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

3

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22

1 **Abstract:**

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

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

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

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

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

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24 or the Department of Health and Social Care.

1 **Background**

2 There is limited evidence of effective treatment for paediatric Chronic Fatigue
3 Syndrome/Myalgic Encephalomyelitis (CFS/ME), compounded by the wide variety of possible causal
4 factors of CFS/ME, and lack of clear evidence around these [1]. Cognitive Behavioural Therapy for
5 Fatigue (CBT-F) and two behavioural treatments, Graded Exercise Therapy (GET) and Activity
6 Management (AM), have been recommended by the National Institute for Health and Care
7 Excellence (NICE) [2] and offered within UK specialist medical care (SMC). All these approaches
8 provide treatment and advice to improve sleep and pain. All three approaches in paediatric settings
9 are designed to support children to convert a “boom-bust” pattern of activity to a more stable
10 pattern of activity which can then be gradually increased. However, these behavioural treatments
11 have only been trialled in adult populations [3]. While CBT-F has been shown to be effective for
12 treating CFS/ME in young people [4-6], around a third do not recover after six months [7]. Though
13 GET and AM have been recommended, there is little evidence of effectiveness in the paediatric
14 population [8,9]. A review of the NICE guidance is currently underway (revised guidelines are due to
15 be published in late 2021) [10]. There is a clear need to improve treatments for paediatric CFS/ME.

16 The Lightning Process® (LP) is a trademarked, commercially-available alternative intervention for
17 multiple conditions, including CFS/ME [11-14] with around 1000 people accessing it each year
18 globally (600 in the UK; two thirds for CFS/ME) [15], at personal cost. The SMILE (feasibility and full)
19 Trial provided evidence of the effectiveness of LP in improving outcomes in paediatric CFS/ME
20 treatment if given in addition to SMC [16-18]. The trial found that compared to those receiving
21 SMC, young people receiving SMC+LP had:

- 22 • improved physical function at 6 months: Short-Form Health Survey Physical Function
23 Subscale (SF-36-PFS) adjusted difference in means 12.5 [95% CI 4.5, 20.5], $p=.003$),
24 increasing to 15.1 (95% CI 5.8, 24.4, $p=.002$) at 12 months

- 1 • reduced fatigue: Chalder Fatigue Scale (adjusted difference in means -4.7 (95% CI -7.9 to
2 -1.6), $p=0.003$) and reduced anxiety: Hospital Anxiety and Depression Scale (HADS) (-3.3 ,
3 [95% CI: -5.6 , -1.0], $p=.005$) and Spence Children's Anxiety Scale (-8.7 , [95% CI: -16.9 , -0.5],
4 $p=.039$), at 6 months, continuing at 12 months
- 5 • reduced depression at 12 months: HADS adjusted difference in means -1.7 [95% CI -3.3 ,
6 -0.2] $p=.030$)
- 7 • reduced pain scores at 6 and 12 months (though confidence intervals were wide)
- 8 • improved school attendance at 12 months (adjusted difference in means 0.9 days of school
9 per week [95% CI 0.2 , 1.6] $p=.018$).

10 The trial also reported evidence that combining SMC with LP was cost-effective and no serious
11 adverse events attributable to treatment were reported within the trial. A recent systematic review
12 of LP effectiveness for any condition [19] found all studies showed benefit from the intervention,
13 commonly for a majority of participants, though concluded that more research is needed as beyond
14 the SMILE Trial, the evidence is mainly comprised of surveys and anecdotal reports. Two qualitative
15 studies have investigated patient experiences of LP for CFS/ME. Reme *et al* [20] interviewed young
16 people (aged 14 to 26 years), who reported helpful aspects of the approach (e.g. theoretical
17 rationale, practical exercises) and less helpful aspects (e.g. intensity, short duration). Sandaunet *et*
18 *al* [21] interviewed adults, who reported mixed experiences of the intervention and one review
19 focused on paediatric CFS/ME [22] including LP and healthcare practitioner interviews, and
20 reported that LP is positively regarded though intervention content is vaguely defined.

21 Before further trials of LP for paediatric CFS/ME are conducted, we need a better understanding
22 of what the intervention involves and how it compares to current treatments employed in SMC.
23 Understanding the ways interventions are similar as well as different can enable hypotheses to be
24 generated about what is unique and potentially effective in any one approach [23]. It can also help
25 to specify and operationalise what the intervention is and how it is differentiated from existing

1 treatments for the purposes of testing in future intervention studies and for explaining to patients
2 the range of treatment options.

3 LP draws from multiple disciplines and techniques, some with limited evidence base (e.g.
4 Neurolinguistic Programming [NLP]), which has contributed to scepticism about the approach [24].
5 The designer of LP describes it as addressing dysregulated physical stress responses that can serve
6 to maintain conditions such as CFS/ME, proposing that LP improves neurology, drawing parallels
7 with literature on the physiological effects of psychological techniques such as mindfulness [25].
8 This remains theoretical at present due to lack of evidence.

