



# Qualitative study of the acceptability and feasibility of acceptance and commitment therapy for adolescents with chronic fatigue syndrome

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## ABSTRACT

**Background** Paediatric chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is disabling and relatively common. Although evidenced-based treatments are available, at least 15% of children remain symptomatic after one year of treatment. Acceptance and commitment therapy (ACT) is an alternative therapy option; however, little is known about whether it is an acceptable treatment approach. Our aim was to find out if adolescents who remain symptomatic with CFS/ME after 12 months of treatment would find ACT acceptable, to inform a randomised controlled trial (RCT) of ACT.

**Methods** We recruited adolescents (diagnosed with CFS/ME; not recovered after one year of treatment; aged 11–17 years), their parent/carer and healthcare professionals (HCPs) from one specialist UK paediatric CFS/ME service. We conducted semi-structured interviews to explore barriers to recovery; views on current treatments; acceptability of ACT; and feasibility of an effectiveness RCT. Thematic analysis was used to identify patterns in data.

**Results** Twelve adolescents, eleven parents and seven HCPs were interviewed. All participants thought ACT was acceptable. Participants identified reasons why ACT might be efficacious: pragmatism, acceptance and compassion are valued in chronic illness; values-focused treatment provides motivation and direction; psychological and physical needs are addressed; normalising difficulties is a useful life-skill. Some adolescents preferred ACT to cognitive behavioural therapy as it encouraged accepting (rather than challenging) thoughts. Most adolescents would consent to an RCT of ACT but a barrier to recruitment was reluctance to randomisation. All HCPs deemed ACT feasible to deliver. Some were concerned patients might confuse 'acceptance' with 'giving up' and called for clear explanations. All participants thought the timing of ACT should be individualised.

**Conclusions** All adolescents with CFS/ME, parents and HCPs thought ACT was acceptable, and most adolescents were willing to try ACT. An RCT needs to solve issues around randomisation and timing of the intervention.

## INTRODUCTION

Paediatric chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is relatively common (prevalence 0.55% across

## What is known about the subject?

- Not all young people with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) recover.
- Acceptance and commitment therapy (ACT) is a possible alternative therapy for CFS/ME, which focuses on improving functioning and quality of life rather than symptom reduction.
- ACT is efficacious in paediatric chronic pain, and preliminary results show promising effects in adults with CFS/ME.

## What this study adds?

- ACT is an acceptable therapy for young people with CFS/ME.
- Participants thought the 'pragmatic', 'compassionate' and 'values-based' focus of ACT would be helpful.
- Adolescents, parents and healthcare professionals support a randomised controlled trial of ACT.

community, primary care and hospital populations)<sup>1</sup> and can be severely disabling with persistent fatigue, chronic pain, postural instability and cognitive dysfunction.<sup>2</sup> It negatively impacts on children's emotional,<sup>3–5</sup> educational<sup>6</sup> and social functioning.<sup>7</sup> Despite specialist treatments (cognitive behavioural therapy-for-fatigue (CBT-f), activity management (AM) and graded exercise therapy (GET)), at least 15% of children with CFS/ME remain symptomatic after one year of treatment.<sup>8</sup> Alternative treatment approaches are needed.

Acceptance and commitment therapy (ACT) is an approach used in related conditions in children.<sup>9,10</sup> A randomised controlled trial (RCT) in paediatric chronic pain suggests ACT is better than standard care at improving functional disability and health-related quality of life,<sup>11</sup> and recent WHO



guidelines recommend ACT for treating chronic pain in children.<sup>12</sup> Studies of ACT in CFS/ME have focused on adults. One feasibility study in 40 adults with CFS/ME showed ACT resulted in sustained improvements in CFS/ME-related disability at 6 months.<sup>13</sup>

ACT offers a similar but different approach to CBT-f.<sup>14</sup> Differences include: focussing on improving functioning and quality of life by aligning behaviour with chosen values, rather than reducing symptoms; stepping away from thoughts (cognitive defusion) rather than challenging them; and acting presently in the moment at whatever current functional capacity is possible (psychological flexibility).<sup>15 16</sup>

We aimed to determine if ACT is an acceptable treatment approach for adolescents who remain symptomatic after 12 months of treatment, and whether it would be an acceptable intervention for an effectiveness RCT of ACT.

## METHODS

### Design

A qualitative study using a truth and reality-oriented approach<sup>17</sup> to provide a real-world, multi-perspective view on ACT and a potential RCT of ACT versus treatment-as-usual.

### Recruitment

Participants were recruited from one UK specialist paediatric CFS/ME service. It was not deemed feasible to contact all eligible participants in the service, so sampling was opportunistic that is, individuals who had clinic appointments with a clinician or therapist in the CFS/ME service within the recruitment timeframe were approached. Inclusion criteria: adolescents (11–17 years) with CFS/ME,<sup>2</sup> not recovered after one year of treatment (ie, ongoing care with the service); their parents; CFS/ME healthcare professionals (HCPs). Eligible participants were approached in clinic, given information leaflets and, if interested, provided consent to be contacted by the study lead (PC) who answered any questions and consented them into the study. Parents were eligible if their child was eligible and consented to participate. They were recruited alongside their child. HCPs were given information leaflets in a team meeting and via email, and if interested, consented into the study by contacting the study lead (PC).

