**Safeguarding: Perplexing Presentations and Fabricated Illness in Children**

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0:55 **Speaker:** Hello. Well, thank you so much for joining me for this webinar. This is another one in our safeguarding series. Today we're looking at safeguarding children in primary care with fabricated or induced illness or perplexing presentations. Now, I'm well aware this is generally a paediatric or a CAMHS problem, and that's where it's primarily managed. But what I recognise as a GP is actually an awful lot of these cases that don't quite meet the threshold are being looked after in primary care,

and we're carrying quite a lot of risk associated with that.

So, I thought this was a useful presentation to really focus on how we manage these cases in primary care. I certainly wouldn't be aiming this talk at anyone in secondary care. And, you know, there's different expertise that's needed for that. But this is for us, GP's.

0:56 **Speaker:** So, over the next sort of 45 minutes, I'm looking at how the new Royal College of Paediatrics and Child Health Guidance has changed. It's come out this year. I think it came out in February. So, we are going to have a look at why this condition is just so uniquely challenging to manage. I mean, most of safeguarding is nuanced and complicated. This condition is really tricky. The guidance tells us how we should best be safeguarding children who present with these problems. And the guidance really is emphasising that here in the UK we are shifting towards trying to recognise these problems earlier, get in there, intervene before we've got definite proof of deliberate deception; trying to pick up problems before they become catastrophes, which is always good with safeguarding.

We are going to look at how cases we present, consider the perpetrator, how we should best manage suspected cases, have a look at the outcomes which are really quite worrying for this condition, and then have a look at further resources.

It's really important to note, actually, that that children and young people with these perplexing presentations will often, in addition, have a degree of underlying illness, and that makes it much harder for us, because if you've already got a medical problem and your symptoms are being exaggerated, it's much harder for us health care professionals to manage and treat appropriately and work out exactly what's going on. So, it's always worth considering that verified illness and fabrication can co-exist side by side.

2:41 **Speaker:** Just looking at what we had before, the Royal College of Paediatrics and Child Health Guidance was last written in 2009. There's been a big gap and quite a lot has changed in that time.

And we've got various other government documents that that make a difference. But this is really looking at the sort of whole parameter of the most severe cases, but also the sort of less concerning ones that we still need to make a difference with.

3:11 **Speaker:** So, as I say, this is a really challenging area. Working with families where there's concerns about the child's welfare is always sensitive and difficult to navigate. More than any other condition, here I think it's essential that we have effective cooperation between the different agencies and professionals. So, you really want to be working closely with paediatrics, with education, with the teachers or the nursery nurses, health visitor. All of us work together with social services to try and get the best outcomes that we can. Professional judgement is absolutely key here. You know, we can really make a big difference. Always got to follow safeguarding procedures. As I say, often our cases in primary care don't quite meet the threshold for formal proceedings. And I guess it's our responsibility and role to then be aware of our concerns, share our concerns in our clinical meetings. You know, this is a potentially vulnerable child. Everybody don't over investigate, make sure everybody's aware of the concerns.

It's a tricky one, but we do know very well that health care professionals play a role in inadvertently contributing to harm in these children. And the new guidance is encouraging us to, as always, practise evidence-based medicine, but retaining that professional curiosity and setting appropriate boundaries so we don't always investigate, investigate, investigate if we don't really feel there's a need.

For us in primary care, we're often aware of family dysfunction and if we've got concerns, it’s very important that we share those with secondary care, you know, make sure everybody knows what's going on. It’s tricky doing that, though, you know. This is such a sensitive and litigious area of medicine, but we've got to keep at the forefront of our minds the United Nations Convention on the Rights of the Child. Children have the rights to the best possible health. They have the right to privacy and for their views to be sought. And most importantly, they're entitled to protection from all forms of abuse and to rehabilitation when they've been maltreated.

So, to produce the new guidance, Royal College of Paediatricians did a survey looking at just what the professional concerns were about treating this condition. And, of course, the primary one that we can all relate to is that terrible fear that you're saying this is fabricated or induced illness and actually you're missing a rare but treatable condition. We can't get away from that. Safeguarding is always walking that tightrope between missing things or over investigating. And I think the key thing here is sharing concerns. Talk to your colleagues in the practice, talk to your Safeguarding Lead, talk to the Safeguarding Lead Nurse, or refer to paediatrics, sort of sharing the concerns about what you're feeling are. Other fears that professionals highlighted were fears for the child's safety while investigations into possible fabricated and induced illness continued. And I can so relate to this. Over a third of the respondents said it will be impossible to quantify the amount of time spent on a typical case.