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

15

16 **Methods**

17 Two comparative tables of key components of LP, CBT-F and behavioural treatments for
18 paediatric CFS/ME were populated by the lead author (EA), a researcher with a background in
19 Health Psychology and intervention testing and development. The tables were based on key
20 elements of the TIDieR template (the why/what/who/how/where/when) of interventions [26] to
21 describe the mode of delivery, theoretical conceptualisation of the problem, key therapeutic
22 content and rationale (theoretical mechanisms of effectiveness) of each intervention approach. We
23 utilised published information which detailed the approaches. For LP details, information was
24 gathered from LP books, websites and publications describing the approach [11-14,27]. This was

1 supplemented by observations made by the lead author shadowing a three-day course (June
2 2018)* and
3 s with LP practitioners – two of whom are co-authors (PP, FF). SMC details were drawn from
4 NICE guidelines [2], Magenta Trial protocols for AM/GET [28], and PACE protocols [29,30] for
5 further details (though PACE was designed for adults with CFS/ME). This was supplemented by
6 observations made by the lead author shadowing SMC sessions at a specialist paediatric CFS/ME
7 clinic in an NHS hospital (25/07/18 and 06/08/2018) and discussions with paediatric CFS/ME
8 clinicians – three of whom are co-authors (JS, ML, EC).

9 These initial comparative tables, together with a written summary of LP, formed the basis of a
10 stakeholder consultation to discuss and refine the differentiation of intervention approaches. This
11 consultation process included email exchanges, individual discussions and a one-hour group
12 meeting (held on 14/02/2019) comprising of: LP designer (co-author PP) and LP practitioner (co-
13 author FF), medical clinical lead of a specialist paediatric CFS/ME NHS service (co-author EC), two
14 clinical psychologists who deliver CBT within the NHS service (co-authors ML, JS) and three
15 independent researchers (lead author EA, and co-authors RB, LB). In the group meeting, the lead
16 author presented the initial tables and the LP practitioners and NHS clinicians discussed the key
17 elements in more detail, advised on any changes to be made, and via discussion reached consensus
18 on the elements that were similar and distinct between interventions based on their clinical
19 expertise. The tables and descriptive comparisons presented in this paper were refined within and
20 after this meeting in collaboration with these key stakeholders/co-authors to ensure the core
21 elements of each treatment approach were captured.

22

**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.*

1 **Results**

2 **Mode of delivery**

3 Differences in the mode of delivery of LP compared to SMC approaches are found in the
4 format, practitioner background, intervention location and mode of access, as presented in Table 1.
5 Key differences are described below

6 SMC treatments, whether CBT-F, GET or AM, are typically delivered to patients individually,
7 usually with the parent/carer present (family-focused therapy [31]) over 6-12 weekly/fortnightly
8 sessions. LP is typically (though not exclusively) delivered as a group, often including different
9 issues, not solely CFS/ME, and always delivered intensively over three consecutive days. SMC
10 approaches frequently (but not always) include parental/carer involvement in treatment sessions
11 whereas in In LP, parents/carers take an observer role (though can ask questions).

12 SMC approaches are delivered by NHS clinicians such as Clinical Psychologists (mainly CBT),
13 Occupational Therapists or Physiotherapists (mainly behavioural treatments) with specific
14 additional training to work with paediatric CFS/ME. LP practitioners have mixed professional
15 backgrounds, (e.g. management/education/marketing/coaching/law/communication and allied
16 healthcare professions) and undergo months of LP-specific training. (see table 1). While not a
17 requirement, many LP practitioners (anecdotally, two thirds) have recovered from CFS/ME or other
18 problems using LP, and disclose this to clients (true for both SMILE Trial LP practitioners). While CBT
19 training promotes self-reflection and practice [32] [33] , it is not usual practice for NHS therapists to
20 disclose personal experiences of illness or treatments they deliver.

21

22 *[Insert Table 1 about here]*

23

1 **Intervention content.**

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

6 *[Insert Table 2 about here]*

7

8 ***Pre-course assessment: diagnostic suitability versus readiness for change.***[†]

9 Criteria for being offered ongoing care after assessment differ between LP and SMC approaches; LP
10 assessment focuses on psychological readiness to engage with the training and its concepts, while
11 SMC assessment focuses on diagnosis. LP clients are encouraged to engage with LP materials
12 (audio/book) before completing an online form and pre-course telephone call which includes
13 assessment of their psychological readiness to engage, belief that change is possible using the LP
14 and belief in capability to recover. For example questions see Parker 2012, p122 [11]. Telephone
15 coaching is provided to support clients to become psychologically ready to proceed to the course at
16 the facilitator’s discretion. By contrast, SMC approaches begin with CFS/ME diagnostic assessment
17 including whether a different primary diagnosis (such as mood/pain) may need treating via referral
18 to another service prior to beginning CFS/ME treatment. In SMC approaches, if no other primary
19 diagnoses are identified at assessment, treatment is offered without explicitly assessing
20 psychological readiness: patients can accept treatment or not. In contrast to SMC approaches, LP
21 may be offered to those with different/multiple diagnoses as it does not exclusively apply to
22 CFS/ME.