### Data collection

Semi-structured interviews and one HCP focus group were undertaken (PC) February to September 2020 until data saturation was achieved.<sup>18</sup> Participants were interviewed at home, the CFS/ME service or over Skype. From March 2020, all were over Skype due to the COVID-19 pandemic. Adolescents and parents were asked to be interviewed separately but were given the option to be together.

Topic guides (see online supplemental material) were developed with psychologists (JS, AL), a qualitative

researcher (RMP), clinician (EC) and Young Person Advisory Group. Questions explored: treatment needs; acceptability of ACT; and trialling ACT. HCPs were asked additional questions on delivering ACT. Interviews were checked with an experienced qualitative researcher (RMP) to adapt topic guides, and monitor and improve interview technique. A standardised easy-to-understand explanation of ACT called 'James' Story' (written by JS and AL) was provided written and orally to participants before and during the interview. It highlights the key elements of ACT and how it differs from CBT-f that participants may be more familiar with (see online supplemental material).

### Analysis

Interviews were recorded, transcribed, anonymised and imported into qualitative data-management software NVivo (PC). Notes were made during interviews. Transcripts were analysed using thematic analysis<sup>19</sup> to identify patterns within the data. Transcripts were double-coded (CL, AL, JS, JL) and disagreements discussed. Deductive coding was used to create a coding framework around the pre-existing 'sensitising concepts'<sup>20</sup> of overarching themes 'ACT acceptability' and 'trailing ACT'. Inductive coding was then used to derive codes from participants' own words to provide more detail and generate subthemes. Data were checked between participants to explore the range of views.

## RESULTS

### Participants

We interviewed 30 participants (online supplemental table 1): 12 adolescents (10 were female; age=12–17 years, median=15.5 years; in the service for 2–5 years) and 11 parents (10 were mothers; one was the parent of two adolescents). Of 14 adolescents approached, one declined to participate, one was ineligible. Three child-parent dyads were interviewed together, the remainder separately. We interviewed seven HCPs (clinicians, psychologists, physiotherapists and occupational therapists). Five took part in a focus group, two were interviewed individually. Interviews lasted 30–110 min.

### Thematic analysis

Table 1 summarises our results. Illustrative quotes are presented throughout. 'ID-a' denotes adolescents, 'ID-p' parents and 'ID-h' health professional.

### Acceptability

#### *Extra possibility for those struggling*

All 30 adolescents, parents and HCPs said ACT would 'have value' (ID-a). Adolescents saw it as an 'extra possibility' (ID-a) for managing CFS/ME, especially for those struggling. They felt therapy options were lacking, therefore an alternative treatment provided hope. HCPs welcomed ACT, agreeing 'it'd be great to offer something else' (ID-h).

**Table 1** Results describing views on ACT and a potential trial presented as themes and subthemes

	Deductive themes	Inductive subtheme
Views on ACT	Acceptability	An extra possibility for those struggling
		Better than CBT-f
		Not suitable for everyone
Views on a trial	Barriers and facilitators to trial recruitment	Attitudes toward research
		Treatment fatigue
		Reluctance to be randomised
Views on ACT	Feasibility	Accepting the word 'acceptance'
		No more difficult to deliver but need specific training
		Timing of delivering ACT should be individualised
Views on ACT	Reasons why ACT could be efficacious	Pragmatism, acceptance and compassion are valued in chronic illness
		Cognitive defusion is less tiring but difficult to achieve
		Focussing on values helps to 'get through'
		Addressing both psychological and physical needs
Views on ACT	Reasons why ACT could be efficacious	Normalising difficulties is a beneficial life skill

ACT, acceptance and commitment therapy; CBT-f, cognitive behavioural therapy-for-fatigue.

What do we do with the kids who don't recover? It's a really big issue ... (ID-h)

Ten of the 12 adolescents reported they would try ACT. Although, some were cautious because they were not 'the biggest fan[s] of change', they thought it was 'worth trying' (ID-a) if it provided a new possibility for treatment. Two participants said they would not try ACT because they did not need the treatment and would be 'wasting a space for someone who needs it' (ID-a) but recognised it could have been helpful for them earlier in their illness. See online supplemental table 2 for quotes.

#### *Better than CBT-f*

Two participants who had already received ACT thought it was more acceptable than CBT-f because it was 'more gentle and kinder' (ID-p), which was important for managing pain and fatigue. One adolescent found it 'impossible' (ID-a) to challenge thoughts in CBT-f because of the cognitive effort required, so preferred the 'values' and 'person-centred' focus in ACT.

CBT makes you feel like you're constantly being challenged whereas ACT just feels like it's more accepted

[...]whereas CBT is trying to push you back into your old [life] despite now having a chronically ill body. (ID-p and ID-a)

Others preferred ACT over CBT-f because it offered a 'bigger picture' and 'journey approach' (ID-p). One participant thought CBT-f was too focused on 'nitty-gritty' (ID-p) anxieties and could leave adolescents stuck in the past. They preferred how ACT, compared with CBT-f, has 'goal setting' and 'practical elements [...] focussed on values [...] to move forwards in a positive direction about looking at what motivates people' (ID-p).