These are such time consuming, challenging cases to manage. And of course, the one thing that all of us are so short of in primary care is time. These are always tricky.

6:40 **Speaker:** So, the essential things we have to be thinking about with this condition, the essence of fabricated and induced illness, is that the parents focus is on engaging and convincing doctors or health professionals about their erroneous belief, about their child's state of health. Now, that may be motivated by anxiety and they're convinced that their child is really poorly when actually they're not, or it may be motivated by gain. It doesn't always have to involve deception. And I think a key message is that we should be thinking about fabricated and induced illness with the same rigour that we do organic disease. It's not a diagnosis of exclusion. You don't have to do every single possible test you can think of before you get to the point where you think, actually, I don't think this is real.

It's really, really important that we focus on the harm to the child rather than the perceived severity or type of parental motivations. Honest communication of our concerns is really important unless doing that is going to place the child at risk of serious harm. And if you feel that is the case, it already needs to have been escalated to paediatrics and safeguarded by then.

I quite like this point. If secondary care isn't involved, teachers or GPs are advised to refer to Paediatrics or CAMHS's so that the child has a responsible consultant. Now, that's quite tricky because I've often felt, you know, the last thing this this family needs, is over investigation. Oh, you know, if they're referred to Paeds, perhaps that suggests I do think there's something wrong. But the guidance is clear. If we've got to worry about fabricating induced illness, they need to be referred with that made clear.

8:27 **Speaker:** So, there's lots of different definitions over the years. The first one that I ever came across was Munchausen by proxy. This was first described by Professor Roy Meadow back in 1977. We don't really use it anymore in the U.K. The term was based on an 18th century soldier who was notorious for telling sort of outrageous and highly embellished stories about his adventures. We talk a lot more now about medically unexplained symptoms, and this is where we believe a child's symptoms are genuinely experienced. You know, they really do have a horrible tummy ache or a bad head. But we feel the symptoms are likely to be based on psychosocial factors rather than organic pathology. And this is acknowledged by both clinicians and parents.

Medically unexplained symptoms are the names for this have been over the years, functional disorders, nonorganic disorders, psychosomatic symptoms. And I think we're all familiar with that. Experienced clinicians tell us that on occasion, medically unexplained symptoms may also include perplexing presentations or fabricated and induced illness. So, these things sort of exist on a spectrum really.

Now, perplexing presentations is where there are alerting signs of possible fabricated induced illness, where the actual state of the child's health isn't yet clear. But we haven't got any perceived risk of immediate, so serious harm to the child. So, we've got alerting signs which look at discrepancies between the history given and independent observations of the child or implausible descriptions or unexplained findings and sort of odd parental behaviour. You know, our ears are suddenly pricking up. We're thinking this just doesn't hang together quite right.

And then there's a further end of the spectrum. The fabricated induced illness is a clinical situation in which a child is or is very likely to be harmed due to their parents’ behaviour and action. And those actions are carried out in order to try to convince doctors that the child's state of physical or mental health or neuro development is impaired.

Now, really important, we know fabricated and induced illness results in physical and emotional abuse and neglect as a result of these actions and also from the doctor's responses to this.

Now, the parent doesn't necessarily intend to deceive, and their motivations may not be initially evident. So, again, it's clinical judgement, thinking curiously, always wondering what else could be going on here.

11:09 **Speaker:** So, lots of research and experience has taught us that, yes, fabricated or induced illness is rare. It is thought to be one child per year, per million people. But actually, it is thought this is probably an underestimate. And it's thought to be underreported nationally. Lots of studies show paediatricians tend to feel that identification needs to be virtually certain before they call a case conference. And there's lots of reasons for this. As we said, you know, the fear of calling this fabricated induced illness when actually there's some incredibly bizarre and rare medical condition underlying it or, you know, fear of litigation. It's a tricky one to get wrong.

It's really important that we distinguish between very anxious parents who we've all come across, you know, new mums and dads with crying babies where there's nothing wrong but they're terribly worried about it. And, you know, we've all got a duty as GPs to sort of support and help parents with that. Those sort of extremes from abnormal behaviour. We also need to be thoughtful of cultural behaviours and practises.