23

[†]Included here rather than in mode of delivery/access section due to comparing assessment *content*

1 **Conceptualising CFS/ME: physiology, behaviour, cognitions, neurology**

2 Both LP and all SMC approaches socialise the patient/client to the intervention including some
3 illness explanation and treatment (or ‘training’) rationale. While all recognise that CFS/ME has
4 multifactorial aetiology, often triggered by a physiological event (e.g. acute infectious illness) in
5 combination with other biopsychosocial triggers or predisposing factors (e.g. stressful life events,
6 genetic predisposition) [34] [25], the factors involved in the *maintenance* of CFS/ME are central to
7 interventions, and explanations focus on these.

8 CFS/ME maintenance is conceptualised as a combination of physical and behavioural factors in
9 all SMC approaches (GET, AM and CBT-F), with CBT-F adding cognitive factors to these (Table 2).
10 Examples of CFS/ME-maintaining *physical* factors in SMC approaches are sleep deregulation and
11 circadian dysrhythmia [35]. Behavioural conceptualisations focus on ‘boom-and-bust’ activity
12 patterns of patients doing too much (physical activity in the GET model, or all types of activity in
13 AM) when feeling well, suffering payback (exacerbated symptoms) which can lead to continued
14 reduction in activity and ongoing symptoms. Behavioural patterns associated with poor sleep such
15 as irregular waking/bedtimes, and daytime resting/napping are presented as part of the problem,
16 as ongoing fatigue is related to circadian dysrhythmia and compromised sleep quality. This
17 explanation establishes the rationale for behavioural interventions to regulate activity levels and
18 sleep.

19 CBT-F additionally focuses on cognitive aspects of maintaining cycles, for example boom-and-
20 bust patterns and over-focusing on symptoms can lead to fears that any activity will cause harm or
21 exacerbate illness [36,37]. Socialisation to CBT-F involves explanations of the link between
22 thoughts, behaviour, emotions and physical symptoms, often presenting an illustrative diagram
23 individualised around the patient’s presentation, such as shown in *Figure 1* - taken from a clinical
24 manual recently developed by two of the authors (ML, JS) [38]. This establishes the basis of the
25 CBT-F approach in addressing cognitions and behaviour to help break maintaining cycles of CFS/ME.

1 *[Insert Figure 1 about here]*

2

3 Contrastingly, LP maintains entirely neurophysiological and biological explanations,
4 conceptualising CFS/ME maintenance as sustained arousal of the autonomic system (or heightened
5 physical stress response), described as the ‘Physical Emergency Response’ (PER) [25]. The rationale
6 centres on neurological rewiring to enable enhanced physiology and reduce the PER. Socialising to
7 the model includes taught explanations (using illustrative examples, metaphors and anecdotes) of
8 brain-body connections and neuroplasticity (e.g. placebo effects) which establish concepts of the
9 brain’s power and adaptability, and expectations for achieving rapid change via brain training.

10

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

12 The LP and all SMC interventions include behavioural goal setting and progress checking, with
13 key differences in focus and timing. All SMC approaches focus primarily on sleep regulation and
14 activity management [39]. Sleep regulation involves advice and goal-setting to normalise sleep
15 amounts, stop daytime napping and set consistent waking/bedtimes to restore circadian rhythms.
16 Behavioural approaches aim to break ‘boom-and-bust’ patterns, beginning with assessment and
17 monitoring of current activity levels (AM and CBT-F focus on *all* types of activity; GET solely on
18 *physical* activity), and establishing manageable daily baseline activity levels, usually involving
19 activity *reduction* (to a level maintainable on ‘bad’ days). Once baseline activity level is established
20 and maintained, the practitioner helps patients implement planned incremental increases over
21 many weeks, aiming to regain normal functioning at a safe and individualised pace. Longer-term
22 goals usually focus on increasing school attendance and resuming social/leisure activities. Fully
23 normal activity may not be achieved by the end treatment, though treatment aims to equip
24 patients with tools for continued improvement, and CFS/ME relapse prevention.

1 The specific CFS/ME behavioural elements (addressing sleep, monitoring/regulating activity) of
2 SMC approaches do not feature in LP, though client-led behavioural goal setting does. Each LP
3 course day ends with clients being asked to set behavioural goals to demonstrate change since
4 starting the LP. Goals usually focus on achievable activity increase (e.g. shopping, walking, eating
5 meals). By contrast to SMC approaches, goals within LP are immediate, to be completed on the
6 same day (after the 4 hour group session) to report back the following day. This fits the intensive
7 (three-day) format, as well as the rationale of immediate neurological change. Clients are
8 encouraged to use brain training state management (the 'mat work', see below) to achieve an
9 appropriate physiological/emotional state for goal achievement.