#### *Not suitable for everyone*

Parents said ACT sounded 'scary' (ID-p) or 'confrontational' (ID-p) for younger or timid children to dismiss thoughts (cognitive defusion), rather than challenge them. In contrast, some adolescents felt this fear could be overcome: 'Just the initial thought is quite scary but then after some time working on it would be okay' (ID-a). The emotional engagement required for discussing values was felt 'too challenging for some people [because] talking about stuff that's really important could upset them' (ID-a). Some questioned whether ACT was sufficiently CFS-focussed: '[ACT is for] anxiety and depression ... I'd like to be explained why it would be helpful in CFS' (ID-a).

#### *Accepting the word 'acceptance'*

HCPs had concerns parents might think ACT means 'you've just got to deal with it' (ID-p) and misunderstand ACT to be about 'where you're at now' (ID-h), whereas it is 'more about where you're going, it's still about moving things forward just through a slightly different approach.' (ID-h). In their experience, parents were always searching for treatments and may find it hard to accept therapy advocating acceptance so thought the word 'acceptance' needed clarification.

It's being really clear about what we mean by acceptance ... that acceptance [is] of thoughts and commitment to that bigger life in terms of your values ... but I think sometimes when people hear that word 'acceptance' it can feel like just putting up with things. (ID-h)

#### *Feasibility*

##### *No more difficult to deliver but need specific training*

All HCPs felt it would be feasible to deliver ACT as it wasn't 'any more difficult' (ID-h) than current psychological therapies and is currently being used, just 'less formally and without a label' (ID-h). However, a need for specific training was identified because 'CBT is a part of core training but ACT isn't' (ID-h).

##### *Timing of delivering ACT should be individualised*

However, HCPs disagreed about *when* ACT should be offered or delivered. Some said at 12 months was not appropriate because patients may not have attended

sufficient appointments by 12 months due to waiting times: '[treatment] is a year but our actual clinical contact with them is probably only six months' (ID-h). They felt ACT would be more suitable for those 'stuck' (ID-h) after initial treatments, regardless of how long that took. Others felt ACT would be 'beneficial from the get-go' (ID-h) and should be offered from the beginning, not only at 12 months.

Adolescents' opinions differed about whether ACT should be delivered after or alongside current treatments. For some, 'doing the activity management and CBT [simultaneously] was too much' (ID-p), especially while coming to terms with the diagnosis and 'losing' their former life. Other adolescents reflected how their mood was inevitably affected by CFS/ME and thought psychological treatment alongside AM/GET would be useful. Adolescents and parents repeatedly described the importance of preventing comorbid mood disorders in CFS/ME.

[CFS/ME] should be looked at more holistically and [ACT] offered not just if you're struggling with your mental health but more as a starting point. (ID-p)

All participants agreed that the decision *if* and *when* to offer ACT should be a clinical decision 'on an individual basis' (ID-h) because 'everyone's different, [...] what suits one person doesn't suit another' (ID-p).

#### Reasons why ACT could be efficacious

##### *Pragmatism, acceptance and compassion are valued in chronic illness*

Participants talked about ACT being pragmatic, realistic and accepting. They noted how thoughts and feelings around CFS/ME were valid and grounded in true events or understandable anxieties, so it was unhelpful to challenge thoughts by 'changing being chronically ill to a happy thought' (ID-a). Adolescents felt compassionate acceptance was a more appropriate approach for managing the loss and grief associated with CFS/ME, than 'constantly telling them to challenge feelings and distract themselves from [thoughts]' (ID-p).

##### *Cognitive defusion is less tiring but difficult to achieve*

Some adolescents expressed stepping away from thoughts (cognitive defusion) was a good tactic for dealing with negative cognitions and 'get on with stuff' (ID-a) because constantly filtering negative thoughts exacerbated fatigue. However, some thought dismissing thoughts was too difficult. They were unsure how to subsequently deal with dismissed thoughts: 'I'd be all ... what ... like where ... what am I supposed to do with [the thought] ... just leave it?' (ID-a).

##### *Focusing on values helps to 'get through'*

Adolescents described losing 'core values' (ID-a) and thought ACT's focus on values would be useful. They

liked the practical element of committed action to values to help them 'get through' their illness (ID-a).

##### *Addressing both psychological and physical needs*

Families felt ACT recognised the wide-ranging health and social impacts of CFS/ME. Adolescents liked ACT's holistic 'universal' (ID-a) approach to addressing both their 'psychological condition, but also [ACT] helps you accept your physical one too' (ID-a).

##### *Normalising difficulties is a beneficial life skill*

Parents thought that 'normalising difficulties' in ACT was helpful to understand worries and setbacks as part of 'the human condition' (ID-p) and felt that 'we would all benefit from' (ID-p) these life skills. HCPs agreed that normalising difficulties is especially important for managing CFS/ME in teenagers because they 'struggle with feeling weird and unique' (ID-h).

See online supplemental table 3 for illustrative quotes for theme 3.