So, it's really important if we're worried, as always, with anything complicated, really careful documentation. You need to put down specific facts, not opinions. It always carries a lot more weight. So, name the person who's describing any observations about the child. Record parental response to information given to them. Always keep parents informed of findings of medical investigations unless sharing concerns with them could jeopardise their child's safety. Try, if you possibly can, to see the child without their parents and have a look in the GP records for inconsistencies in the chronology of what's been going on.

13:08 **Speaker:** The perpetrator is nearly always the mother. Half of these people work in medical professions, which gives them a sort of background knowledge that enables them to sort of carry out this sort of deception. Specific aspects of the perpetrator's histories are likely to be troubled. They could have experienced loss or bereavement. They could have their own health problems, physical ones or psychiatric. It is very common to have relationship problems between the parents. Sometimes the perpetrator has had difficulties taking on the role of parenthood, or they may have had obstetric complications that sort of left them vulnerable. Now the dad can be actively involved, or they can just be sort of going along with it and ‘oh, Mum knows all about everything’ and aren't that aware. But don't assume the father isn't aware. You know, they may be. Psychiatrists feel that perpetrators have a disturbance in their sense of reality. They were often not nurtured or cared for themselves, are probably highly likely to have had childhood ACEs. And it's thought that the pathological functioning sort of stabilises their sense of self. They very often lack the capacity for self-reflection. They don't have much insight into what's going on and they can have difficulties so that regarding any emotional response is real. Somatising is a way that they cope with their problems and then they transfer that somatisation over to their child. They often have long histories of deception, which can date right back to adolescence.

14.55 **Speaker:** So, we understand the sort of background of why perpetrators do it, but the sort of immediate gain is that they can, by describing their child is unwell, get sympathetic attention, they can get sympathetic attention from, you know, the medics around them, but also perhaps from the teachers, from family and friends. So, a lot of sort of positive focus can come their way because of it. They may find that their child being ill means that they can have a continued physical closeness. You know, they may be very dependent on the child and it stops from going to school, for example, or, you know, your poorly come and have a cuddle up on the sofa with me and let's watch a film together rather than going out to play with your friends. It may be that they're having difficulty managing their child, so they seek inappropriate mental health diagnosis to sort of justify what's happening. You know, they may feel, if I can say my child's got ADHD or is on the autistic spectrum, then that's why it's nothing to do with my parenting. They may also have some material gain from this. You know, if they've got a sick child, they could get financial support, they could get support with housing, with mobility, all sorts of things. The other reason why parents may do this, or perpetrators may do this is they may have erroneous beliefs about their child's health. Often, you know, really extreme concerns and anxiety about them. This may be focussed on their health, their conviction that they're really sick. And we've got to get to the bottom of this. You know, we can't go on like this. Or they may have a sort of educational focus and feel that their child needs additional support at school. Some parents may be unconscious of the sort of motivations behind their behaviour and both motivations may be present, but usually one or the other will dominate.

It's tricky for us because both of these are very different motivations, but they both faces with equal and very difficult dilemmas and can both, most importantly, lead to similar forms of harm in the child. Looking at sort of erroneous beliefs of health problems. Social media and support groups we know very well can be superbly helpful for parents with children with chronic ill health. A really important source of support and giving them extra information. But sometimes these groups can post inaccurate information. They can even sort of give information about how to obtain diagnoses, which the child doesn't have, which, of course, can lead to harm. Parents are just typically not reassured by health professionals, are not reassured by negative investigations.

17:50 **Speaker:** So, this is always a colossal dilemma. Should we or should we not intervene? These judgements about safeguarding and child protection unavoidably will entail an element of risk. And we're always balancing the two extremes of leaving a child too long in a dangerous situation versus removing a child unnecessarily from their family. And both of them are, you know, enough to keep us awake at night. They're really tremendously difficult situations to manage. And so, we've got to be using our professional judgement after a sound assessment of the child's needs, trying to work out the parental capacity to respond to those needs in the wider family circumstance. If we can possibly try and spot these problems early, we can stop them escalating.

It is tricky, though, because our desire to trust and work with parents, you know, it's just fundamental to general practice. If you've got a mum who's worried about her child, everything we've been taught is that we should listen to the mum, we should sort of hear her, we don't want to miss anything, they're usually right. And course with fabricated induced illness that's turned on its head. But that that sort of deniable belief that we live with, does make us unwitting accomplices in these situations. And so, it takes an enormous shift in attitude for us to accept a story that doesn't ring true, even if it's a sort of active case of fabricated induced illness that we're aware of, we still tend to sort of fall into the sort of pattern of believing what parents are telling us. Often as well, just to complicate the issue, the child does have an existing medical diagnosis. And so, the parents account may well be partially true. So, in these situations, good medical practise, you know, in arranging investigations and referrals, treatments or say, ‘well, I think you're right, I think going to school every single day is going to be a bit too much for her’. All of those things can contribute to iatrogenic harm. And we've got to strive to avoid over medicalisation of the child's reported symptoms despite our feelings of concern. And we should never, never carry this alone. We've got to be sharing this with our colleagues, our Safeguarding Lead, Safeguarding Lead Nurse and paediatrics. You know, this isn't one for us to carry alone.

