

# The Impact of Managing a Child's Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME) on Family Relationships

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## Article Information

Received date: Sep 07, 2017

Accepted date: Sep 29, 2017

Published date: Oct 05, 2017

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**Keywords** Chronic fatigue syndrome; Myalgic encephalomyelitis; Children; Parents; Family; Qualitative

**Abbreviations** CFS: Chronic Fatigue Syndrome; ME: Myalgic Encephalomyelitis

## Abstract

There is little qualitative data on the impact of Chronic Fatigue Syndrome/Myalgic Encephalopathy (CFS/ME) on family relationships. Semi-structured interviews and thematic analysis were used to explore 18 parents' experiences of the impact of a child with CFS/ME on family relationships. Five main themes emerged: "Long and Difficult Journey", "Uncertainty", "Isolation and Restriction", "Focus on the unwell person at the expense of family life" and "Parental roles". Parents felt the illness could have a destructive force but many also described the beneficial effects on family relationships. Health professionals should be aware that parents of children with CFS/ME may need additional support.

## Introduction

Chronic Fatigue Syndrome/ Myalgic Encephalopathy (CFS/ME) in children is defined as disabling fatigue persisting for over 3 months without another cause [1]. It is relatively common with a prevalence of 0.5-2.3% [2-5]. Children miss on average a year of school [6], 50% are bedbound at some stage [7] and children experience a significant decline in quality of life [8-10].

Having a child with a chronic illness can have a detrimental effect on parental health. Self-reported Health Related Quality of Life (HRQoL) is lower in parents of children with chronic conditions compared to those with healthy children [11-13]. In addition, there is an impact on parental mental health; the experience has been described as an "emotional rollercoaster" by parents of chronically ill children [14] who feel: stress, guilt, depression, fear, sadness, bitterness, and have difficulties coping with everyday life [15,16].

Parents of children with CFS/ME are at higher risk of psychopathology including distress, anxiety and depression [4,17-19] with higher rates of "illness-related family disruption of family interactions" and feelings of isolation, compared to parents of children with Juvenile Rheumatoid Arthritis (JRA) [20]. Mothers of children with CFS/ME describe negative emotions such as frustration, low mood, guilt and physical symptoms such as headaches, cold sores, nausea and weight gain [18]. Adolescents with CFS/ME can also experience eating difficulties which in turn has a negative impact on mothers psychological wellbeing [21]. Adolescents with CFS/ME describe both an increase in family stress but also a tightening of family bonds [22]. CFS/ME in 16 year olds is positively associated with family adversity [23]. Siblings of children and young people with CFS/ME describe changes in family function and/or a reduction in social support which they relate directly to their sibling's illness [24].

Managing a child with a contested illness may introduce additional uncertainty into family life. Ware [25] found that stigma and de-legitimisation are common for patients with CFS/ME, finding that their subjective experiences can be trivialised or assumed to be psychosomatic. Similar findings have been borne out in subsequent research [26-32]. De-legitimisation can occur outside the family, from healthcare providers for example and also from within the family [26]. Families have been found to be divided in their view of the condition as "genuine" or "intentionally used for advantage" [33]. There is currently a lack of research into how this impacts family relationships [34]. The aim of the current study was to explore parental experiences of having a child with CFS/ME, with a particular focus on the impact on family relationships.

## Method

### Participants

Families were recruited from routine follow up appointments in a South West Paediatric CFS/ME service. Each year the service treats over 350 children and young people up to the age of 18. The treatment model is based on the guidelines published by the National Institute for Clinical Excellence [1] which covers the clinical management of patients given a diagnosis of CFS/ME. Young people with CFS/ME will typically be seen with one or both of their parents by members of the clinical team. Parents were included if their child had a diagnosis of CFS/ME [1] and were excluded if their child's symptoms had another potential cause or parents who could not speak or read English. Purposive sampling was used in order to achieve a mix of single parents, couples and individual parents. A mix of parents would ensure a breadth and depth of data, essential when taking a qualitative approach [35]. In addition this was important because previous research suggests that mothers and fathers cope differently with childhood illness [36,37].