#### Barriers and facilitators of trial recruitment

##### *Attitude toward research*

Seven of ten adolescents who said they would try ACT, said they would consent to an RCT. A key facilitator to recruitment was appreciating benefits of research. Participants expressed wanting to help others, even if the trial didn't benefit them directly: 'it's not necessarily doing it for right now, it's doing it for the longer-term' (ID-p). Five participants had previously participated in trials, so had insight into research involvement.

##### *Treatment fatigue*

Two adolescents said they would not consent to an RCT because they felt de-motivated and new treatments were 'passed [them] now' (ID-a). HCPs also recognised that some might feel negative about another treatment because they 'had tried everything' (ID-h).

##### *Reluctance to be randomised*

Most understood randomisation was necessary for a trial. However, some were reluctant, stating that one RCT arm would suit them better, so if they got the opposite arm it might affect their engagement or belief in treatment efficacy. While most parents also agreed to randomisation, one would prefer if their child could 'have the chance to do the other [arm] afterwards [...] so if [they] can [receive] both [treatments], then that would be ideal' (ID-p). Similarly, adolescents who found randomisation unacceptable said they might take part if they could subsequently receive the therapy they had not received in the trial.

See online supplemental table 4 for illustrative quotes for theme 4.

## DISCUSSION

All participants said ACT was acceptable, and most adolescents would partake in an RCT. Parents and adolescents

thought ACT was suitable for those with persistent CFS/ME symptoms because of its pragmatic and compassionate approach. Issues with delivering ACT and an RCT were discussed, including: extra training required for psychologists; timing of when ACT should be offered and concern that patients might confuse ‘acceptance’ with ‘giving up’.

Strengths of this study include: multi-perspective views from three participant groups; interviewing adolescents with a variety of ages and illness durations; good engagement (only one adolescent declined to participate); and recruiting from the pool of adolescents who would be eligible for an RCT. Limitations are that: participants provided opinions based on information about what ACT would involve rather than actually undergoing treatment; participants were likely biased toward being engaged in treatment and research which could overestimate acceptability of ACT and the proportion who would consent to a trial; few (four) males were interviewed; not all eligible patients in the service were contacted as sampling was opportunistic; and recruitment was from one UK paediatric specialist CFS/ME service, so results may not be generalisable to all eligible patients, males or other centres.

Our findings are consistent with results from a feasibility study with adolescents with functional somatic syndromes, where 90.5% completed group-based ACT and all would recommend it to a friend.<sup>21</sup> In our study, some adolescents appeared to have a treatment preference for ACT or treatment-as-usual. This should be borne in mind when designing a trial.

Our study found that participants wanted pragmatic and values-focussed strategies in treatment, which is consistent with research on ACT in paediatric chronic pain,<sup>9</sup> where the core elements of ACT (ie, ‘functional contextualism’<sup>22</sup> to facilitate behaviour in line with personal values and goals<sup>15</sup>) have demonstrated efficacy.<sup>23</sup> Adolescents highlighted the loss of their core-values during their illness, so perhaps values-based treatment serves as a motivational factor.<sup>24</sup> They said a compassionate approach was also needed to address the grief and loss of sense-of-self which is common in CFS/ME.<sup>25</sup> Similarly, they expressed the need for treatment that validates their thoughts, rather than challenges them. This is a key difference between how ACT and CBT-f approach cognitions<sup>14 15</sup> and might be why some participants said they preferred ACT to CBT-f. While CBT-f also enhances acceptance,<sup>26</sup> its centrality in ACT is unique.

Comparable to adult CFS/ME literature,<sup>26–30</sup> our study identifies ‘acceptance’ as fundamental for being able to enjoy life while affected by CFS/ME. Although this is common to chronic illness,<sup>31</sup> CFS/ME presents particular challenges related to stigma, contested diagnosis and uncertain aetiology.<sup>32</sup> In adults, it has been suggested that acceptance should be targeted before commencing other treatment, to maximise clinical benefit,<sup>27</sup> aligning with opinions of some participants in this study who

proposed ACT should be offered at the beginning of treatment.

## CONCLUSION

This work suggests ACT is acceptable and most adolescents and parents would consent to randomisation for an RCT. Given patients and HCPs feel there is a lack of options for those who have not yet fully recovered after receiving currently evidenced treatments, we recommend further work to develop a pilot study of ACT to inform an effectiveness RCT. Issues raised for designing an RCT of ACT included: extra training required for psychologists; clear explanations to patients and parents that ‘acceptance’ is not synonymous with ‘giving up’; timing of when ACT should be offered; and consideration of trial design as some adolescents had a treatment preference for ACT versus treatment-as-usual.

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**Contributors** EC (MBCbB, PhD) conceptualised the study. EC, PC (MBBS, BSc), AL (PhD), JS (PhD) and RMP (PhD) contributed to study design. PC conducted data collection, data analysis and interpretation, and wrote the manuscript. CL (MA, BSc), AL, JS, RMP and JL (MBBS, MSc, MSc) contributed to data analysis. All authors were involved in revisions of the manuscript and have approved it for submission.

**Competing interests** EC acts as a non-paid medical advisor for the Sussex and Kent ME society.

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**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. Qualitative data can be requested provided the request does not breach anonymity protocol.