Another thing that makes it quite tricky is the children themselves will often protect their abusers and resist making revelations to the professional from either health or social care or education. who could rescue them. And then, of course, that's because the child's family is so precious to them. And on some conscious or subconscious level, they may well see that that they're their Mum is gaining something that she desperately needs from the continued sort of health input. And so, the child calling it out is going to put their mum at risk of harm. And no child really wants to do that.

21:00 **Speaker:** But we have to be aware of this because there are really significant harms that can come to the child as a result of this. So, their health and their experience of health care will be damaged by sort of repeated unnecessary appointments or examinations, investigations and treatments. And also, you know, like the boy who cried wolf, genuine illness may be overlooked due to the repeated presentations. In a more extreme case, and this is where the risk of harm is very, very high indeed, illness may be induced by the parent. I remember a case about a decade ago where we had a baby who was failing to thrive under the care of the paediatricians. And I was seeing them regularly for a while. We had absolutely no thought of anything other than that this baby was, you know, organically not well. But it turned out that the mom was adding lactulose to the baby's formula, and that was what the problem was.

And then it can have significant effects on the child's development and daily life. So interrupted school attendance, the child sort of takes on the sick role and that becomes, you know, part of who they are. They can be really socially isolated and have a very limited, normal life with, you know, significant consequences. And, of course, it can have a huge effect on the child's psychological and health related well-being. They may be very confused and anxious about their state of health, that they might well develop a false self-view of being sick and vulnerable, particularly teenagers, can get very caught up in that, and it's part of their identity. And equally, they can actively collude in the deception or they may get silently trapped in falsification of illness.

The nature of the parents’ motivations and the severity of their actions actually bear very little relation to the severity of harm to the child. And we need to be focussing very much on the child in front of us, although as GPs, quite often the perpetrators are patient too. But just whilst focussing on this, we've got to prioritise the needs of the child.

The siblings as well, they can be affected. They may well be very anxious about their brother or sister and their state of health, or equally, they may feel quite neglected themselves because their parents are so focussed on their sibling that they sort of miss out on anything.

23:30 **Speaker:** So alerting signs are signs and symptoms that are not explained by any medical condition where physical examination and tests don't explain what the presenting history is. You can have a sort of inability to corroborate the history provided by the carer. That the symptoms are never observed independently. You know, teachers say ‘Oh they're always fine at school’ or nursery reports no concerns. You can get sort of bizarre test results. You know, Mum said that they've been bleeding and bleeding and bleeding from their nose, but the haemoglobin is completely stable. Or they can have a sort of bizarrely poor response to treatment. You know, you have to titrate the laxatives up and up and up, and actually, the mum's not giving them anything. And also, where the child's daily life is sort of abnormally curtailed; where you know other children with this condition who are actually going to school and thriving and getting on well, these children are often, you know, unable to do even sort of basic things because they're their Mum or Dad say they just physically wouldn't be able to do it, but you think perhaps they could.

24:44 **Speaker:** Alerting signs in the carer. I guess persistence is the biggest key to this. You know, the perpetrator will absolutely insist on continued investigations rather than focussing on symptom alleviation. They just can't accept reassurance, or they won't accept the recommended management, particularly if that involves watchful waiting. You know: ‘We got to do something. How can you possibly just leave it like this? This is this is outrageous!’. There's often a huge amount of pressure. They oppose objective assessments. They sort of come up with new symptoms when you've resolved the original ones. It is very common to have repeated presentations. This can include the emergency department or moving from one GP to another, either within the same larger practice or changing GP's, which makes it very difficult. But that's common. They will often inappropriately seek multiple medical opinions, you know, say, ‘Oh, she was rubbish.

She just didn't listen. She didn't she didn't give me any time at all. I want to see somebody else’.

