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TRANSCRIPT OF "FILE ON 4" – "*CHILDREN WITH ME*"

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“FILE ON 4”

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ACTUALITY - FOOTSTEPS

HILL: I've come to a terraced house in the middle of nowhere in the countryside. It's miles from any railway station. The family don't want me to identify where they are.

ACTUALITY – KNOCK AT DOOR, DOOR OPENED

HILL: Matthew Hill – hi.

SARAH: Hi.

HILL: Nice to meet you.

SARAH: Nice to meet you. Do you want to come in?

HILL: Down in the kitchen, it's a normal scene of family life. A labradoodle bounds around, but it's a very different scene upstairs on the third floor.

SARAH: We've got the top floor nice and quiet for our daughter, so she's away from this noise [laughs] and general kind of, because she needs to be in a quiet atmosphere, because she's very noise sensitive.

HILL: Well, shall we go up and see her?

SARAH: Yes. Okay. Just come up here, I'll show you where it is.

ACTUALITY – FOOTSTEPS GOING UPSTAIRS

SARAH: She's got a room with an en suite so she's got some privacy.

HILL: So there's two flights of stairs.

SARAH: Two flights of stairs. So she's just up here on the left. Okay.

HILL: As far as I can see, it's a normal teenager's bedroom with a fan whirring by the bed. There are two guitars in the corner, but I'm told they've not been played for a long time. The family weren't even sure we'd even be able to talk to her because of the nature and severity of her illness, it means even a short conversation with us is draining. This very sick teenager doesn't want me to use her real name, so we'll call her Jane and an actor will speak her words. She doesn't want to be heard discussing her illness in her own voice, but she still wants to tell us about her condition.

JANE [SPOKEN BY ACTOR]: There aren't words to put it into, it's just my body is always uncomfortable and I'm always hot and I'm always in so much pain. I'm always exhausted and I always feel sick and just being in the world feels like I'm being attacked by things – smells and sounds. It's just not, it's not a nice way to exist.

HILL: Jane's mum is her full time carer. We'll call her Sarah. She had to give up her job as a teacher when her daughter became ill in 2013. Up until that point, Jane lived the carefree existence of a teenage girl.

SARAH: She was just such a normal teenager. She was 14, she biked, she swam, she was reasonably active, you know, like a fairly sporty 14 year old. She loved playing the guitar. She had friends, she was very high achieving at school. She was just a happy, normal kid.

HILL: So tell us how, when she got ill.

SARAH: Ah, well, she became ill just suddenly really overnight. It was just a complete shock, it was just a bolt from the blue.

HILL: What were her symptoms over time?

SARAH: Well, immediately her symptoms were that she had a really, really high temperature, she couldn't really walk; she could actually walk, but it was just really, really hard for her to walk - she was kind of shuffling, she leant on me all the time if she did have to get out of bed. She couldn't eat, she didn't eat or drink really for about eleven days initially, so that was a big worry. We just treated her like she had the flu - that's what we were advised to do - and she just never got better.

HILL: Jane was suffering from Myalgic Encephalomyelitis, which is also sometimes referred to as Chronic Fatigue Syndrome, a condition that affects around 25,000 children in the UK. It's the biggest cause of long term sickness absence in schools. The main symptom is extreme, debilitating fatigue. Some patients also have pain and problems with short term memory and attention span. In Jane's case, her family says it affected her ability to eat and she rapidly lost weight. There was initial confusion about what might be wrong with her - doctors were divided, with some suspecting an eating disorder or mental health problem. It took six months for her to be diagnosed with ME. The family said it was a relief.

SARAH: She had so many tests for so many things. She's had MRIs and ECGs and, you know, CTs and all the rest. She's had so many bloods done, and this was the only thing that could possibly explain her range of symptoms. So it was, thank goodness, but I had no idea whatsoever that that was not going to be the end of it, that there were still going to be people for years afterwards saying that that might not be what she had.

HILL: The family were living in Bedfordshire at the time. Their local NHS started to put in place a complex package of care for Jane. She was admitted to a hospital so that staff could observe her eating habits more closely, but Sarah felt they didn't seem to understand her daughter's condition and were offering what she saw as inappropriate care.