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## Supplementary Material: Tables

**Table S1:** Participant IDs

ID	Child, parent or HCP
01	HCP
02a	Parent
02b	Child
03	HCP
04a	Parent
04b	Child
05a	Parent
05b	Child
06a	Parent
06b	Child
07	HCP
08	HCP
09	HCP
10	HCP
11a	Parent
11b	Child
12a	Parent
12b	Child
13a	Parent
13b	Child
14	HCP
15a	Parent
15b	Child
16a	Parent
16b1	Child
16b2	Child
17a	Parent
17b	Child
18a	Parent
18b	Child

Key: a=parent, b=child; HCP=healthcare professional

**Table S2:** Illustrative quotes for theme 1 on participant views on acceptability of ACT and whether they would try it.

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**Adolescent participants who expressed they would try ACT (or had already)**

*"I think it would be interesting ... like actually do it, and see what it's like doing it." (ID02b)*

*"Quite, like useful because it can like, because the therapy might get those thoughts and like accepting them, like you said and like being able to like do what you want even with those thoughts. [...] I think it might have been helpful before I was starting back at school because I used to think that I'd never be able to go back to school." (ID04b)*

*"I think ACT is a good idea... I know my psychologist uses part of ACT [...] I think ACT is a really good way of looking at it rather than just saying you shouldn't do this, you shouldn't feel like that. I think it's a quite good approach towards it." (ID12b)*

*"I think it has been useful [...] I think it's quite a healthy way of working [...] I've found yeah I definitely really prefer it to the CBT." (ID13b)*

*"I think that it would, that there'd be no harm in trying it and I feel like that it would maybe or give the opportunity for help." (ID15b)*

*"Yeah, definitely. I think it sounds really useful. Especially for people that are like coming out of it, because there's not really... I don't know if there's kind of like a therapy for like people that are like nearly out of it, like... like pretty much... like really nearly out of it. So I think it would be really, really useful, yeah. I would try it." (ID16b1)*

*"I think [ACT] sounds like a really good idea because I imagine a lot of people who like really suffer, mentally with it. [...] it sounds like quite a good idea for a lot of people to be honest." (ID16b2)*

*"I think it sounds like a good way to help you get over things ... I know that chronic fatigue does always bring up a lot of like bad thoughts and stuff. So I think that [ACT] is useful for chronic fatigue." (ID17b)*

*"Well, it's worth a shot, it's definitely worth a shot – if it can help me with not only my chronic fatigue but everything else, then it's definitely worth a shot." (ID18b)*

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**Adolescent participants who were nervous and cautious, but said they would try ACT**

*"It would be a very different turn around to going onto something different and I'm not the biggest fan of change...but I guess if there's any kind of possibility of it helping me then I'm not gonna completely go no not doing it.... I think it's worth trying to go ahead with it." (ID05b)*

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<b>Adolescent participants who said they wouldn't try ACT at this point in their illness, but recognised its potential usefulness for others or themselves earlier on in illness</b>	<p><i>"I wouldn't [do ACT] now because I'm like more or less better, it would just be wasting a space for someone who needs it ... but I could understand other people doing it, people who are still struggling."</i> (ID06b)</p> <p><i>"I think personally if it was like a year ago or something, um, but now I feel, because I'm on medications and things I feel like it's kind of given me a more thing of looking at things in a different perspective anyway. But if it was a year ago or something or if it was when I got ill then it definitely, yeah I definitely would have thought about it, it sounds good."</i> (ID11b)</p>
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**Table S3:** Illustrative quotes for theme 3 presenting participants' views on why ACT might be particularly useful or efficacious for adolescents with CFS/ME .

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<b>Pragmatism, acceptance and compassion are valued in chronic illness</b>	<p><i>"I think that compassionate element is what's needed more than the challenging because um you know if someone's feeling so awful that they hurt everywhere to sort of be challenged is really difficult I think and I think that's what's needed with the illness is compassion yeah definitely."</i> (ID05a)</p> <p><i>"I feel like it would be a good way to actually accept it, what's going on. I feel like everyone would, I think everyone would feel more relieved if they accepted it rather than just running away from it."</i> (ID11b)</p> <p><i>"So like some thoughts and things are based on things, they're not just sort of random and unrealistic, they are like real worries and things [...] I like that idea of accepting the thought rather than saying every like anxious thought is wrong [...] ACT is a really good way of looking at it rather than just saying 'you shouldn't do this', 'you shouldn't feel like that' [...] It kind of makes your feelings more valid."</i> (ID12b)</p> <p><i>"yeah, it's unnatural to um like think like try to change your opinion of being chronically ill to like a happy thought, so I think it's definitely better"</i> (ID13b)</p> <p><i>"I think it's quite realistic, like still having chronic fatigue with you. Like you can't just kind of forget about it. It's always going to be there [...] kind of like accepting that it's always going to be there, it might not be present but it's always going to have happened. I think it's like you accept that."</i> (ID16b1)</p> <p><i>"A big thing is the loss that these young people experience and trying to challenge them on this loss with almost maybe a CBT approach actually just with the ACT it feels quite positive to .. You're not fighting it, not necessarily fighting it, but you're not kind of saying you're challenging your thoughts you know it seems like you might be working together a bit and it for a non-psychologist it seems quite a positive way to go."</i> (ID09)</p>
<b>Cognitive defusion is less tiring but difficult to achieve</b>	<p><i>"I think that's a brilliant idea about taking that away and not having to filter them I guess but just stepping back."</i> (ID05b)</p> <p><i>"I think that the thoughts are still gonna be there whatever happens but I think turning away from them ... still acknowledging that they're there but turning away</i></p>