And then on the flip side, whilst they attend frequently, they often aren't brought for sort of planned appointments. So, if you're desperately trying to set up some boundaries and say, OK, we will see your child once a week, because obviously there's lots of concerns. If we have one appointment every week with me, then, you know, we can make some progress and they will often not attend that planned and scheduled appointment and then keep coming back to see the duty doctor on a different day.

Another common thing is that they refuse communication between professionals. So, we've got a case of this and we're a border practice. So, we can refer to hospitals in Gloucester, in Bristol and also Neville Hall and the Royal Gwent. And, you know, we've got this patient who has been investigated in all four, refuses to allow any of the investigations from one hospital to be shared with the next hospital because they say that it was incorrectly done, then you know, that's clearly not acceptable really for that child because you can't put them through the same investigation twice. But it's quite tricky to manage. And equally, you know, the biggest thing and probably one of the reasons is so much time tied up with these cases is that there are often vexatious complaints about professionals coming from these families, which just adds to the complexity. They often won't let the child be seen on their own. There may well be factual discrepancies in their reports. And sometimes they'll be pushing for drastic or irreversible treatment options. He needs a peg feed. He needs, you know, a stoma. Sort of really dramatic things that wouldn't have been on the table really if it wasn't for a strong parental push.

This can result in conflict between the clinicians and the perpetrators. It can also, more challengingly, result in conflict between professionals where one professional thinks there is an organic problem and another thinks this is fabricated induced illness. And one of the things that's really important to recognise is this sort of toxic combination of pressures in these consultations increases the risks of clinical mistakes being made and you doing the wrong thing because your head is, I suppose so fried with all the sort of conflicting problems that you're trying to deal with.

So just remember, when you've got these cases in front of you to slow everything down, think twice as carefully, you know, check with other people. Don't allow yourself to make that mistake because you're feeling stressed or frazzled.

28:35 **Speaker:** It's really important with cases like this that we always explicitly explore whether

there are adverse childhood experiences present because they are much more common. So, you remember the ACEs are physical, sexual or emotional abuse, neglect, really common in the whole family. Look at the siblings. Domestic abuse is much more common. Even child sexual and criminal exploitation can go on. Bereavement may be underlying some of this. There may be parental alcohol or drug abuse. Quite often you may have parental mental health issues. And, you know, a parent in prison is the one that we often don't think about with ACEs, but it's quite significant.

29:21 **Speaker:** So how do we manage these individual cases? Never more important to remember our Hippocratic Oath of ‘do no harm’. Don't introduce iatrogenic harm here. We must remember as GPS that all parents demonstrate a range of behaviours in response to their child being ill. We're taught to listen, listen, listen to the concerns of parents and we're taught to act on them. Part of our role is to assist parents to respond appropriately to the state of their children's health. You know, with new mums I always say your job isn't to know whether your child is unwell or not at this stage. You know, if you're worried, talk to us and we can advise you. And then you'll get to know, you know, and we know, you know, a mum who presents with her third baby being unwell we’ll perhaps be more alert that this may be significant because they know what they're doing by that usually. So that's part of our role. And if we're skilled at this, our interventions are likely to enable most parents to learn to interpret the child's state of health and manage their own anxieties. But if we see an alerting sign is really important that we look for others. And yes, if we find these in primary care, it is appropriate that a paediatric or child and adolescent mental health referral is made because that's where the resolution lies to get to the bottom of what's actually going on with this child. So, we can refer but refer with it with enough information that they know that we've got some worries.

31.04 **Speaker:** Of course, if there is an immediate serious risk to the child's life that needs an admission, or it needs the police involvement or social services immediately. Always think as well about other children in the family or vulnerable adults. Illness induction is the biggest risk here, I think, in this situation. Be careful about informing parents of a referral if that's going to place the child at increased risk of harm. And documentation is really key. There's a really nice phrase that can be used that shouldn't end up with a sort of a complaint, but you know, expresses your concern so you can document:

‘This unusual constellation of symptoms reported but not independently observed is worrying to the extent that, in my opinion, there is potential for serious harm to the child’.

Now, that will alert other clinicians without you saying anything definite. You know, you're hedging your bets and there is no way the GMC are going to have a concern about that being written in the child's notes. If you're documenting and alerting signs, it's absolutely fine. Is that same thing where, you know, every urgent suspected cancer referral does not have to result in a cancer? You know, we don't have to get 100% hit rate because if we do, we're missing cases.

32:33 **Speaker:** So, we're going to start looking at managing perplexing presentations. Now, this denotes the presence of alerting signs to possible fabricated and induced illness but in the absence of the likelihood of immediate, serious risk to the child.