### Semi-structured interviews

Interviews were semi-structured and designed to elicit the participants' subjective experience of having a child with CFS/ME; including their expectations about relationships and recovery. The five areas recommended by Rolland in the Family Systems Illness model [38] helped to focus the topic guide and prompts. Once consent was obtained, the parent(s) were contacted and an interview was arranged at a convenient time and location. For all families, this was at their own homes. Interviews were all conducted by the same researcher (AHF). The researcher used a topic guide of open ended questions, alongside expanding and exploratory prompts, to ensure flexibility throughout the course of the interview. This method allowed participants to talk freely about their experiences. The duration of the interviews was between 30 minutes to 2 hours. Only the parent/parent couple being interviewed were present at the interview. Participants were recruited until no major new issues or themes appeared to emerge during the coding process (data saturation) [39].

### Ethical issues

Ethical approval (16/06/2011, ref: 10/H0102/28) was obtained from the Local Research Ethics Committee, the University of the West of England ethics committee and local Health Board Research and Development Units.

### Data analysis

The interviews were transcribed verbatim and the data analysed by AH-F using Braun and Clarke's guidelines for Thematic Analysis [40]. Thematic analysis is suited to an inductive, data-driven approach. This method of analysis allows for greater flexibility, with both sampling and its allowance of identification of themes at a semantic level [40]. This is in accordance with the idea that participants' experiences can be accessed through their verbal accounts. A strength of this approach is that it is "a data, rather than theory-driven process, enabling the researcher to describe and summarize the data in its entirety rather than seeking only parts of the data that were deemed relevant" [41]. The process began with reading and re-reading the data, initial codes were generated to describe what participants were saying, codes were then organized into similar groups and finally themes were finalized using direct quotes from patients to create a "vivid sense of what a theme is about" [40]. The researcher took steps to ensure the analysis was credible and robust by keeping a reflective journal, having regular supervision meetings and also utilising inter-rater reliability. An additional analyst (LB) who was fully competent with Thematic Analysis provided support in reviewing the data and analysis and offered some elaboration to the initial analysis. In addition to this a consultant Paediatrician (EC) considered an expert in the field of Paediatric CFS/ME also provided valuable feedback regarding the initial analysis. In addition to this, research participants were invited to comment on the initial themes in order to confirm whether the researcher's perspective accurately reflected their experiences. They confirmed that this was the case. Incorporating other perspectives enhanced the interpretation of the data [42-44].

## Results

Eighteen parents were interviewed from 12 families. Demographic details for each of the participants are shown in Table 1. Five main themes emerged: "Long and difficult journey", "Uncertainty", "Isolation and restriction", "Focus on the unwell person at the expense of family life" and "Parental roles". Family members felt the

**Table 1:** Participant details.

Family No.	Pseudonym		Parent description
	Child (age)	Parent (interviewee)	
1	Karen (13)	Barbara and George	Couple interviewed together
2	Jenny (16)	Sally	Mother of couple interviewed alone
3	Gemma (17)	Carol	Mother, single parent
4	Zoe (12)	Janet	Mother, single parent
5	David (16)	Brian and Sue	Couple interviewed together
6	Rachel (16)	Paul and Anna	Couple interviewed together
7	Hayley (16)	Debbie	Mother of couple interviewed alone
8	Mark(11)	Andy and Claire	Couple interviewed together
9	Julie (14)	Richard and Vicky	Couple interviewed together
10	Emma (15)	Simon	Father of couple interviewed alone
11	Kate (15)	Stephen	Father of couple interviewed alone
12	Tom (17)	Laura and Angus	Couple interviewed together

illness could have a destructive force but many also described the beneficial effects on family relationships.

## Long and Difficult Journey

Parents expressed a feeling that they were on a long, difficult journey, “going on too long” (Sue). This is explored through the sub themes “up hills, through tunnels”; “a constant struggle”; “exhaustion”; “is the worst behind us?”

### Up hills, through tunnels

Twelve parents (6 mothers, 6 fathers) from 8 families described living with their child with CFS/ME as an uphill struggle with an uncertain duration and destination.

“It’s a bit like walking towards the top of a hill and you think you’re at the peak and then you get to that bit you see there’s another bit beyond, and another bit beyond, I think we’ll get on top of it eventually but it’s the fact, it’s a journey of an unknown length that makes it difficult.” (Sally).