10

11 ***Thoughts and beliefs: Cognitive restructuring versus changing neurology***

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

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

1 Similar elements are found in LP, which involves teaching the 'structure of excellence' in which
2 the practitioner introduces the idea of 'recipes for success', teachable patterns to consistently
3 produce results every time (illustrative examples include footballers' penalty shooting and a
4 practical exercise in which the group learns to spell a difficult word [40]). LP introduces the concept
5 of 'Excellence of Limited Function' (ELF), describing unhealthy patterns of thinking and behaviour as
6 'genius' (e.g. a client can be a genius at discounting positives or focusing on symptoms). Clients are
7 taught that changing recipes can change patterns to become excellent at what they want. This
8 element includes explanations of differences between *facts* and *opinions*, how different people
9 respond in different ways, the power of positivity and practical demonstrations of optical illusions
10 and perception filtering. Through these means, clients are encouraged to see the benefits of
11 filtering for positives and shifting away from symptom- and problem-focusing.

12 LP maintains physiological explanations throughout treatment, including for the use of the
13 ostensibly behavioural and cognitive techniques described above. While CBT describes work on
14 patient thoughts as 'reframing' or 'cognitive restructuring' [41], LP characterises such techniques as
15 'changing neurology'.

16

17 ***How to talk: Symptoms and problems versus 'dûing' active, positive language***

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

20 In LP, clients are coached to use positive descriptive language and focus on positive experiences
21 (e.g. "I feel excited"; "It was awesome"), rather than negative reflections on present/past ill health
22 (e.g. "I felt awful all the time"), drawing on the neurological shift rationale. LP practitioners coach
23 clients to use 'congruent' vocal tone and body language (e.g. talk in upbeat, confident tone, stand
24 tall, smile), particularly when reflecting on achievements since starting LP when reporting back on
25 behavioural goals. During coaching for positivity, expression of negative elements is deliberately

1 discouraged. Negative reports are addressed separately in terms such as clients feeling 'stuck').
2 Similarly, the LP intervention is termed 'training' rather than 'treatment', and young people are
3 'clients' not 'patients', aiming to distance from an illness model and foster an active approach. This
4 is different from SMC approaches where practitioners routinely ask about symptoms, negative
5 emotions and negative impacts of CFS/ME as well as positive progress made, with little/no
6 emphasis on communication style and language choice.

7 LP goes further and teaches the linguistic concept of 'dû' and passive versus active language
8 [13]. Clients are taught to change passive statements using the term, so for example "I have
9 anxiety" becomes, "I'm dûing anxiety"; "I'm tired because..." becomes "I'm dûing tired" aiming to
10 transform problem feelings into active verbs. It is designed to sound odd to disrupt habitual
11 thinking, reminding clients of their agency in creating solutions. CBT would term this 'cognitive
12 restructuring', though would tend to foster patient agency by examining unhelpful thought
13 processes and conducting behavioural experiments rather than changing language *per se*.

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

24

1 ***In the moment: Cognitive control versus emotional/physical state management***

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

13 As a comparison, a technique described as ‘CBT in a nutshell’ (an online resource for use by
14 clinicians and patients) [42] parallels this exercise, based on the acronym ‘STOPP’– see figure 2.
15 While there are key similarities between these techniques (e.g. concise real-time techniques,
16 aiming to break response patterns based on thought/reaction monitoring and a self-referential
17 ‘stop’), there are key differences. CBT-F and the STOPP encourages analysis of cognitions aiming for
18 outcomes of (cognitively) decided actions. The LP discourages engagement with cognitions, aiming
19 instead for physiological/emotional shift using visualisation, which is not a core component of CBT-
20 F (though can be included as part of a suite of CBT techniques) [43]. The kinetic elements and
21 language emphasis are unique to the LP technique.

22

23

1 **Discussion**

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

6

7 **Findings in the context of literature**

8 That overlaps exist between LP and SMC approaches is not unexpected. Comparisons of many
9 talk-based treatments/interventions have shown trans-therapeutic elements to account for
10 variance in post-treatment outcomes for different conditions, for example; fostering positive
11 expectations of treatment, therapeutic alliance, empathy and collaborative goal agreement [44,45].
12 The importance of the therapeutic relationship has been well documented, for example a task force
13 presentation of meta-analyses concluded that the therapeutic relationship is fundamental to the
14 outcome of all talking therapies, independently of the specific treatment type and method itself
15 [46]. Looking specifically at CFS/ME treatment, a Dutch study has shown the patient-rated
16 therapeutic relationship to explain 25% variance in post-treatment fatigue after CBT treatment for
17 adults with CFS/ME [47]. Interestingly, key elements of the therapeutic relationship measure used
18 in this study included *expectations of recovery* and *task agreement*, with the authors commenting
19 that task agreement is likely related to the perceived credibility of the rationale of CBT for CFS,
20 which we discuss further below.

