Wetenschap voor Patiënten (Science to patients)
Seminar 28: Interview with dr. Nigel Speight

Interview with dr. Nigel Speight, paediatrician. Broadcast 7th January 2014

I'm Rob Wijbenga, chair to the ME/cfs association in the Netherlands, and I'm a representative for the project Science to Patients. In that function I'm here to talk to Nigel Speight, paediatrician, who has been willing enough to participate in this project and to give six short talks on different aspects of ME/cfs based on questions from patients.

Welcome doctor Speight and thank you so much for participating. I believe you have been involved in quite a number of cases where children with ME have been threatened with removal from their families by social services. Could you tell us about this area?

Well this is a very painful area. It's one of the most unpleasant things I witnessed in my entire medical career. It's something that I've seen all over the British Isles, I've had cases scattered throughout the map of Great Britain. And they all seem to have similar causes, and a lot of it comes from a simple failure of doctors to protect patients by diagnosing them with ME/cfs. Which then leads them at risk of being persecuted for alternative explanations.

I have had about over thirty cases which have all resulted in child protection proceedings with case conferences being held and the threat of removal. Fortunately most of them we have managed to avert by early intervention, giving second opinions. But quite a few have actually, has been a real threat of removal, and one or two children have actually spent time away from their families against their will. Because of court proceedings.

Could you tell us about any particular case, which demonstrates this problem?

Yes, there is one from an area in the Midlands. We'll call her Tiffany, it's not her real name for confidentiality. A lovely 13 year old girl, lively, talented, musical and she was in perfect health until she was struck down with quite acute onset ME, at the age of 13. And she was so ill that her mother had to turn to hospital doctors for admission to hospital. She did this openly and trustingly, and once in hospital she was under a paediatrician who believed in ME and everything seemed all right.

But gradually the multi-disciplinary team, including a child psychiatrist, an occupational therapist and a physiotherapist, took over the management of this case. And they set up weekly meetings where the girl was set targets, where she had to reach these targets. And she'd be taken to these meetings in her wheelchair with her head sagging, and have to sit through them and agree to try and achieve the targets next week.

She was in hospital for three months, she got steadily worse despite cooperation. The professionals could not tolerate this failure to improve, and they blamed the mother. So the mother' s visiting was limited till 6 p.m. So the physiotherapist had her all day long. The nurses used to leave her food outside her reach, so she would have to fight to get to it. Whenever her mother came in she found her demoralized and tearful.

Subsequently despite the mothers visiting being limited, the child continued to get worse. The first paediatrician said: "You might as well take her home", and so the mother took her home.

And then the family doctor came and subjected her to 30 minute intense interviews to try to find out what her mental state was and why she was in this state. The girl was reluctant to keep talking to this GP and he reduced her to tears. The family doctor then informed social services that she couldn't accept responsibility. And social workers came with police and removed this girl from her mother again, and then treated it as a case of Münchhausen syndrome by proxy. Mother's visiting was restricted to when there was a social worker present. And the plan was to remove her to foster care for six months. And this was the aim that she then would get better, because it was her mother who was making her ill.

I was called in by the independent social worker, and met this girl, totally demoralized, resigned going to foster care. And I simply put in the opinion that their management of ME had no evidence to support it, and that it wasn't the mother's fault. And fortunately we did manage to get that girl discharged home, after which she made a slow but steady recovery. She has now completed university. So that was a happy ending, but a lot of unnecessary unhappiness on the way. And that was a reasonably typical case that went quite a long way down the line.

That was a nice intervention you could say.

Well that is the virtue of the independent social worker system. How far down the court system goes there is often a chance for second opinions and to try to oppose these sort of proceedings. I'd like to say I have been successful in 28 out of 30 of the cases I have been involved in. But the two that I have lost have been very unpleasant.

That's marvellous. And do you know of other cases, taken care of by other paediatricians.

Yes, I had a case which was similar but different in some ways in which the influence of psychiatry was greater. And this was again a girl of about 13 or 14 in Scotland and she was under the care of a paediatrician who diagnosed ME quite confidently and she was moderate, moderately severe. But then she got more severe and this is one of the risk factors. The severe case of ME is not tolerated by professionals.

The paediatrician lost her nerve and referred her to psychiatry who made the alternative diagnosis, not of Münchhausen syndrome by proxy this time, but of a thing called the 'Pervasive Refusal Syndrome'. It wasn't a case of pervasive refusal syndrome. She was cooperating, she was just very ill.