SARAH: There was a weekend when she was allowed home on home leave, but we had to leave the hospital at 8 o'clock at night after she'd had their last observed meal and come back at 8 o'clock in the morning to have her first observed meal, because they had to be observed. And that's ridiculous for somebody with ME - she can't get up, and even though we'd had that diagnosis we felt that we weren't being believed anymore. I had a report back from somebody, a verbal report. It was something like, the trouble is nobody thinks that she can be as ill as she is with just ME.

HILL: Sarah says they had a supportive paediatrician, who was clear about the diagnosis of ME. But she started to feel suspicion was falling on them in some way. Unbeknown to the family, the local NHS remained concerned that Jane's low weight could be due to an eating disorder rather than ME, and that her mother was dismissive of professional advice. They were referred to social services because of concerns Jane was likely to suffer significant harm. It led to a local authority safeguarding meeting between social services and nurses. Sarah was shocked when she found out about it a year later.

SARAH: What we discovered as we kind of went on is that behind the scenes there was safeguarding activity going on. There are two reasons for not telling people about safeguarding activity, both of which mean that they think that if they tell you, you're more likely to cause greater harm to your child. And one of them is sexual abuse and one of them is something which used to be called Munchausen's by Proxy, which is where usually the mum is feigning or inducing illness in the child.

HILL: The family say they were appalled to learn that part of the reason for the safeguarding was a suspicion that Jane's mum might have this extremely rare mental illness where a family member deliberately makes a child sick. It's known as Fabricated or Induced Illness, or FII. Sarah asked what had caused the authorities to suspect them of this.

SARAH: Keeping her in a dark room, excluding her from seeing her friends, limiting her access to food – well, she has a limited access to food because she's limited in what she can eat, and anybody who is a specialist in ME knows that's a normal, very common symptom with severe ME.

HILL: Were you excluding her from friends and restricting her diet?

SARAH: She tried to keep in touch with people. It's very, very difficult when you're so poorly and it's also really hard for teenagers to understand. As for food, I would spend almost all my day thinking about what kind of food I could give her to tempt her appetite. She's never ever hungry. It's a real basic fundamental of being a mum, that you can nourish your children, so to be accused of limiting my child's access to food was totally devastating.

HILL: By this time, Jane's family had declined some of the treatments on offer, including talking therapies, because they felt they made her more exhausted. Jane now was severely underweight. So that's quite serious then, isn't it?

SARAH: That's incredibly serious.

HILL: So you can understand why the doctors would be concerned about her?

SARAH: I can absolutely understand why they're concerned about her, but I'm utterly contemptuous of them saying that it had to be an eating disorder and it couldn't be ME. People with ME don't have problems with eating, they say, and it's just poppycock.

HILL: By September 2016, Jane had three specialist opinions confirming she had severe ME, yet faced with more safeguarding referrals, in desperation the family decided to move over a hundred miles from their then home in Bedfordshire. I asked Sarah why.

SARAH: To get away from the local services that didn't trust us, didn't believe us, that made I don't know how many safeguarding referrals against us abusing, neglecting, emotionally abusing our daughter, for doing all the things that our specialist told us we should be doing. It's devastating. You feel like a complete failure. I can't underestimate the impact it's had on us as a family and me as a mum, to be accused of making my daughter ill.

HILL: We asked Bedfordshire Clinical Commissioning Group for its response to claims that the specialist's medical diagnosis of ME had not been believed. It's told us that it never disputed the diagnosis and paid for a paediatrician and CFS specialist to work with Jane to aid recovery. But it says on occasions her family denied professionals access to her. The CCG says safeguarding concerns were raised independently from a number of healthcare professionals and had to be fully investigated. When we also asked Bedfordshire Council to comment on whether the safeguarding action was a result of FII, it said it can't comment on individual cases because of confidentiality. So what of the condition mentioned in their case? Professor Peter Fleming from the University of Bristol is one the UK's most experienced paediatricians dealing with cases of Fabricated and Induced Illness involving babies. He says it's a pattern of behaviour ranging from exaggeration of symptoms right up to deliberate harm, which can be life-threatening. He says the most serious form of FII is extremely rare, but it can happen.