21

22 ***Intervention delivery:***

23 While not all LP practitioners have recovered from CFS/ME (or other conditions) using LP, the
24 two thirds who have tend to disclose this. In doing so, they are role-modelling success from
25 following LP, which according to Social Cognitive Theory (SCT) [48] powerfully influences behaviour,

1 an element absent from SMC approaches. This aspect may also tap into key aspects of successful
2 therapeutic interventions: building trust in the therapist and increasing engagement and belief in
3 the intervention.

4 While LP describes the group delivery as enhancing learning and neurological shift from
5 increased volume of learning/observing the processes (i.e. repeated for each member of the group
6 in turn), it will also add further SCT behavioural motivation in role-modelling of success by group
7 members. There is evidence of patients' positive experiences of group delivery that fits these ideas
8 [20], with young people reporting that the group aspect fostered learning from each other and
9 enhanced engagement and commitment. Interestingly, group-delivered CBT-F has not been found
10 to be effective in adults [49] [50], though young people with CFS/ME have a desire to connect with
11 peers with similar experiences [51]. Inevitably the therapeutic relationship, key to treatment
12 success, is somewhat limited in a brief group format compared to longer-term one to one
13 approaches. Patient preference will be paramount. While a group format may have a role in
14 enhancing some treatment effects or commitment for those who engage with this, it may be
15 prohibitive for some young people suffering CFS/ME who are more comfortable with a one-to-one
16 relationship.

17

18 **Intervention Content:**

19 By comparison with the SMC focus on diagnosis in assessing treatment suitability, LP assessment
20 of readiness may enhance client engagement in the intervention from the start. This relates to the
21 Transtheoretical model [52] concept of the need to match clients' state of readiness to engage with
22 appropriate interventions. As described by Miller [53] in discussing effectiveness of Motivational
23 Interviewing interventions, taking action (e.g. making change plans) before a client is
24 psychologically ready can be counterproductive. It is worth noting in this context that the current
25 reality for paediatric CFS/ME in the UK is that families often struggle to gain a diagnosis and

1 treatment access, had varied primary care assessments and/or prior treatment, often meaning
2 pushing through multiple barriers to reach SMC [54,55]. While not a measure of 'readiness to
3 change' *per se*, families may have had to exceed a threshold of determination and motivation to
4 reach specialist treatment, though this may be more indicative of parent, rather than patient,
5 motivation.

6 The LP's consistent physical/neurological explanatory framework for intervention content, even
7 for largely behavioural (e.g. goals) and cognitive (e.g. challenging beliefs) elements, may enhance
8 acceptance and engagement from some clients compared with the (behavioural/cognitive)
9 treatment rationale in SMC approaches. CFS/ME is a stigmatising condition for which any
10 psychological explanations can be problematic [56]. Qualitative studies showed both adults and
11 children found the LP theoretical rationale and CFS/ME explanation helpful [20,21], and
12 quantitative evidence indicates that a biological rationale for CFS/ME treatment can enhance
13 patient engagement and outcomes [35]. In a review of evidence of common factors in therapy,
14 Wampold [57] states that the *expectation* of a successful outcome from treatment is essential to
15 treatment engagement - and the self-efficacy and mastery beliefs required to implement changes -
16 and that patients' belief in the therapeutic rationale provided is critical to this expectation pathway.
17 Where many CFS/ME patients attribute symptoms to a physical cause [58], there are good reasons
18 to suggest a physical justification for (and throughout) treatment may be beneficial to patients.

19 We identified the LP focus on language style as distinct from SMC approaches. Parallels can be
20 drawn with narrative therapy, which encourages patients to move on from limiting self-descriptions
21 and choose a story of who they want to be [59], and solution-focused therapy, which directly
22 encourages positive filtering and focusing on strengths and solutions [60]. Hansen and Zech [61]
23 provide a compelling argument for the importance of clinician language and directing of patient
24 attention in influencing clinical outcomes, describing evidence of nocebo (poorer outcomes from
25 clinicians' negative suggestions) and placebo effects of clinicians' verbal communication across a

1 range of medical interventions. While positive filtering/focus is a core component of both positive
2 psychology and solution-focused therapy which have influenced CBT and behavioural approaches
3 [62], it is not core to SMC treatments for CFS/ME. While CBT-F often includes shifting patient
4 attention away from symptoms (to break negative cycles), language style is not addressed. There is
5 evidence that shifting focus away from symptoms in CFS/ME treatment mediates fatigue outcomes
6 [63] [64]. Corresponding shifts in language (away from illness narratives) could serve to enhance
7 such attentional shift effects.

8 There is limited, though mixed, evidence of perceived benefits from those who have taken LP of
9 both the 'non-ill' language and the immediate behavioural changes (as opposed to the more
10 gradual change in SMC approaches) encouraged by the approach. Some found these aspects
11 helpful, and others interpreted it as denying illness limitations and feeling blamed for not
12 recovering [20]. LP encourages immediate activity-based goals to be selected by clients and
13 enacted on the same day, whereas SMC approaches encourage gradual change always starting with
14 sleep regulation and usually activity reduction. These differences are likely to impact task/goal
15 agreement, which as we have stated, is a core trans-theoretical feature of successful therapy, and
16 worth exploring further with respect to CFS/ME outcomes.