In the first instance, talking to the parents about the different perceptions that they've got compared to our perception of what's going on and how this could cause harm to the child can be really helpful, especially if it's done early on and done in a really sensitive way. Our first job is to sort of establish the true state of the child's health and the family context as well as we can. We need to address the child's whole holistic needs. You know, their physical, their social and their emotional outcomes are what we're thinking about. Need to involve child safeguarding if we're concerned. And that will result in a carefully planned multidisciplinary team response, which is usually led by secondary care. We tell the parent what the term perplexing presentation means and then talk about the management approach. Now we do that with both the parents and the child, if the child is old enough to understand. And when you have a multidisciplinary team meeting, very important that the minutes of that are agreed by everyone present because they may well be used in sort of complaints down the line. It's really important that we recognise outcomes are much improved when you've got a clear protective framework and a sustained therapeutic programme with the whole multiagency, multidisciplinary basis involved. We very much need long term follow up because there may well be sort of ongoing emotional and behavioural issues as a consequence of the abuse or the perpetrator may well sort of fall back into its previous patterns of behaviour. So, you don't just discharge these children or not follow them up if you think, oh, that's great, everything's resolved. Always think if you've got a past history of fabricated illness and the perpetrator becomes pregnant, that that perpetrator needs a flag on their notes. Hopefully nothing will happen, but you need to be very, very thoughtful about that if that happens.

34:56 **Speaker:** If you make a referral - the usual thing - you follow the sort of safeguarding procedures for your area. You would want to be documenting what are the genuine medical conditions the child has. What are the concerning presentations they've got? What's already been tried? What's been the impact on the child? What is their current level of functioning? And start a brief chronology of what's happened, if you possibly can, if you've got time. It's important to recognise when we're working with children and families that of course children attach great value to their family relationships. Family members know more about the family dynamics than any professional ever could. And if we work together, we get the best outcomes. Children of an appropriate age need to be kept fully informed with what's going on. And decisions about their future really does need to take account of their wishes. Try and get the parents to play as large a part as possible in decisions about the child. Partnership with the parents doesn't necessarily mean we're going to be agreeing with the parents, but we're working together to share concerns whilst always, always keeping the safety and welfare of the child is our paramount priority.

36.17 **Speaker:** Now, this is a flowchart which hasn't actually come up very well on this, but if you Google - chart perplexing presentations, Royal Society of Paediatrics and Child Health, that will come up and you can get a copy to put on your wall if you if you want it.

36:40 **Speaker:** It's very important that we share responsibility for this. I've probably said five or six times. Don't carry this burden, this concern on your own. The consensus about the child's state of health needs to be shared between all health care professionals involved with the child and family. So, we're looking at GPs, we're looking at secondary care, private doctors, which often get involved. You know, ‘I'll pay for a second opinion’. They are important as well. And any other significant professionals who have observations about the child. So that's education, social care. All of these people who are involved, are really important. We need to be sharing information, collaborating. If professionals disagree, need a sort of open discussion about concerns and feelings so that so that we get to a sort of agreed consensus in the end. Important to have strong leadership from senior members of each agency to foster these constructive relationships. Strategic cooperation really, really makes a huge difference to outcomes for these children. Again, just highlighting the fact that just one case like this can make significant demands on an agencies, resources, you know, small primary care team. This will be whole weekends of work trying to get a chronology together or go through all the records and hospital that is trying to tie it all together. It's very tricky. But the majority of cases are confirmed in a hospital setting.

You need to make a decision between you (this multidisciplinary team) about whether the perplexing presentation is explained and resolved by a verified medical condition or whether concerns do still remain. And then once a consensus is achieved, you have a meeting between the parents and at least two doctors. I've had that with paediatrician and GP quite often. And then you sort of explain to the parents that the child's *issues*, which is perhaps a better term in these situations, and symptoms may actually have no diagnosis. You need to be clear in your acknowledgement that this might differ from what they've previously been told by other professionals, and it may diverge significantly from their own views and beliefs. These are really, really challenging consultations. You then, if you possibly can, develop a plan for rehabilitation and as I say, the child must not be discharged until it's clear that rehabilitation is proceeding, and the child is safe. And if you feel that's not the case, you need to refer to social care.