FLEMING: If professionals dealing with the care of a child do not know what's going on and a child is presenting with signs and symptoms that the professionals don't understand, then clearly one of the things one always thinks about is, is

CHAUDARY: We know that that's the case with self-selecting groups. However, we did promote it more widely on the website and through social media. Regardless of whether they're skewed or not, the numbers are still quite high, and that means that we need to do further research to understand what is actually going on. So if you can imagine a child with ME that's lost everything they know about their lives, they're too ill to go out and play, they're too ill to go to school, they're too ill to even have their friends round, and for about 25% of them they're in bed, unable to be touched or cuddled by their families. They're then faced with disbelief by teachers and schools and health professionals, who don't believe that they're ill, and then you add to that the fact that they're referred into a system that's designed to protect children. That's a triple whammy for that child.

HILL: There will be some genuine cases though of induced illness.

CHAUDARY: Absolutely. Despite the fact that it's rare, it can happen. However, what our findings suggest are that that's not the case. 70% of the cases are being dropped within a year. That suggests that the allegations of child protection are not being substantiated. Therefore you have to ask questions - why is that the case?

HILL: Why do you think it is the case?

CHAUDARY: We know that there's significant lack of understanding and disbelief. ME is a complex issue to understand, and if you do not understand the illness, then actually you can draw conclusions about why children are ill and how they're being parented, and I do think that there needs to be a better understanding.

HILL: Almost every aspect of this condition has been subject to misunderstanding and dispute, even down to whether it should be called ME or CFS. The term ME was coined in 1955, when a number of staff and patients at the Royal Free Hospital in London came down with a mystery polio-like illness. So many people fell ill that the hospital had to be closed. But it was later dismissed by psychiatrists as mass hysteria. Dr Phil Hammond, who is an associate specialist in CFS and works in Bath at the largest ME centre in the UK, concedes even in the medical profession, there was a historical tendency to regard the condition as all in the mind.

HAMMOND: I have a lot of guilt, because when I was trained we used to call it Yuppie Flu, and the whole medical profession felt that it was something that middle class people got when they didn't quite achieve what they wanted to, and that was the most foul slur. In fact, we know Chronic Fatigue Syndrome, like most illnesses, is more prevalent in poorer people, and we also now know it's clearly a neurological condition, so I think to start with it was the dismissal of that that caused a huge amount of pain and anguish for people who are suffering such an unpleasant illness, and I'm not sure we've ever fully recovered from that. I think those seeds of distrust, where patients still feel that it's being dismissed as a psychological condition, I think are very hard to eliminate.

HILL: With uncertainty about the cause and the absence of a cure, most research in the UK has focused on two types of therapies - Cognitive Behaviour Therapy, described by NICE as a psychological talking treatment to help people understand how their behaviour can affect the condition, and Graded Exercise Therapy. This involves settling goals to achieve planned increases in activity or exercise.

ACTUALITY WITH DOG

PARKER: Dexter! [LAUGHS] Dexter, down!

HILL: For 15 year old Lewis Parker, taking his dog Dexter out for a walk around his Cumbria home is not only fun, it's part of his therapy. He was diagnosed with post-viral CFS last year.

PARKER: Dexter – paw! Other paw. Lie down!
I came down with glandular fever in February, and then that lasted for about four months, three months, and after that I was off school most of those months, I was in bed, I could barely move. I was in a lot of pain. And after I got rid of the glandular fever, what started happening is I started picking up bugs, I couldn't function properly. For a few months we didn't know what was happening, I was off school for most of the time and the problem we had is there was no plan. It was literally just I would go into school for a full day and maybe I'd get a full day in out of two to three weeks, but the rest of the time I would be in bed.

HILL: Since October, Lewis has managed to attend school more frequently. He puts that down to the programme of Cognitive Behaviour Therapy and Graded Exercise. Lewis's mum Tracey constantly monitors how he is doing. His daily routine is planned and plotted using a colour-coded chart.