17 Reme et al [20] also provided evidence that young people with CFS/ME experience the main LP
18 simple practical technique (the 'mat work') as helpful. While LP has elements that address
19 cognitions, the main technique explicitly targets affective/physiological shift while bypassing
20 cognitions in a way that does not feature in SMC approaches to paediatric CFS/ME, using
21 visualisation, compassionate self-coaching and kinetic elements drawing on somatic learning
22 approaches [65], towards this aim. Compassion-focused therapies such as acceptance and
23 commitment therapy (ACT) similarly foster self-soothing of emotions and avoidance of engaging
24 with cognitions [66,67] and ACT has also shown promise in treating CFS/ME. A recent study showed

1 a 3.5-week ACT program reduced fatigue and increased quality of life in CFS/ME patients [68],
2 though the mechanism of action remains unclear.

3

4 **Strengths and limitations**

5 This paper is the first to explore key similarities and differences between the Lightning Process
6 and NHS Specialist Medical Care approaches for treating paediatric CFS/ME and its strength lies in
7 illuminating core features of the LP approach in the context of established NHS therapies. We
8 selected a recommended intervention reporting template (the TIDieR template) [26] to structure
9 our presentation of the key intervention elements to enable clear comparisons. We recognise that
10 interpretation and selection of intervention elements to report in a paper such as this can be
11 influenced by author backgrounds (a limitation of any such paper). In consideration of this,
12 consultation with practicing specialist NHS paediatric CFS/ME clinicians and LP practitioners (and
13 their inclusion as co-authors) ensured a balanced approach across the interventions of interest and
14 clinical expertise represented,. We acknowledge that including the designer of the LP (PP) may have
15 influenced the presentation of LP compared to SMC approaches as designers of GET, AM or CBT
16 were not involved. However, LP is less understood than CBT and behavioural treatments with far
17 less literature, and we chose to include PP to enable a full check of understanding to strengthen the
18 presented comparison. A limitation is that SMC clinicians came from one South West UK service
19 which may have limited the discussion on generalised SMC approaches, though the service is the
20 largest in the UK and follows national treatment guidelines.

21 The SMILE Trial, which inspired this further exploration of LP, gave impressive results of LP
22 improving outcomes for young people with CFS/ME. However, a limitation of the trial is that patient
23 and parent preference influenced families' willingness to consider participation [69] [70], and the
24 trial was relatively small, so the results may not be applicable to all. Those who had LP had SMC
25 simultaneously, and the LP has not been tested in a trial as a standalone treatment. SMILE Trial

1 participants reported conflicting activity advice between SMC (e.g. initial activity reduction then
2 very gradual increase) and LP (e.g. immediately start returning to normal such as attending school),
3 and had to navigate these themselves [71]. Therefore more research is needed before LP should be
4 recommended within the NHS.

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

11

12 **Research recommendations.**

13 We recommend the following areas for future research: i) Conducting a large-scale clinical trial
14 comparing LP alone against CBT-F for treating paediatric CFS/ME and including measures of
15 candidate mechanisms of intervention effects (e.g. therapeutic alliance, readiness to change,
16 treatment engagement/belief in the model, attention shift, goal agreement); ii) Conducting trials to
17 test adding distinct elements of LP to SMC approaches to explore effectiveness (e.g. training SMC
18 therapists in LP language style; provision of physiological rationale for all treatment elements;
19 compassionate self-coaching and visualisation for shifting affect/physical state); iii) Exploring in
20 detail interactions between practitioners and young people within interventions, with a particular
21 focus on the LP language coaching and how this might impact recovery from CFS/ME. A
22 conversation analysis of audio-recordings of LP sessions is underway.