And by the time I was called in to intervene I found her on a psychiatric ward, curled up in a foetal position, being tube fed and very very sensitive to light and sound. And every time the nurses closed the door a shudder went through this girl's body. But the psychiatrist would not allow her to have ear protectors because that would increase her sense of withdrawal. And the psychiatrist insisted on talking to her in a loud voice and this way they would cure her of her Pervasive Refusal Syndrome. I'd like to say the court order was reversed a week later and she went to a gentle nursing home where she has been allowed to make a slow but steady recovery.

But how you can change from having ME to having a purely psychiatric diagnosis just because you have been handed from a paediatrician to a psychiatrist I don't really understand***.***

What is your understanding of the factors leading to this state of affairs?

I think it is easy to blame the social workers because when they come in what they do seems to be so cruel but I think we actually have to blame the medical profession first. It is the medical profession's duty to be able to make a confident clear diagnosis of ME/cfs. And if they do that, this should be protection. But many of the cases I have seen have not even be diagnosed and then care proceedings are started by the education authorities for non-school attendance.

So doctors have to get it right to start with. The social workers will only get it wrong if the doctors don't protect the child with a diagnosis. I should say, I have seen a lot of real abuse in my life, and I have been involved in protecting a lot of severely abused children. And to now being on the other side and to see innocent families being persecuted by the social workers who should be protecting other children is remarkable. I once saw a 9 year old boy who was threatened with care proceedings and as part of my assessment I asked him his three wishes. Which is one of the things you do to understand a child's state of mind. And beautifully he said: ' I wish there were better judges and social workers in this world who would do better protecting children who need protection and not troubling families like mine'.

And this is a child of nine ???

A child of nine. Out of the mouth of babes and children.

I should say that once someone pulls the trigger to set child protection proceedings in motion it is like an ocean liner. It is like a juggernaut. It is very difficult to reverse. You have a social worker who is trained in child protection. They are used to parents protesting their innocence they have to overpower them and they keep going. And the further the proceedings go, the more the professionals dig in and cannot afford to lose face or to admit that they are wrong. I should say I have had one beautiful experience of a social worker who was completely converted by seeing the film 'Voices from the shadows' which touches on this, that she became an advocate for the family, refused the psychiatrist's diagnosis of child abuse and helped them to withstand further pressure. So that film did a lot of good there.

Fortunately there are cases like that.

There is not much independent thinking in most of the cases, there is a sort of collusion when the whole case conference has met and as one they have voted the same way. They all feel supported by each other.

And you don't see a development for better in this country?

I have got three cases going at the moment and that is not good.

How can you explain the spectacle of otherwise caring professionals inflicting what you have described as child abuse by professionals?

Dr. Leonard Jason as a social psychologist said very perceptively that as a group professionals can commit acts of cruelty that they would not be capable of as individuals. But somehow their kind of self-righteousness of a cut case conference, all agreeing together allows them to proceed down these lines. I keep yearning for there to be a little boy who says ‘the emperor’s got no clothes on’, but there’s a lack of independent thinking in the process. So once the process starts it’s very hard to reverse.

I’m just astonished at how few doctors can confidently diagnose ME/cfs and protect children. I say I’m only seeing the bad cases. Maybe lots of children are being protected.

The educationalists have a pressure on them to ensure school attendance. So if children aren’t protected by a diagnosis they will set the motion going. I sometimes think the child-protection social workers who are handling these innocent families are relieved to have such a soft target. Because most of the time their families are very tough to deal with. And if I was a social worker in child-protection I would much prefer to be drinking tea with a respectable innocent family and just taking one or two years of my time over it, than going to a house where my tires were slashed and I was threatened by Alsatians.

But I have to say there is something once the whole process gets going, there is a kind of almost sadistic element to some of the worst cases. They must be able to see the suffering they are causing. And so often as a group the professionals fail to actually speak to the child who is usually quite old enough to tell them their opinion and to put them right. And if you talk to the child it all comes straight.

I sometimes think we should make a dossier of all the cases. I haven’t got round to it but we should take it to people in parliament and colleges and paediatrics and everywhere because it is not getting better at the moment.

So you don’t see any change of attitude at all?

I sometimes feel it is getting worse.

And then you talk about a group of psychology who is at work. Everybody feels supported by the unanimity of the club.

Yes.

So you see independent psychologists who are driven along with this current

I have seen quite a few cases where the fact that the family have declined the help of a psychiatrist has led to the child protection proceedings. The psychiatrists have felt rejected and have instituted child protection proceedings almost as a revenge.

I should say there is another aspect to all this which sometimes comes more from paediatricians, and this is doctors who believe in their therapies. Whether it is graded exercise or cognitive behavioural therapy. And if it is a severe case and they can’t travel, the families are accused of ignoring medical recommendations. Now adults can do that, but parents refusing on behalf of their child instantly makes the paediatrician say they are refusing medical advice, this is child abuse.