39:24 **Speaker:** If it's all going well, you develop a health and education rehabilitation plan and you can't underestimate really the importance of primary care in this. Individual professionals often don't have all the pieces of the safeguarding jigsaw puzzle. And so, you need this coordinated approach. GPs have got lifelong relationships with parents. Often, we've got extensive knowledge of relationships with multiple generations of families. So, it's really, really essential that secondary care, social care keep us fully informed. And we're then best placed to support children and their families. You know, it's tough. We're often looking after the victim. The child may very well have the perpetrator as our patient as well. And then in addition, you may have paternal granny who's worried sick but doesn't know what to do. And, you know, you've got to be terribly careful with confidentiality and supporting everybody. But, you know, that's our bread and butter. That's what we do best to.

40:18 **Speaker:** The Health and Education Rehabilitation plan requires us to rationalise and coordinate medical care. And that might be medicines management, reducing medication, changing medication, titrating it down. It may be resuming oral feeding from a peg feeding fed child or offering support with graded physical mobilisations. You might need some psychological support to help the child adjust to a better state of health. And it's really important that the family is supported to construct a narrative to explain the evolution of the child's difficulties. You know, you could imagine big sister being given a really hard time at school because her terribly unwell little brother has suddenly come back to school and seems fine. That's really tough for families and siblings to cope with. And just emphasising again, all of these children need long term follow up.

41:13 **Speaker:** The brutal reality of why this is such an important topic is that 10% of these children die and half of them have long term consequent morbidity. It's very often the case that siblings have previously been physically abused. It's often ACEs (adverse childhood experiences) going on in these families. Some of the children do suffer from verifiable medical conditions, so they still need managing as well. Over three quarters are younger than five at the time of identification. It's more common in little children. And the median age of diagnosis is 20 months, but it's often over six months before identification occurs. And you can imagine how many investigations and how many presentations may have happened before that's done, so it's just so important for us all to be to be thinking about this.

42:09 **Speaker:** Record keeping is really key, particularly in, thinking about complaints. Very important to consider the confidentiality to the child. Your Caldicott Guardian is someone to talk to about this and how to go about this carefully. Keep really careful, complete notes at every stage. Who reported the concerns, what was observed, by whom etc. Record, what has and has not been discussed with parents. Now, this is a really tricky and one that a lot of us, I don't think, are fully aware of. Any emails about the child form part of the health record. Now, that can be emails between health professionals, between the parent and the health professional and between the children and the clinician. Now, obviously, you can redact things that you think could cause harm, but it's just worth thinking if you bang out an email to the to the paediatrician sort of raising concerns, you're feeling sort of between professionals that could still be asked to go to court. Because the truth is that subject access requests from parents in these cases are not uncommon at all. So, they're much easier to manage if there's been open communication previously. If you're not sure what you should and should not retract, seek legal advice, you know, that's what we pay our MPS or MDU fees for. That's what the GNPI is about. You know, we're not expected to be experts in absolutely everything. And if we're not sure, ask somebody else. The Child Protection Lead is also a really good source of information.

The key thing always is the child's best interests must be our overriding consideration. Take the advice of designated professionals, use clear, concise, accurate language. We don't have to give parents access to records if we think that could cause harm to the child. And also, if the child has explicitly or implicitly made it clear that they don't want information disclosed to their parents, you can justify denying it. Always try and think holistically. The whole family, the whole picture for the child, rather than just about the presenting symptom.

44:25 **Speaker:** So, there's a lot of horrible consequences for these poor children - physical,

psychological and emotional consequences. The involvement actually by the child forms a continuum. So, they may be absolutely clueless that there's anything untoward and think that they are poorly, or they may be just passively accepting, or they may be actively participating in the deception or they may start self-harming themselves. Some of these children remain fully dependent on their carer and some grow up, you know, become teenagers and then start to collude and develop their own somatisation disorder. Horrible thing. Some of them, as they get older, just can't recognise if they are actually unwell. You know, they don't know what's real and what's not. And many of them feel really guilty about the perceived collusion. And you know that they're not real, that they’re dishonest.

45:22 **Speaker:** We've got a key role to play in this, and I felt we needed a bit more of a mention in the new guidance, to be honest. We are just so well placed to recognise early signs and symptoms, and we've often got unique knowledge of uncorroborated old presentations, you know. We know who the frequent attenders are. We may be able to see lack of discrepancy between signs and symptoms from what's observed and know about a sort of previous history of abnormal illness behaviour in a family. Family structures they are so often really complex these days. And it's important that we pay attention to all of those people in a family who may have something significant to contribute to decisions about the child's future. It's a good idea to ask the child.