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*from them and realising that you're still gonna have to get on with stuff even if they're there. I think that's quite a good approach to have."* (ID15b)

*"if I could step away from those thoughts, I think it would be helpful, but I don't know if I can."* (ID18b)

*"I feel like it would be quite difficult to just yeah step away from it."* (ID11b)

*"That does worry me slightly, like if I... if I started it like I'd be all... what... like where... what am I supposed to do with it, like how... just leave it?"* (ID12b)

*"Well, a lot of young people overthink very negatively so there's a positive with that"* (ID14)

**Focusing on values helps to 'get through'**

*"I think you should definitely stay focussed on your values because that's something that can get you through [...] by having a focus, not always thinking I have to get rid of this now, but it's your body getting through it to get to your goal".* (ID06b)

*"If you've got something to kind of focus on it always helps me get through certain things especially and yeah having kind of values set down I feel like that would be quite helpful."* (ID11b)

*"In chronic fatigue you do kind of lose some of your core values a little bit. It is quite hard to keep focused on them when you aren't really doing anything. So I feel it's quite good to have a reminder about like what kind of person you are, or like were, or... yeah, were before chronic fatigue. ... because I feel like you probably do shift your values and what you're focusing on quite a lot in chronic fatigue."* (ID16b1)

*"Some of those people seem like or feel like they've lost a lot in their life then maybe that focus on values as a bigger part of therapy is maybe more helpful for those people."* (ID08)

*"I think ACT sounds like it's similar to CBT but actually, perhaps there's a little bit more of a practical element [...] on being focused on values and um trying to move people um move forwards in a positive direction about looking at what motivates people. So I think, yeah, I can see it being positive ... I think it's a bit more like goal-setting so it gives people a focus"* (ID15a)

**Addressing both psychological and physical needs**

*"ACT like I guess it can help psychological conditions, but it also does help you accept your physical one too. So I think it's like more universal"* (ID13b)

*"...someone telling me like how I should be doing things, and then someone more like just to talk about like how I was feeling. So it was like quite good to have like a mix of those."* (ID16b1)

*"I've got... I've definitely got to do... I've definitely got to manage both, like, I can't overdo it mentally and I can't overdo it physically, I've just got to work things out mentally and then just... not... not limit myself, but not... not extremely on the physical side"* (ID18b)

**Normalising difficulties is a beneficial life skill**

*"It seems like we would all benefit from it really. Everybody gets too ahead of themselves and it can take everything away. Whereas you know, to be able to sit back and think well actually "why am I thinking like this"... Any techniques to help that doesn't involve just grabbing a tablet that makes you feel a bit calm is definitely beneficial because once you've learnt those techniques I imagine you can just play them throughout any situation um which is helpful, especially you know again on days when she's frustrated because of pain and tiredness and when she wants to do it but it just feels too much. Um, you know, it's a balance... it sounds more, like almost a bit like a life skill that is something that once you've— It's not just gonna get her over this, it would keep her going. Once you've learnt the techniques you just carry on with those techniques. It's not just "I'm having this because I'm ill" it's a technique that will carry you on through" (ID04a)*

*"it's just important to have a full tool box so instead of just having spanner set that you have the drill set, the saw set and all of that to go with it." (ID12a)*

*"So, I think helping him to understand that, you know, the human condition is that you have worries and things that happen that you don't all... you know, things that you have to live with, that you have to learn." (ID18a)*

*"I think normalising that idea that life will be up and down, rather than think positive all the time.. We evolve to think negatively to keep us safe – if you think you're going to try and cross a road with positive thinking you'll generally get knocked over. I think realism is really important." (ID03)*

*"The bit that sounds really exciting for me, not just for chronic fatigue but any chronic condition, is that actually just saying well you've got a really you're facing some really difficult things there's a technique that can that's been used to help people deal with longstanding difficult situations really, do you want to do you want to sort of try using that? If I was in that situation that would be something that would be of value that I would be up for." (ID01)*

*"I think it's really important that they, that we normalise the feelings that, you know just help them understand that what they're going through, that some of the negativity that they're feeling or frustration, anger, some of the physical anger that they display...throwing phones, punching walls, is actually a normal reaction to a horrible chronic condition, you know, and the losses that they're going through. ... quite a bit of work I do is around normalising... any chronic condition, any physical chronic condition can have a psychological impact." (ID14)*

**Table S4:** Illustrative quotes for theme 4 of participant views on barriers and facilitators of recruitment to a potential trial of ACT

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**Facilitators of recruitment**


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<b>Positive attitudes toward research and a willingness to help others with CFS/ME</b>	<p><i>"I mean it's good that you know it's gonna in the end, it's going to help somebody" (ID2a)</i></p> <p><i>"I just want to try and help a bit with the research of it and hopefully help try and find a cure. I managed to raise about 800 pounds [for a recent CFS/ME charity</i></p>
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event]. And I wouldn't want someone to go through all what I have, so if we can find a cure and they didn't have to" (ID06b)