Parents felt trapped by their circumstances, walking in complete darkness due to the uncertainty of CFS/ME. The CFS/ME service served as the first glimmer of hope or rescue from a desperate or hopeless set of circumstances; “You were the light at the end of the tunnel” (Laura). However, the “light” may not be the salvation first thought. There still could be a number of obstacles to overcome or crucial decisions to make before the source of the light can be reached.

“From there being a light at the end of the tunnel suddenly there was another rock fall to clear away” (Stephen).

### A constant struggle

Many of the parents felt that dealing with the CFS/ME was complicated, and they engaged in a constant struggle. This began prior to diagnosis as parents fought for a diagnosis. CFS/ME made life much harder and more challenging; everyday tasks were harder and things that may have been taken for granted in the past would now almost feel impossible to tackle. Eleven of the parents mentioned that there was “additional work” and “a lot of pressure”. Vicky described this as constantly “juggling balls in the air, keeping pots boiling”. There was a feeling that part of the struggle was that parents were “constantly trying to, not gloss over it, but make it seem normal” (Laura) for the unwell child. This ongoing struggle could lead to conflict between parents and in the family. Sue described family life as being like a “battlefield”.

### Exhaustion

Seven parents referred to overwhelming “exhaustion”. The experience is tiring for the whole family. Sue and Vicky referred to the overwhelming “exhaustion” that they experienced as parents managing their child’s CFS/ME, while from a father’s perspective Angus mentioned that although managing their son’s CFS/ME was “tiring” for both himself and his wife, he conceded that this probably impacted his wife more than himself, suggesting a potential imbalance between husband and wife. Anna commented that families managing CFS/ME “need quite a lot of stamina to keep going”

### Is the worst is behind us?

When talking about the CFS/ME there was a sense that although

parents felt that it had a massive impact on their lives they tried to “never feel it’s pointless and hopeless” (Anna) and that “it’s going to get better” (Brian). Some parents described positives such as being better equipped to deal with illness in the future. Richard commented that his daughter had been through a “significant journey” and that “she’s learnt and gained some other skills as part of it as well”.

## Uncertainty

A common experience for all of the parents was a feeling of overwhelming uncertainty about their child’s prognosis and a lack of understanding about what causes CFS/ME. This is explored in the sub themes “What are we dealing with?”; “who are they and what will they become?”; “there must be something we can do”.

### What are we dealing with?

Uncertainty was something that all of the parents talked about, particularly in the period before the child received a CFS/ME diagnosis. This period is characterised by high levels of fear and helplessness: Janet described “frightening times” when she “didn’t really know what was happening” and that she “didn’t know what to do” for her daughter. Some families expressed how getting a diagnosis raised more questions: “how long is it going to last?” and “where has it come from?” (George and Barbara). Parents also talked about uncertainty caused by the fluctuating nature of the illness itself, it was felt that the experience of CFS/ME could “morph and vary from individual to individual quite considerably” (Anna).

### Who are they and what will they become?

Parents questioned their child’s future. There was a sense the parents felt like they had lost their child as CFS/ME turned them into people they no longer recognised. Parents described two versions of their child; the person before CFS/ME and the person with CFS/ME; Sue commented that her son changed from “a very sociable person turn into somebody who, it doesn’t feel like it’s quite him at the moment”. Parents felt a sense of loss and described it as “a bit like a grieving process.” (Stephen).

For some parents it felt like their child had regressed to an earlier stage of development. Vicky refers to her daughter as a “little child” when actually Julie (her daughter) is a teenager. This may reflect an increase in their parental dependency. Parents felt that their child was unable to cope and thus found it difficult to relinquish some support, Anna reflected that it was “hard to let go of [Rachel] and do things on her own”.

Five parents talked about losing who their child might have been able to become. For Anna, her daughter’s CFS/ME meant “a loss of her life that she should be having”. There was a sense that CFS/ME disrupted the ‘normal’ course of life and something that could not be recaptured. Sally expressed a sense of injustice that, like a thief, the CFS/ME had stolen part of their child’s life. Simon worried about what the future would hold for his daughter; “I worry about her later life, I worry about that tremendously if I’m honest”.