So this is more or less a law…?

Yes. Well it is the false believe that they have got effective treatments. So often these treatments, the physiotherapy actually make the children worse.

Can you think of anything which will cause, let’s say a new way of thinking? Which tools are available right now to help to effectuate that, if there is any?

I have great difficulty thinking of anything at the moment. There is nothing actually happening. Maybe that a cure is found then the doctors will get ME right and the social workers won’t have any referrals. But we need something dramatic to happen. Another possibility is that some families actually take legal proceedings against the professionals and begin to counterattack. But I think most of them are so downtrodden and are so frightened of further action that’s beyond them. So at the moment I am still quite pessimistic.

Thank you so much for participating. People all over the world will look forward to your share in the talks we are broadcasting on our Youtube channel . Thank you so much.

Seminar 29: What is ME and what is CFS?

Dr. Nigel Speight, consultant paediatrician. Broadcast 14th January 2014

How did you get involved with ME?

I am doctor Nigel Speight. I am a general paediatrician. I worked in the north-east of England and over 25/30 years in paediatric practice I developed a major interest in paediatric ME/cfs. I ended up in having seen over 500/600 patients throughout the country and I am still seeing them today.

When I first qualified as a consultant I didn't know anything about ME and I heard my colleagues talking negatively about adult patients with ME. One of my colleagues said: 'They are all nutters'. And then I saw a 14 year old girl in a wheelchair. She told me she had ME and I asked her to tell me about it. And I found that her symptoms were so genuine, I just had to believe in her. Once the word got around that I believed in ME I had a lot of patients sent to me.

What is ME?

We don't understand it enough to call it a definite clear-cut disease. So it is best described as a clinical syndrome. A clinical syndrome is a collection of symptoms and signs which breathe through. You just see them again and again and you can say: 'Yes, this fits into a pattern'. So at the moment it's a clinical syndrome which is still poorly understood and for that reason unfortunately rather controversial.

What are the main features of ME?

The cardinal feature of ME is the symptom of undue fatigue and fatigability. It is not just being tired. It is being tired but it gets worse with physical or mental exertion. It is this worsening after exertion that is the cardinal feature. There are a lot of other additional symptoms which are well recognized, and that can be up to twenty different symptoms, all of which are reasonable typical. But this cardinal feature is the central thing and it separates it off from just general poor health due to other conditions.

What is CFS?

There is a problem there. Some people regard chronic fatigue syndrome and ME as the same, and I personally think it is useful to think of it like that. But the trouble is some of the definitions of chronic fatigue syndrome by some people include other people who don't have pure ME like a simple depression. And this may have led to some of the controversy and some of the arguments about the results of individual trials. But in general it is quite respectable to use the terms almost congruently and synonymously.

Does the term 'ME' cover the disease?

I think one of the virtues of using the term 'ME' or Myalgic Encephalomyelitis is that it is a very strong term which implies a physical, organic illness. That is why most of the patient groups strongly prefer ME as the label for their condition. And in contrast the term 'chronic fatigue syndrome' is in the opinion of many rather mealy-mouthed and not very strong and can lead to disbelief and lack of support for patients who just get that label. And I tend to see that doctors that use the term ME are better advocates for their patients and they are more popular with their patients than those who use chronic fatigue syndrome.

Wetenschap voor Patiënten

(Science to patients)

Seminar 30: diagnostic tools for ME

Dr. Nigel Speight, consultant paediatrician. Broadcast 14th January 2014

How should ME be diagnosed?

How should you diagnose ME? Basically the diagnosis should be made on a very, very careful history. And this may actually take up to one hour because the patients can have so many complicated symptoms. So, because there are no tests for this condition, taking a very careful history is the absolute main tool for making the diagnosis. So it's a diagnosis which we call a clinical diagnosis on the balance of probability without any strong confirmatory test available in present times.

What diagnostic tests should be done?

In paediatrics the diagnostic picture is relatively clear. There are far fewer differential diagnoses than in adults, and as I've said a careful history is the main way to make a positive clinical diagnosis, if any. There are no definite tests which can confirm it. And the reason to do tests is simply to exclude other conditions which might mimic ME. In practice there are not that many conditions that mimic it very well in paediatrics.

What are the main illnesses to be excluded with ME?

When you're making a diagnosis of ME you clearly have to have a differential diagnosis and you have to think of other possibilities. In paediatrics that position is usually quite clear cut, but clinically you can just consider whether there's something a-typical about it. I've seen cases referred to me with ME who turned out to have a brain tumour. They could possibly have myasthenia gravis, they could have Addison's disease, all these conditions are very rare and ME is relatively quite common. But routine clinical testing and good clinical approach should help to clarify the situation.