23

1 **Conclusion**

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

7 **Data availability statement:**

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

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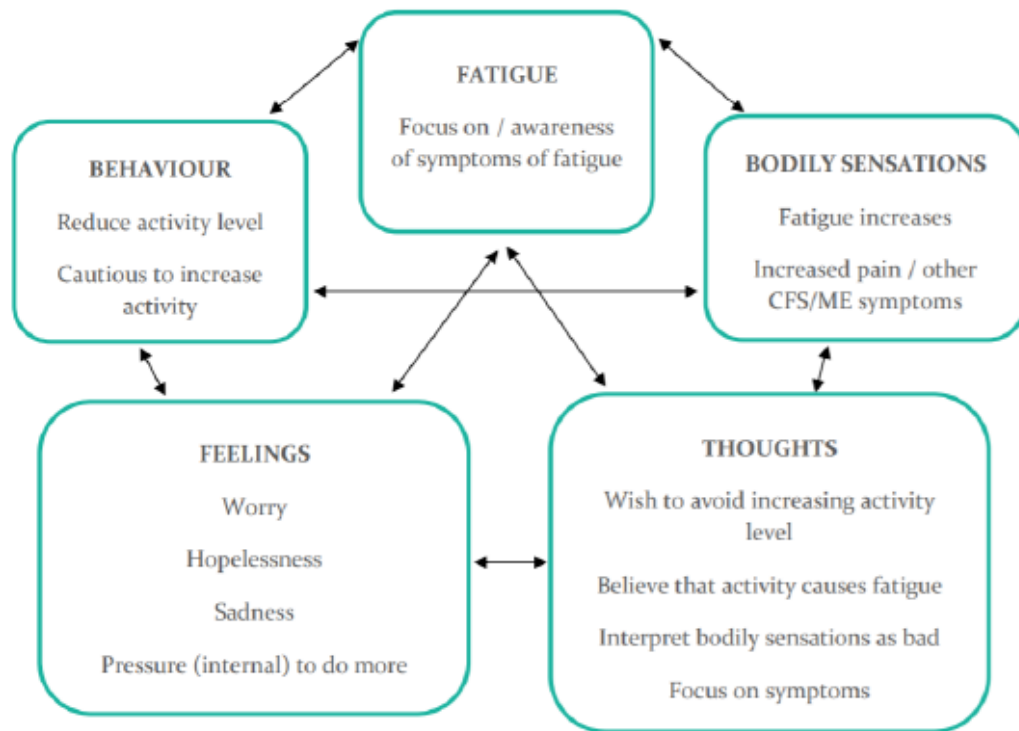
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6

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



1

LP: The 'mat work'	'STOPP' (CBT in a nutshell)
<ul style="list-style-type: none"> • Self-monitoring of thoughts/conversations (recognising 'the pit') • Thought stopping: Actively saying "stop!" with taught (arms/body) stop motion • Active choice (between 'the pit' and the 'life I love'); verbalising this • Verbal compassionate self-affirmation ("well done, you are a powerful genius...") • Verbal self-coaching: "What do you want?" (i.e. what state do you want to be in) and "How will you achieve this?" • 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. 	<ul style="list-style-type: none"> • Stop – say this to self and pause for a moment • Take a breath – calms the physical reaction (emotion/adrenalin); focusing on the breath reduces focus on distress and enables more rational thinking • Observe – thoughts and focus, sensations, what reacting to • Pull back – gain perspective. Consider other possible views of the situation • Practise what works/Proceed – choose the best course of action

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

2

3

TABLE 1: Comparison of mode of delivery

	Name of intervention/ treatment:	LP Lightning Process	CBT-F Cognitive Behavioural Therapy for Fatigue	GET Graded Exercise Therapy	AM Activity Management
WHO PROVIDED	Practitioner characteristics	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	Physical or informational materials used	LP audio/book (pre-course) Handouts (during course, including information for friends/family) Graduation CD (post course)	Activity diaries Some written CBT material may be provided or generated within sessions	Activity diaries Information leaflets e.g. about sleep, activity	
HOW	Mode of delivery (group/ individual/ face-to-face/ other)	One-to-one via telephone (pre and post-course) Group course - one practitioner usually with 3-4 attendees 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) 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) Online delivery of treatments is available for individuals and families within some NHS services	
WHERE	Location and access	Usually non-clinical setting Usually accessed by self-referral (online form) and client payment for the course.	Usually NHS clinic Usually accessed by GP referral with no payment required by the patient	Usually NHS clinic Usually accessed by GP referral with no payment required by the patient	
WHEN AND HOW MUCH	Duration, intensity and frequency	Telephone assessment and coaching (pre-course): usually 2 phone calls Main course: 4 hours/day on 3 x consecutive days plus: 3 hours post-course available as phone calls (e.g. 3x1hr calls/more frequent, shorter calls)	≥6 x weekly/fortnightly 1-hour sessions with follow-ups as clinically necessary	≥6 x weekly/fortnightly 1-hour sessions with follow-ups as clinically necessary	
TAILORING	Tailoring	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