"I think it's worth trying to go ahead with it and just seeing. It's just trialling it and seeing isn't it." (ID11a)

"I support any research I really do" (ID16a)

"Well, it sounds like it's worth a try and if... if the research the helps children moving forward, then that would be great." (ID18a)

"I'd like to, just to... just to see if it would work, and then it would be able to help out others [...] it's for the future of like, well, just research." (ID18b)

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**Participants understand the need for randomisation as part of a trial**

"If you found you were getting the [treatment trial arm] you'd already done you might be a bit like 'oh (disappointed tone)'. But then again it's all helping isn't it? It's gonna help. And if the trial comes good and the new one looks brilliant then you're there! And if you don't do it you're not gonna get that far, so you know, yeah. As I say, it's um, that's what you're doing when you're taking part and that's why you do it. Um you know it's, like I say, if it helps, then it helps doesn't it? That's the aim. It's not sort of necessarily doing it for help right now, it's doing it for longer term, which these conditions are what they are, they do seem longer term than short." (ID04a)

"well it's a bit like when [name of young person] did [name of trial] because it was either GET or the pathway that she was put on in the trial" (ID05a)

"I've already done one trial and it... that, I don't think it would... there was anything that would really stop me from doing another one [...] I'd be okay with [randomisation] because it's part of the study. I [think] with the [name of trial] one it was random whether you got the graded exercise or the activity management..." (ID12b)

"I mean even if it doesn't necessarily help, like if the [trial arm] you've been put in isn't the most effective, then the findings of the research would help you determine what one would actually be effective" (ID13b)

"Because like maybe one therapy wouldn't work for one person whereas it would work really well for someone else especially if it's randomised. I guess that's the point of the trial" (ID16b1)

"I mean, I suppose it... you know that it's still going to help even if you get one that... you preferred to have one of the treatments over the other one. But I suppose you'd still know that you're helping the trial happen and you still might benefit from it." (ID17b)

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**Barriers to recruitment**

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**Treatment fatigue**

*"I think because I've got stuff that I'm focusing on now and I've actually got stuff to do it's going to make me feel better, I don't want to speak to someone ... no I don't want to talk to anyone else. It's passed me now." (ID06b)*

*"if you're saying you're going to wait until they've not made any progress over a year, they might be pretty demotivated by then, thinking "oh God here's another acronym, what does that stand for?" (ID03)*

*"...[young person] may just buckle at the thought of [another treatment or trial] because she's tried everything and she's been let down by her health so she's probably quite negative about any... I think she would turn down ACT if I offered it to her." (ID14)*

*"I don't know whether there's a bit of a treatment fatigue [...] I think, you know, when you when you're looking at children who haven't recovered. Then, you know, sort of psychologically I'm not quite sure what place, you know, that group are in. So it might be that you have people start it and then not finish it and you know that's not very good for a research project is it." (ID15a)*

**Views of participants reluctant to be randomised** because they would: **(a)** want to choose which treatment arm would work better for them (ACT vs. supportive pathway), or **(b)** receive both ACT and the supportive pathway.

**(a)**  
*"If you've like already read about ACT and like you already want to do ACT and then you find out that you're not doing it, it could like make it, the other treatment, like maybe they'll think it's worse and not even try to do it." (ID04b)*

*"if you get one [trial arm] and you were hoping for the other [trial arm] and you feel like the other one would have worked more, that might be difficult, because obviously the other one (referring to the supportive pathway control trial arm) is like check-up every like once a year, so that would work better for me ... but the other one where you're talking to someone constantly, that wouldn't be right for me." (ID06b)*

*"I think having a choice would probably be better because you could think of what would be best for you and do that rather than just being put in it whether you like it or not." (ID15b)*

**(b)**  
*"I would wonder whether the [trial arm] my child was given was the right one for my child and if it isn't, whether I would have the chance to do the other [trial arm] one afterwards... Just to make sure that they get the best treatment that they possibly can... Because I... as important as research is so is my child getting better [...] I think putting [patients] on the two [treatments] would make sense but obviously that doesn't help you with your research [...] I think you also need a third [arm or option], which is to combine the two [treatments] together [to see] if that's more effective [...] so if you can achieve both [treatments] then that would be my ideal" (ID12a)*

*"I just guess having the opportunity to switch [trial arm] if it doesn't get better for them." (ID11b)*

## Supplementary Material: Vignette and Topic Guide

### The easy-to-understand explanation of ACT as provided to participants:

#### James' Story

James was struggling with worries about going back to school. He thought everybody would stare at him and talk about him when he walked into class, and that it would be so scary he wouldn't be able to say anything if the teacher picked on him. James was so worried about this, he couldn't sleep for the whole week before going back to school.

#### [In a CBT session:](#)

His therapist Sarah helped him to *challenge* these worries. She helped him to see that his worries might not be realistic. Sarah encouraged James to think:

"How likely is it that people might stare at you?"

"What else might people at school be thinking about?"

"What advice would you give a friend, if they were worried about this?"

James talked about these things with his therapist Sarah and was gradually able to see that maybe it wouldn't be as bad as the thoughts predicted. He was able to challenge the thoughts and come up with some more realistic, calmer alternative. He felt a bit less worried about going into school.