### There must be something we can do

While parents seemed desperate for their children to get better, they were uncertain as to what they could do to help. Sally described the “stress and strain” caused by uncertainties such as “should we be

firm, should we try and make her get up, try and make her get into school?”. Brian described the frustration of trying to “keep on the straight and narrow” whilst all the time just “wanting it to be fixed”.

Parents expressed a sense of helplessness and an inability to fulfill their role as parents. Sue felt “helpless because I don’t feel like I have any level of control at all, you know, as a mum I’d just like to take the ME away....I just feel guilty that as a parent I should be managing the whole thing a lot better than I am”. It was evident that parents were putting huge pressure on themselves, Stephen would question himself when his daughter felt more unwell “is it something we’ve done wrong?”. Parents additionally felt their parental skills were questioned by others. For Sue there is a perception that other people are critical of her and view her as an “overprotective parent”.

### Isolation and Restriction

There was a strong sense that both single and couple parents felt isolated, “we have felt quite on our own really”. This is explored in the sub-themes “no one can see this”; “only we know”; “our world has shrunk”; “a need to escape and a feeling of guilt”.

#### No one can see this

There was a sense that the parents felt they were the only ones to truly understand what it was like to have a child with CFS/ME. Six parents talked about CFS/ME as an invisible illness such as an “illness within” (George) where there are often no visible signs that the person is unwell. Anna and Debbie highlight that although their child may, to an outsider, look fine, looks can be deceiving. Managing an “invisible” illness can be incredibly isolating for both the unwell person and the family:

“it is isolating. A lot of people don’t really understand about...they see Rachel and they see that she’s fine and don’t understand that she can’t do things” (Anna).

#### Only we know

All 18 parents talked about others, including family members, not always believing them. Lack of belief from outsiders such as family and medical professionals created a sense of isolation. Carol commented that her other children felt that her unwell daughter was pretending to be ill. Angus talked about being disbelieved by health professionals and thus being “dropped through the cracks in the floorboards”.

#### Our world has shrunk

Fifteen parents talked about how their lives were restricted because of the CFS/ME. Having a child with CFS/ME meant that parents did not “go out very much” (Carol), one parent even said that she felt “housebound” (Janet) a lot of the time. On the occasions when they did manage to go out for a leisure activity, parents found that the activity would be restricted, perhaps not spending “as long as [they] normally would” (Simon). Plans often had to be “cancelled or rearranged, cancelled again and rearranged.” (Carol).

The many restrictions on family life left parents reflecting that there was a lack of “fun” in their lives, Paul encapsulates this when he says that “we’re living fairly boring existences” and describes life as “stuck”. Once parents started to miss social events, the restriction imposed on them could become self-perpetuating. Anna and Laura describe life “shrinking” and a feeling “like you’re in a prison”.

Parents described a loss of independence and freedom for themselves as well as their other children “[his sister] has felt restricted” (Andy). A feeling of resentment was expressed by parents when they talked about how having their child constantly with them has restricted what they could do, for Anna this meant being “out of the loop of socialising with people and so you don’t get asked places”.

#### A need to escape and a feeling of guilt

Eight parents talked about wanting to get away from the CFS/ME and the guilt associated with this. Janet cherishes the times she can “go out with a friend, have a cup of coffee and talk about their problems... the state of the world instead of CFS/ME” (Janet). However, even though parents still have to “do the things [they] like to do” they then feel guilty for leaving their child at home (Barbara).

### Focus on the Unwell Person at The Expense of Family Life

Parents’ reflected on how their focus was often on their unwell child and their needs, leading to other family members feeling marginalised, particularly siblings. The theme contains the sub themes “life revolves around them”, “destructive force” and “resentment”.

#### Life revolves around them

Eleven of the parents reflected on feeling that the unwell child was “always there”. Brian commented that his son “should be having more time away from us”. For Sally, her daughter’s constant presence had more of a practical impact; she felt that she could not get on with chores or relax and her comment that she had “no space” suggests that she had feelings of restriction and confinement. Claire described life “revolving” around her son and “his limitations”.

Parents felt their relationship with each other was inhibited by the constant presence of their unwell child. Angus suggested it was like “a permanent threesome”. Parents described their relationship being “inhibited” (Laura) and “more distant” (Angus). Andy reflects on this saying that the amount of quality time he has with his wife had been reduced and that they had to “grab our moments to talk when we can” (Andy).