TRACEY: We started doing this in October, when he was first diagnosed, so you can see here the periods in deep red where he was sick were pretty big compared to the periods when he was well. These are the periods off school. In December he started the Graded Exercise Therapy with a qualified paediatric physiotherapist. In January he started his CBT with a clinical psychologist and then you can see through January, February, March and through to April the periods of sickness are still there, but they have reduced and the periods of wellness and wellbeing have increased. It's about finding a balance for Lewis to work towards. It's always been small amounts, see how he goes with it, and Lewis and myself and Conrad to use our judgement on how he's coping with that.

HILL: Children are known for getting better spontaneously, much more so than adults with ME. You don't think this could just be that?

TRACEY: Yes, it is statistically a fact that children do, which is really reassuring for us, because Lewis is a child and he'll be one of the 75%, it looks like, from his progress that he's making, that will go on to make a full recovery from it. I can only talk from a parent's point of view. I can only go on Lewis's experience and our experience of it.

HILL: Lewis is by no means recovered, but he feels he would not have improved as much if he'd been left to judge for himself how much he could do.

PARKER: If I hadn't had this, I think there would have been a lot more days where I would have been not able to do much and there was no way of telling how much I should do and how much I shouldn't do, so this was, this was good. I think the Graded Exercise has definitely helped me.

HILL: So Lewis is hopeful for the future.

MUSIC

HILL: But the therapies, like everything else to do with this disease, have been the subject of fractious public debate. The ME Association and others recommend a completely different therapy called pacing, which involves balancing activity and rest without imposing targets. It's also conducted a survey of its members which it says suggests that CBT doesn't work and that Graded Exercise can make patients worse. But this appears to be at odds with a large-scale trial in adults published in *The Lancet* in 2011. It's known as the Pace Trial. Costing £5 million, it's the most expensive piece of research ever to have been conducted into therapies for CFS. It found Graded Exercise and CBT to be moderately better than standard medical care such as pain management or pacing. But the study has generated controversy. In 2013 there was a debate about the trial in the House of Lords.

EXTRACT FROM DEBATE

WOMAN: The Pace Trial was funded by the MRC, the Department of Health, the Scottish Chief Scientists Office and the Department for Work and Pensions to the tune of £5 million.

HILL: This was followed a protracted battle by patient groups to obtain some of the raw data for the Pace Trial, culminating in a court order which stated the information should be released. In another twist, in April this year, a reanalysis of the original data by a different team of academics examined later findings from the Pace team that more patients showed some degree of recovery with Graded Exercise and CBT again compared to pacing and general medical care. It concluded the Pace team's findings were 'highly misleading' and pointed out that they'd used a different definition of recovery between the design of their study and the analysis. The new study used a higher threshold and found lower rates of recovery. Pace researchers rejected the criticisms, saying there were valid reasons to change the criteria. They say their findings have been replicated in other international studies.

So where does this leave patients? Well, at the moment, guidelines from the National Institute for Health and Care Excellence, NICE, recommends CBT and Graded Exercise for mild to moderate Chronic Fatigue Syndrome, but there's one important safeguard. Patients

MOTHER: We should have done. We did try initially, but she was struggling to manage the programme as it was and we were just too concerned, to be honest, with these symptoms that she was having.

HILL: What were those symptoms?

MOTHER: Pain predominantly, chest pain, back pain, which was quite concerning. Breathlessness as well and then just deterioration of all her existing symptoms as well. Isla just basically over the months continued to deteriorate. She was then needing to use a wheelchair for the journey to and from school. Although she could walk, she couldn't walk that distance at all. Cognitively she was struggling more, and that to us was really concerning, because we knew those are ME symptoms.

HILL: Because of their concerns, Isla's family decided to discontinue the therapy. The specialist service that was overseeing her treatment have told
File on 4:

READER IN STUDIO: It is important that our young patients, and their parents or guardians, are involved at every stage of their treatment. When concerns were raised by the family, we worked with them to explore alternative options, but these were declined and the patient was discharged.

