery/access section due to comparing assessment content.

## Data availability statement

Data sharing is not applicable to this article as no new data were created or analysed in this study

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This report is independent research. The views expressed in this publication are those of the authors, not of the Linbury Trust, the NHS, the National Institute for Health Research or the Department of Health and Social Care.

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