Additionally, other parts of the family were neglected, this was more apparent in families with multiple children. Angus referred to his other children not getting “their fair share of attention that they perhaps would have had”. Laura expanded on this saying: “I’ve got the mother’s guilt of stretching myself too thinly with the family”.

#### Destructive force

Parents talked about the destructive effect that CFS/ME had on family life; the family was described as being “divided” or “split up” (Laura, Carol) in order to accommodate the needs of the unwell child. As well as whole families being divided up, there was an increase in “tension” (Richard) between couples because of the CFS/ME. Carol identified that they had “had a few arguments” as a direct result of the CFS/ME. Increased frustration was evident for Vicky who referred to “tearing our hair out” and “often having a row”. Stephen felt that his relationship with his wife was “ok”, but due to the “regimented regime” there was often “a bit of strain here and there”. Parents also talked about the conflict between each other regarding their approaches when managing their unwell child. For married couple

Brian and Sue, there were clear differences of opinion on how to “control and discipline” their unwell son who often led to “conflict” and Brian felt that it was “difficult to know what’s right”.

### Resentment

Eight parents commented on the resentment siblings felt towards the child with CFS/ME. The resentment could sometimes stem from siblings perceiving that the unwell child was exempt from doing certain chores or got “special treatment”, as mentioned by Sue. Parents reflected on how this was “not fair” (Vicky). In addition to parents observing sibling resentment, there was evidence that the parents themselves sometimes felt resentment too:

“There’s a lot of conflict between the children and he’s probably responsible for most of it” (Sue)

### Parental Roles

Differences between parents were revealed through their explanations of how they dealt with and managed their child’s CFS/ME. The sub themes are “Good cop/bad cop”; “it’s a mother thing”; “Parents work as a team”

### Good cop/bad cop

Parents took different roles in caring for their child and these could change over time. Richard commented that “we both work in very different ways”. Sally described the roles as “the firmer and the softer one”. Sometimes the mother might be cast as the bad cop whilst the father would be the good cop, Barbara commented that her husband would often be “a bit lenient” whilst Brian perceived his own approach as “wishy washy” and Paul felt that he “used to under-react to things that happened”.

### It’s a “mother” thing

There was a suggestion among 11 of the parents that differences in care giving were partly due to gender. Carol felt that mothers provide more emotional support than fathers. There was an assumption that emotional support was part of a mothers “maternal instinct” (Claire) whereas it’s a male thing to be able to “just switch off” (Sue talking to Brian). There was also an additional unspoken assumption that mothers should take on the main caring role. Fathers Paul and Andy reflected on that their wives took on the main caring role, which could have a negative impact i.e. Andy’s wife is put under “quite a strain” because of her caring role.

“I suppose mothers are more emotionally involved than fathers (laughs) anyway I don’t know, I think she does feel that she doesn’t get any emotional support from her dad” (Carol)

This is exemplified by one mother in the study feeling like a “single parent” because of managing her daughter’s condition alone despite being married, one father also recognised that his wife provided “the bulk of the caring”.

### Parents work as a team

Nine parents talked about being brought together because of the illness, working together to help their child get better. Barbara felt that “we work well together looking after Karen”. Parents talked about balancing roles, being sensitive to “what the other person

needs” (Paul) and working flexibly together in a “tag team”. Andy described tending to “play off each other and, if one’s fulfilling one role, the other one of us fulfils another”.

In some cases, CFS/ME changed family relationships in a positive way. Parents reflected on how “sharing problems is pretty positive for the relationship rather than negative” (Brian). Sue felt that through dealing with the CFS/ME they had been brought closer together. Six parents talked about how their relationship with their partner had improved since dealing with CFS/ME. Andy talked about improved communication between himself and his wife. Laura felt that the CFS/ME had given her the opportunity to become closer to her unwell son and they were “definitely stronger in that sense”.

### Discussion

Parents described the negative impact caring for a child with CFS/ME has on the family including: the constant daily struggle, exhaustion caused by focusing on the ill child as well as the destructive force on family relationships. However, couples acknowledged the different approaches taken when caring for the ill child depending on gender, as well as the beneficial effects CFS/ME can have leading to parents working more as a team.