HILL: Isla's family are convinced that Graded Exercise made her worse. It's ultimately impossible to prove this for sure. ME is a condition that can fluctuate. But when the family declined a further offer of Graded Exercise at a different clinic, Isla's parents said the authorities then accused them of withholding treatment. By this stage, Mr and Mrs Kidd had misgivings about the way they were being viewed by professionals, so they applied for their daughter's medical notes.

ACTUALITY WITH NOTES

HILL: We've got the notes in front of us now, so if we look, there's a note there from a school nurse. What does it say?

MOTHER: It says for her to contact the Safeguarding Team in view of concerns regarding potential Fabricated Induced Illness and lack of professional medical input and school avoidance.

HILL: So what did you take that to mean at the time when you read it for the first time?

MOTHER: That there's nothing wrong with Isla and that we're making it up, basically.

HILL: Are you?

MOTHER: No. Definitely not.

HILL: What were the thoughts that were going through your head?

MOTHER: Well, I couldn't really believe it and was just really, well, lots of emotions, to be honest. I mean, at the end of the day, we've got a very ill child and we've got a professional that should be helping and who, on no evidence at all, seems to be thinking that we're making it up.

HILL: What effect has that had on you as a couple?

MOTHER: Hmm, a big effect. I mean, it's just taken over our lives. I mean, I think we've just lost the last sort of twelve months really. It's taken over, you know, our kids' lives. I mean, we've got another daughter as well and she's sort of been exposed to it as well, and you know, you can't just help but it take over everything.

HILL: Does Isla know about the accusation against you?

MOTHER: Yes, yes. We're honest with her, because she's less worried then. The child protection thing particularly has been really difficult for her because having sort of random professionals knocking at the door has been sort of really unsettling for

MOTHER cont: her. I mean, that's the stupid thing about all this, you know the child protection is brought about because we're supposedly harming our daughter and yet it's actually made her so much worse.

HILL: We asked Birmingham Community Healthcare NHS Foundation Trust to comment on the school nurses who suggested FII. In a statement it says it can't comment on the circumstances of individual cases, however school nurses will refer to additional services as appropriate. We wanted to speak to NHS England about the levels of confusion about ME among medical staff. We didn't receive a response to our request. Isla's parents say they've engaged in a long battle with her school and social services and have been supported in that by a local councillor, Charlotte Atkins, after she accompanied them to some of the safeguarding meetings.

ATKINS: It became obvious as time went on that the school and the social workers were absolutely convinced that Isla's parents were fabricating her illness, that she didn't really have ME. They wanted her to go down the route of Graded Exercise, which the parents considered not to be in the best interests of Isla. A number of meetings had been held, and despite the intervention of people who knew Isla really well, the social worker and the school were determined to proceed. In November 2016, I became so concerned that I asked for an inquiry into the case. I was finally told in April that the doctor in charge of safeguarding considered that Isla's illness was not either fabricated or induced. The medical evidence was there. Neither the school nor the social workers decided to look at it. As a result, the family has been under this cloud of suspicion, and it has had a huge impact in terms of the stress the family has suffered. It's bad enough having a child who is so ill that she can't attend school, but even worse when the families are accused of some sort of wrongdoing. It's been deeply damaging.

HILL: The school declined to comment about Isla's case, and while her parents acknowledge school attendance and isolation played a part in the referral to social services, they believe refusing treatment was also a contributory factor. A spokesman for Staffordshire County Council told us child safety was paramount and they have a duty to investigate any referral made to them. Two weeks ago, social services held a meeting to officially take her off the Child Protection Register. Their report concludes Isla is not at risk of significant harm and that her parents' response could be considered appropriate to what

HILL cont: they consider to be misunderstanding by professionals of Isla's condition. It says her parents can be appropriately challenging about what she can achieve and sometimes this can be misconstrued as obstructive. Dr Charles Shepherd of the ME Association says these types of misunderstandings are the result of complex interactions between professionals and parents, and once they go wrong, they can snowball.