They tend to be really great at identifying adults that they feel could be important, supportive influences in their lives. You know, he said: ‘Oh, yeah, well, you know, great Uncle Bob's really good.

You know, he's always kind and he know when my Mum's off on one. He comes over and takes me out for chips’. They know who the adults are who have got their back.

We need to try and identify adults who, you know, either knowingly or unknowingly support the perpetrator. Older children will often have a clear perception of what needs to be done to ensure their safety, but of course, many are still knowingly cooperating just to try and maintain family relationships.

46:57 **Speaker:** Practice administration needs to be really, you know, on point for managing these cases. They do, as I say, often move from GP to GP. So, this needs prompt record transfer. And, you know, I tend to pick up the phone and have a word with the Safeguarding Lead in the new practice just to share those concerns and send a written summary while they wait for the records to come. It is really important you professionals have a good idea about the child's history to try and avoid, you know, getting back on the on the sort of role of starting all the investigations again. So, talk to your whole team about that.

47:42 **Speaker:** Child and adolescent mental health have a useful role to play here. Fabricated or induced illness in mental health settings is particularly difficult to identify. And they may also help us with direct interventions for how to support families. They will assess the child's psychological functioning, assess their health beliefs and their anxieties, and they may well be able to offer some family therapy that can help. And in doing so, assess the family's capacity to meet the child's needs.

48:16 **Speaker:** Adult psychiatry. This is for us as GPs really. Supporting the carer after disclosure can be really difficult. So, a psychiatric referral may be helpful. Adult psychiatry may well take a forensic role in court proceedings. They certainly can contribute to the safeguarding process and identify those pathways that we talked about at the beginning that led to the abuse. They can help with risk assessments and in some cases can offer some therapy, which may help.

48:45 **Speaker:** So, to sum up, fabricated and induced illness is rare but the wider spectrum of fabricated or reduced illness concerns or perplexing presentations, medically unexplained symptoms, that is not rare. We see that a lot. And we need to be always thinking carefully about how best to manage. Follow local child protection procedures if we need to. Sort of the worst end of the spectrum, the morbidity is very high, but there's a spectrum of severity that requires different responses. And we don't always have to sort of escalate straight up if we think we can get in there and support early and make a difference. Our leadership is really, really essential here in order to try and minimise or totally avoid iatrogenic harm or other harms to these children. Developing a medical chronology for them really helps. And as with all aspects of safeguarding children, practising with active curiosity, strong leadership, multiagency team working, good record keeping and communication, all are absolutely vital to trying to get the best outcomes for these children.

50:02 **Speaker:** This is really demanding work. It can be distressing and stressful. So, it's important that teams try to recognise the lead clinician and support them, especially if they've got close relationships with the family. These are the ones that often you take home on your shoulder and can keep you awake at night. Use experienced professionals to get advice. Don't carry this on your own. Watch out for differences of opinions. Try to avoid professional sort of antagonism, you know, work together. We're all on the same side, open discussion and let senior staff take responsibility.

50:39 **Speaker:** That's the link to the new guidelines, which is, you know, it's worth a read. It's not to say not too turgid. And then if you want to read a bit more, there's a couple of papers there from the last couple of years which are interesting and go into it in a bit more depth.

If you like, reading, you know, narrative medicine. I was recommended ‘My Cousin Rachel’ which is a Daphne Du Maurier book. I read it. I don't think it's fabricated illness, actually. I think it's poisoning someone to try and get their inheritance, which is slightly different. But I suppose there's some links. I read that book ‘Sickened’. I didn't enjoy it very much. It felt like one of those misery memoirs. But actually, after I'd finished it, I reflected just how many investigations that poor child had and that she'd actually disclosed what was going on to three different health professionals. And they just hadn't believed her because the Mum was so plausible. And it made me think, yeah, actually it's very easy when you're just sitting through a webinar on fabrication and induced illness – ‘well, of course, I'm always going to be looking out for that’. But if this case is tucked in, you know, patient number 14 in a 20-patient morning surgery, it's very easy not to be not to be spotting it. So, it was it was quite a good book to raise my awareness to how this can be missed. And then ‘Murder on Ward Four’ is the story of Beverly Allitt the health care professional who killed all those babies on the special care baby unit. Pretty awful book, actually, and that is us.

So, yeah, I'm now open for any questions. And if you don't get a chance to ask me, I'm very happy to be contacted later on that email or through Twitter. And if I don't know, I'll try and find the answers for you and get back. Thank you very much.