#### [In an ACT session:](#)

James' therapist Sarah helped him to see that he didn't need to pay attention to his worried thoughts. Instead she suggested that James focused on what was really important to him; getting back to school. Sarah encouraged James to think:

"Why do I want to go back to school?"

"How can I make sure I'm a good friend to people, no matter what my worries are about what they think of me?"

"What can I think about instead to shift my attention from my worries?"

James talked about why going back to school was so important for him, and he was able to make a good plan to follow. He was able to see that he didn't need to listen to his thoughts, or to work out whether they were right or wrong. He followed the plan, and was able to reach his goal of going to school, despite still feeling a little worried.

## Topic Guide for Adolescent interview:

This topic guide details the areas that will be covered in the qualitative interviews. The interviewer may ask additional questions during the interview to clarify information. The questions may be minimally adapted throughout the process of interviewing as observations or alternate questions arise.

### 1. Introductions

Explain we are talking to children and young people with CFS/ME who have not yet fully recovered after their initial treatment to help find alternative treatments.

### 2. Interview topics

#### 2.1 Treatment to date

**Can you tell me about the treatment you've had for your CFS so far?**

Prompts: Who have you seen - a physio? psychologist?

*Note: Be mindful that patients might not be able to name the treatment but will be able to say who they've seen (psych, physio etc.) and will be able to comment on some content (e.g. activity diaries etc.). They may also tell you about things they did before the Bath service so may need to specify.*

What did you think of it?

What did you like? Why did you like that?

What did you not like? Why did you not like that?

What was helpful? Why?

Place (in person/remote/need for travel)?

Time of day?

Structured (not enough/hands-off or too much/hands-on)?

**What are the things that have helped you feel better?**

Prompts: Good/favourite?

Bad/never want to do again?

**2.2 Needs from future treatments**

**How do you feel about your recovery?**

Prompt: What kind of feelings come up when we talk about recovery?

**How can we make your treatment better?**

Prompts: What's missing from current treatment?

What needs to change?

How can we help you move closer to recovery?

How can your therapist best support you to make those changes?

Going forward, what do you think would help?

What do you need to work on next?

What's stopping you/getting in the way/holding you back from getting better quicker?

**What sort of treatment would work best for you?**

Prompts: Heard or read about things you want to try?

What is main thing you need help with to get better?

What do you think will help you get better from fatigue?



## 2.3 Perceptions of ACT

### Explain about ACT + vignette (James Story read aloud)

ACT stands for Acceptance and Commitment Therapy. It is a type of psychological treatment which is helpful for lots of people. ACT looks at the way you feel, how you are thinking, and how this affects what you do. It's a bit like CBT. But a big part of ACT is that it recognises it is normal to have tricky thoughts and feelings sometimes, and that you don't have to get rid of them. ACT suggests that trying to get rid of them can cause more problems. Instead, ACT helps you learn to still do the things you want, even when it's hard. In ACT you also think about your values; the things in life that are really important to you.

### What do you think about the ACT treatment James is having?

Prompt: Have you heard of it before?

What are your first thoughts about it? Good? Bad?

Would you want to try ACT? Which parts would you want to try?

The way ACT focuses on your values rather than challenging thoughts?

*Note: May need to explain VALUES. Values are things that are important to you in life. The bigger reason why you do the things you do. Example: a goal is going to school but a value is why you're going to school. For your education or because you want to learn things, want to go to university or want a job.*

The idea of stepping away from thoughts (cognitive diffusion)?

The idea of seeing things can be bad but still trying to achieve your goals?

Do you think it would be helpful for you to think about these things?

Do you think it would help other people with fatigue?

What about it do you think would be helpful?

### **Explain Trial**

We're thinking about delivering ACT as part of a trial. A trial is a type of research study where we want to test 2 treatments. In this case, we would be trialling ACT against the normal supportive pathway that is currently available for children who haven't fully recovered after 1 year. We would assign each child to either ACT or the supportive pathway. This would be random and you wouldn't be able to choose which pathway you receive.

As researchers and doctors we know a lot about how to do trials in an ideal world, however, we need to make sure it suits patients and their parents because we don't know how it feels to live with CFS/ME on a daily basis and what your needs and wants are. We need to make sure it's a realistic and feasible trial. That's why we ask your honest opinions on things like this.

### **What type of things do we as researchers and doctors need to think about when using ACT as a treatment for you?**

Prompt: What would you like to know more about before having ACT?

Would you want to try it after/before other treatment?

Anything you don't like the sound of?

### **If we do this trial, how do you feel about taking part?**

Prompt: How should we ask children like you to take part in ACT?

What would you think about when deciding whether or not to take part?

Barriers to participating?

Who/what would influence you? Therapist? Family? GP? Others?

Would you like face-to-face or skype sessions?

How many sessions would you like?

What would you expect from the trial?

Is there anything we've not thought of that you would want us to know about trialling this treatment?

Any recommendations for how to do trial?

**If we do this trial, how do you feel about being randomised to ACT or supportive path?**

Prompt: What makes you say that answer?

### **3. Close**

**Is there anything else you would like to tell me?**

Thank participant for taking part.