SHEPHERD: There is a sort of chain of events that occurs. It's possibly twofold – it's doctors who are not confident about either the diagnosis or the management of this illness or are recommending forms of treatment for this illness which parents may disagree with, or the child gets worse with particularly the controversial subject of Graded Exercise Treatment. And this is quite often combined then with concerns from the school and the education authorities as to why that child is not going to school. The child is ill at home, perhaps the child is not taking part in what is being recommended in the way of management from the doctors involved. The social workers then get involved, the social workers then, in my view, have very little knowledge and expertise in this illness, which is very unfortunate, so they go around seeking other opinions. If the view is then reinforced that the child is not taking part in school when it should be, is not taking part with a management programme when it should be, then the child then ends up in this process which steadily develops into a child protection case.

HILL: We asked to speak to Isabel Trowler, the Chief Social Worker for Children and Families in England, to ask her whether there was a need for better education about ME for social workers in order to reduce the type of misunderstandings that can lead to unnecessary safeguarding investigations. She was unavailable for interview. But in a statement she told us:

READER IN STUDIO: It's important that all the professionals who work with young people have a firm understanding of conditions like ME and the impact these can have on their daily lives. I have met and continue to meet groups and organisations and will work collaboratively with them and a national network of social workers to further professional understanding of children with ME.

HILL: It seems the one certainty about ME is that nothing is certain. So where does that leave families? Well NICE, the body charged with giving treatment guidance, wasn't due to review the guidelines until at least 2018, but we've learnt that this has now been brought forward to this year, partly due to the new information about the Pace Trial and a growing body of opinion in the United States, which has been brought to the attention of NICE by various ME charities. One important directive from the CFS Advisory Group to the US Government from August 2015 suggested that Graded Exercise and CBT shouldn't be seen as treatments for the underlying condition, but rather helpful coping mechanisms and there should be clear warnings about the potential harms of Graded Exercise. File on 4 has obtained internal emails released by NICE under the Freedom of Information Act, which would suggest the new information is being seriously considered as part of that review. Referring to the American directive in an email, NICE Director for Long Term Medical Conditions, Professor Mark Baker, said:

READER IN STUDIO: The British academic establishment holds an entirely different view.

HILL: He then added:

READER IN STUDIO: Though not necessarily better informed.

HILL: He finished by saying:

READER IN STUDIO: It remains a tragedy that this serious disabling condition has seen so little progress in a generation.

HILL: Acknowledging the difficulty of the task ahead in another email, he said:

READER IN STUDIO: This field is so hamstrung by context and perspective that it is difficult to know how to make progress.

HILL: As the debate continues over the current recommended treatments for CFS, there is a glimmer of hope that a completely different therapy may eventually help patients. In November, scientists in Norway are expected to publish the results of a trial there into how ME patients respond to a cancer drug. But in the meantime, some families continue to find themselves at the centre of allegations that they're making it all up. Sonya Chaudary at Action for ME says there needs to be a concerted effort to improve the understanding of the condition to stop families getting caught up in a web of accusations.

CHAUDARY: I think what we need to do is to really understand what is happening out there – to work with local authorities, to work with schools so that we can educate people to make sure that where the system needs to protect children, it does, and where the system is over-protecting children as a result of a diagnosable disability and illness, that they are not subjected to a traumatic process.

MUSIC

HILL: Back with Jane and her family in their new home, it's nearly four years since she was diagnosed, yet she's still bedbound. Her mum, Sarah, though still hopes for improvement.

SARAH: My hopes are that she gets better, that one day she wakes up well and she says, 'I want to go swimming, I want to get a tutor in, I want to do the normal stuff.' She wants to swim with the manatees on the Great Barrier Reef. Well, I want her to do that too. I want her just to be normal. I want to shout at her for coming home drunk from the pub, you know, I want all those normal things for her. That's what I want.

HILL: The allegations they had hoped to leave behind them in Bedfordshire have now followed them via official records. Old questions are being asked again and they're still being investigated.

SARAH: I just couldn't wish this illness on anybody, or the way that we have been treated. She's being discriminated against, we're being discriminated against because she's got an illness they don't understand.