All of the parents in the current study referred directly and indirectly to the struggle, strain and exhaustion caused by managing CFS/ME. This is consistent with other disease areas where parents of children with disabilities report higher levels of distress than those with healthy children [45-48]. Dolgin et al. [49] found that mothers of children with cancer experienced an increase in stress at diagnosis and observed a decline of stress at 3 to 6 month follow up. This is similar to our study where in some cases, parents struggled initially but as time has progressed they began to see a “light at the end of the tunnel”.

Parents interviewed in this study talked about experiencing a high level of uncertainty with regards to day to day life and the prognosis of their children. The concept of biographical disruption [50], whereby daily life becomes disjointed, is of particular interest here. Chronic illness is seen to threaten one’s sense of the taken-for-granted world, which then produces a need to redesign lifestyles, re-order time and come to terms with an uncertain illness trajectory [51]. Ongoing uncertainty has been found in parents of children with chronic conditions such as: Chronic Pain, Juvenile Rheumatoid Arthritis, Eczema, Heart disease, Diabetes, Epilepsy, Cancer, Downs Syndrome, Cerebral Palsy, Spina Bifida and Cystic Fibrosis [52-57]. Unlike uncertainty in acute illness, which tends to be localised in issues of diagnosis, treatment, and recovery, uncertainty in chronic illness involves broader aspects of a person’s life (e.g. home, work) and influences daily routines and activities [58,59]. Uncertainty in this study is exacerbated by the ambiguous or unpredictable nature of CFS/ME; a fluctuating illness with an unclear prognosis. Continual uncertainty in illness may be preferable to negative certainty because it can enable patients and their families to perceive multiple opportunities and increased flexibility when the illness is viewed as chronic and continual [60,61]. According to Mishel’s [60] Reconceptualization of Uncertainty in Illness Theory, the reappraisal of uncertainty as promoting a variety of possibilities may evolve over time and uncertainty can become a desirable cognitive state leading to positive psychological changes and personal growth. Indeed,

among adult patients and families of children with a chronic illness, researchers have found that continual uncertainty could serve as a catalyst for positive psychological outcomes [60-62].

Parents in the current study sometimes talked about their grief of “losing” their child. Research suggests that parents can experience grief responses to their child being chronically ill [53,63,64]. This can be compared to the Kubler-Ross [65] stages of grief model; denial, anger, bargaining, depression, and acceptance. Parents in the current study seemed to display anger, depression and sometimes acceptance, though denial and bargaining were not observed. An alternative model of grieving is ‘chronic sorrow’, first described by Olshansky [66] and adapted by Worthington [67]. Gordon [68] has defined chronic sorrow as “a normal grief response associated with an ongoing living loss that is permanent, progressive, recurring, and cyclic in nature” (pg 117). This “living loss” may be explained as “ambiguous loss” where a child with CFS/ME’s psychological or physical status is unclear [69]. Boss and Couden [70], have suggested that when people are unable to obtain clarity about the status of a family member, they are often “immobilized”, or as Ellenwood & Jenkins [71] describe it, “families dealing with chronic illness are in a frozen state hyper-focused on the chronic family member’s dysfunction”. This is certainly true of some of the parents’ experiences shared in the current study.

Research exploring the financial impact of CFS/ME on mothers [18] found that mothers experienced a lack of understanding from others, marital tension and concern about their child’s distress with themes such as: “Long and Difficult Journey”, “Isolation and Restriction” and “Parental Roles”. There are similarities between this research and the current study, where parents talked about how CFS/ME had isolated them and restricted their lives as a result of the lack of understanding of the condition. The feelings of isolation that families have when managing a chronic illness can be explained in part by the stigma that chronic illness creates. Åsbring and Närvänen [72] found that CFS and fibromyalgia could be particularly stigmatising because of the lack of understanding and belief among others. Gannoni and Shute [14] in their interview based study of parents of children with cancer, chronic renal failure and type I diabetes, describe how a lack of understanding and acceptance by others can make families feel isolated. This lack of understanding and acceptance can sometimes stem from the fact that, outwardly, the child may not look unwell as described in our study; “no one can see this”.