Name of intervention/ treatment:		LP Lightning Process	CBT-F Cognitive Behavioural Therapy for CFS/ME	GET Graded Exercise Therapy	AM Activity Management
WHY	Conceptualising the problem	<p>Illness model of: Neurological / physiological stress response</p> <p>Specifically</p> <ul style="list-style-type: none"> Elevated state of alertness and persisting activation of the sympathetic nervous system Some recognition that secondary mental focusing may also reinforce unhelpful neurological pathways 	<p>Illness model of:</p> <ol style="list-style-type: none"> 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) Symptom focus and fear avoidance. 3) Sleep dysregulation exacerbates fatigue <p>Specifically:</p> <ul style="list-style-type: none"> Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement Fatigue and muscle pain lead to activity avoidance Resting more = deconditioning (can exacerbate symptoms) 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. Combined with increased focus on symptoms = fear of activity (might exacerbate symptoms) Fears that symptoms = severe illness = further reductions in activity. 	<p>Illness model of:</p> <ol style="list-style-type: none"> 1) Boom and bust pattern of activity based around physical exercise. 2) Sleep dysregulation exacerbates fatigue <p>Specifically:</p> <ul style="list-style-type: none"> Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement 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>Illness model of:</p> <ol style="list-style-type: none"> 1) Boom and bust pattern of activity based around all types of activity (including physical, cognitive, emotional) 2) Sleep dysregulation exacerbates fatigue <p>Specifically:</p> <ul style="list-style-type: none"> Overexertion on days when feel more able overloads ability and patient suffers payback on subsequent days. Cycle continues without improvement) 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.
	Basic model of illness maintenance/ problem	Primarily physiology (implicit behavioural and cognitive maintenance elements, though the LP would not use these terms)	Physiology + Behaviour + Cognition	Physiology + Behaviour	Physiology + Behaviour
	Goal of intervention	<ul style="list-style-type: none"> Explicitly described as restoring neurophysiological functioning Equip client with affective state management techniques Implicit goals are to switch to positive mental focus and belief that wellness can be achieved (akin to self-efficacy) by stopping 'physiological spirals' 	<ul style="list-style-type: none"> Equip patient with behavioural and cognitive techniques Activity regulation – break boom and bust cycle (achieve manageable activities and re-increase to normal levels and pattern). Regulate sleep pattern Cognitive shift away from illness fears limiting activity 	<ul style="list-style-type: none"> Equip patient with behavioural techniques Activity regulation – break boom and bust cycle of physical activity/exercise (achieve manageable activities and re-increase to normal levels and pattern). Regulate sleep pattern 	<ul style="list-style-type: none"> Equip patient with behavioural techniques 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). Regulate sleep pattern

Name of intervention/ treatment:		LP	CBT-F	GET	AM
		Lightning Process	Cognitive Behavioural Therapy for CFS/ME	Graded Exercise Therapy	Activity Management
WHAT	<p>Main ingredients of intervention</p> <ul style="list-style-type: none"> • Explanation of illness maintenance model (as above) + explanation of brain neuroplasticity and the concept of excellence (can be taught) • Language and focus shift: <ul style="list-style-type: none"> - Switch from passive to active language in relating to illness - Positive filtering - Stop symptoms focus – switch to positive focus • Technique rehearsal (with kinetic elements – standing in different positions for each step) the ‘mat work’: <ul style="list-style-type: none"> - Self-monitoring of thoughts - Thought stopping (with arm and body posture change) - Compassionate self-affirmation, and self-coaching - Visualisation for affective/ physiological state change • Goal setting (positive, solution-focused) – taking immediate action to show change using technique; reflecting on previous goal success (in group) <p>Specific elements of intervention (below):</p>	<ul style="list-style-type: none"> • Explanation of illness maintenance model (as above) • Behavioural treatment (primary focus): structuring of daily rest, sleep and activity, to 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 • Cognitive treatment: Assessment of illness beliefs and coping strategies, collaborative challenging of unhelpful beliefs about symptoms and activity (as they come up). • Goal setting and reflection on previous goals (successes, challenges) with practitioner; collaborative problem-solving 	<ul style="list-style-type: none"> • Explanation of illness maintenance model (as above) • Behavioural treatment: Establishing manageable baseline of physical activities (only) – usually begins with reduction of activities • Planned incremental increases in physical activity – on basis of physiological tolerance • Bed and wake time anchoring to establish more normal routine. Cutting out daytime sleeping 	<ul style="list-style-type: none"> • Explanation of illness maintenance model (as above) • Behavioural treatment: Establishing manageable baseline of all activities, including cognitive and physical, social and emotional – usually begins with reduction of activities • Planned incremental increases in activity on basis of tolerance • Bed and wake time anchoring to establish more normal routine. Cutting out daytime sleeping 	
	<i>Monitor & stabilise activity (usually starts with activity <u>reduction</u>) then increase incrementally</i>	N	Y	Y	Y
	<i>Planned increases in activity</i>	Y – immediate increase based on client’s ability to experience physiological change and expanded sense of what is achievable	Y – gradual	Y – gradual	Y – gradual
	<i>Specific encouragement of aerobic exercise</i>	N	N	Type of physical activity negotiated with patient: gentle, manageable activity encouraged, not necessarily aerobic.	N
	<i>Direct challenge of unhelpful illness beliefs</i>	Y (beliefs questioned and discussed)	Y	N	N
	IMPLICIT/ EXPLICIT MECHANISMS OF EFFECTIVENESS	Language and focus shift leads to neurological change which brings improved physiology enabling increase in activity	Changing patterns of thoughts and behaviours that maintain fatigue leads to change in fatigue (and also in feelings)	Changing patterns of behaviours that maintain fatigue leads to change in fatigue	Changing patterns of behaviours that maintain fatigue leads to change in fatigue