This study demonstrated both the positive and negative impact caring for a child with CFS/ME has on family relationships. Childhood chronic illness can make families stronger and improve relationships between parents and children [32,53,56] by increasing parental confidence [14], providing a new appreciation for life [57] and improved family cohesion [73]. It may be that there is an opportunity for families to grow from their mastery of the chronic illness [32,74]. However, in many cases, there is a negative impact on family functioning [75,76]. In this study, parents talked about arguing more and feeling an “increase in pressure”. Marital satisfaction is lower amongst parents of children with chronic health problems when compared to those with well children [77-79]. The burden of childhood illness frequently manifests in parental conflict within the marriage [80,81] and has been cited as a major factor contributing to parental divorce [82].

There is a clear difference between families that reach breaking

point and those that grow stronger. This could in part be explained by the resiliency model of Family Stress, Adjustment, and Adaptation by McCubbin and McCubbin [83]. The model suggests levels of resilience will vary depending on protective factors such as family celebrations and traditions; family hardiness and family time and routines. Parents of children with chronic disease who receive adequate social support, generally perceive that they have less stress in their lives [84,85]. This study also demonstrated that CFS/ME may have an impact on protective factors; parents talked about feeling forgotten by their peers and out of the loop socially.

The fact that mothers and fathers manage and cope with childhood CFS/ME differently is consistent with models of coping in other conditions [36,54]. The burden of care often falls on the mother [82,86,87]. In some cases, this means that fathers sometimes become the primary caregiver to healthy siblings [88]. With the burden of care typically falling to mothers it is unsurprising that mothers of children with chronic conditions are more psychologically vulnerable than fathers, often scoring higher on depression and anxiety scales [36,89]. Mothers tend to report more of a negative impact of chronic conditions than fathers [36,37]. One explanation for this is that fathers are able to escape to the world of work, which may mean that they are not as isolated as mothers. Although mothers may be more vulnerable to the emotional impact of childhood chronic illness than fathers, this should be interpreted with caution as the majority of studies have a greater female to male ratio, and some studies focus exclusively on mothers [90,91]. There is evidence to suggest that although fathers report fewer psychological symptoms than mothers, fathers and mothers do not differ significantly with regard to physical symptoms [92].

### Strengths and limitations

This is the first study to look in detail at the impact of CFS/ME on family relationships from the perspective of both parents. Some of the fathers were interviewed alone, ensuring that the fathers’ voices can be heard alongside that of the mothers’, as this can be lost if parents are only interviewed together [92]. The first four interviews were double coded and all themes were checked by an expert in the field to increase the trustworthiness of the findings [42-44], in addition to this, research participants were invited to comment on the initial themes in order to confirm whether the researcher’s perspective accurately reflected their experiences. They confirmed that this was the case. Participants were recruited from a specialist, tier 3 service, therefore, the findings may not be generalizable to families seen in general practice, community settings or in other parts of the country. In 10 of the families, the unwell “child” was a teenager; therefore, the findings may reflect families with older rather than younger children. The interviewer was a clinician working with the families on an ongoing basis; therefore, this may have affected recruitment or changed the answers given [35].

### Clinical implications

Parents caring for a child with CFS/ME experience a constant exhausting struggle, ongoing feelings of uncertainty, a profound sense of loss of the child they felt they once had, as well as conflict with their partner. Clinicians need to be aware that parents of children with CFS/ME may be experiencing some or all of this at any given time, and therefore, may need additional support both individually and

possibly in a group setting. Parents should be given more information about CFS/ME and its prognosis which could help to demystify the condition. In this way, an individual approach would help to provide parents with a personalised “road map” to help guide them on their “journey” through CFS/ME. In a group setting, parents may be able to gain support from other parents experiencing similar issues to them, which in turn may help to reduce feelings of isolation and normalise their experience. Clinicians should also be aware of the potential of CFS/ME as a destructive force within the family and encourage parents to work as a “team”.

### Future research

Future research could expand on the current findings with a focus on different family structures, cultures and include other family members such as grandparents and siblings. The use of a longitudinal design may help to understand how families adapt and how potential treatment needs to change over time to accommodate these changes.

### Acknowledgement

We are grateful to the families that took part in this study.

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