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.

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.

Seminar 31: ME/cfs and the course of the disease

Dr. Nigel Speight, consultant paediatrician. Broadcast 28th January 2014

How does ME start?

It can often start very suddenly and acutely in the course of an acute infection and a significant number of cases start this way. Slightly more common in paediatrics is that children have a sort of prodromal illness, and maybe for 1 or 2 years they're a bit under the weather, and then they have an acute deterioration often triggered again by another virus, illness or a lot of stress. So it can start in different ways and it's probably more common for it to start gradually rather than suddenly.

How does ME get worse?

Some of the very severe cases present acutely and remain very severe, and can be very very slow to improve and can be effective for many years. If you look at an overall group of children with ME the condition is extremely unpredictable and there can be remissions and relapses out of the blue with no obvious reason. So it can be like a graph going up and down over several years. Of course some things can happen which make the condition worse. And this can be pressure, undue exertion, pressure to get back to school. And those cases can often be made considerably worse by mismanagement.

What can be done to stop this development?

Firstly we have to admit we don't yet have a cure for ME. I think it's very important that doctors face up to that. So we don't talk about treatments, we can talk about management.

And the first law should be to do no harm, to not make the condition worse by allowing the patient or pressurizing the patient to do too much. My motto to patients is always: take two steps backwards before you take one step forward. Because the natural tendency is always to do too much in the early stages.

If you can avoid making them worse, than you can relax and hope that this spontaneously gets better. Pending the discovery of a cure for this maddening condition.

Seminar 32: ME & children, part 1

Dr. Nigel Speight, consultant paediatrician. Broadcast 28th January 2014

What are the main characteristics of ME in children?

One of the most important things is that the issue is very clear cut. I find witnessing ME in children one of the most convincing arguments for this being a physical process. Because you can see a happy healthy child in a nice family, struck down out of the blue. That's what makes it seem like a physical illness and helps us to argue against the psychiatric view of this condition, which has done so much harm for so long. The other thing is that the number of other conditions that can mimic ME in children is very small and the differential diagnosis is really quite easy. So it is not as difficult as it is in adults to be sure that the child has got ME.

Are there subgroups of children with ME?

In general children with ME can be divided into groups according to severity. The mild groups have their activity levels reduced to between 70 and 90 % of normal; the moderate have from 40 to 70 % of normal and the severe have from sort of 10 % to 40 % of normal. And then the very severe, which is a very unfortunate group of patients, is the very severe, bedridden for long periods of time and that is someone who is below 10 % of normal activity levels.

Are there different treatments for different subgroups?

The general principles of management of ME should be the same for all. That you don't make them worse and you support them and protect them and try symptomatic treatment. And you don't let them do too much. But some people believe in the advocacy of treatments like Graded Exercise and Cognitive Behavioural Therapy. The evidence for these has only been done in people who are mild to moderate and are ambulant. Are able to walk to clinics and be helped. There is no evidence that those management techniques should be applied to the severe group.

What should paediatricians be aware of?

When you are handling a case of paediatric ME there are a lot of things you should be aware of. For instance there is the influence of the extended family. It is very, very important that patients with ME are believed in and feel validated by all their nearest and dearest. And quite often there is a member of the family, sometimes a little bit distant, separated, a former husband, an aunt living many miles away - often a semi-professional person - who has strong views. And these people can undermine the families' belief in the child with ME and can be very disruptive. And I think it can be important for the paediatrician to detect these problems and maybe address them by offering to speak to members of the extended family who aren't believing.

Which test should paediatricians prescribe?

When a paediatrician first sees a new case of ME he should do a battery of routine tests, which would exclude all common or rare conditions that might be mimicking the condition. In addition, if they are following the child up for several years they should consider repeating that battery of tests after two or three years. Because children can still develop other conditions on top of their ME and follow up off course it is important to make sure you haven't got the diagnosis wrong. But clinical assessment is probably more important than a large number of tests in this condition.

Seminar 33: ME & children, part 2

Dr. Nigel Speight, consultant paediatrician. Broadcast 11th February 2014

Are there possible treatments for children with ME?

At the moment we have no curative treatment for ME, neither for children nor for adults. Hopefully some day we will have. If we can come clean and admit that we don't have a curative treatment, we should probably stop using the word treatment and use the word 'management'. And then we have to talk about different management strategies.

I personally have a feeling that the efficacy of Cognitive Behavioural Therapy and Graded Exercise has been, perhaps exaggerated and it certainly isn't a curative treatment and its advantages can be actually quite marginal. There is a treatment in the form of immunoglobulin for which there is some evidence from randomized controlled trials. I think it is a great pity that these have not been repeated in recent years. But I have had some therapeutic success with immunoglobulin in my most severe cases and this is an area for future research.

Otherwise the management of a child with ME should be a simple, supportive, sympathetic, validating, empathetic approach in which the doctor, as I have said, gives continuity and support throughout the illness together with good advice.

What should absolutely be avoided with a child with ME?

There are some things that children with ME deserve protection from. They deserve protection from their own drive to do too much, because children naturally want to get better quickly and will exploit any temporary remission by tending to overdo things. So helping to advise them to protect them from those tendencies. After that of course there are many other sources of pressure on children not least from their parents, from their families, from their doctors and from the educational system. And again the main role of a paediatrician can be to protect the child from these pressures and allow them to convalesce at their own stage.

How can a child with ME be protected from being forced to go to school?

There is always a pressure from the educational system to try to get children with ME to go to school even when they are not well enough for this. I think this is where the doctors have to be firm and to override the pressures from the education. They have to say this child is not well enough for school. I sometimes say it is harder to have ME mildly than it is to have it severely because you have so many more options. So the child who is operating at about 70 % of full capacity can just about attend some school and therefore the doctor has to help the school to be very flexible and understanding about the condition. So they don't keep sucking the child into more pressure.

It is sometimes easier for children to be off school completely and to have home tuition which is an ideal way of delivering education to sick ME children. And for them to allow themselves to catch up later when they recover from their ME.

What is the main instrument to protect children from being threatened with removal from their family?

There is a very unfortunate and regrettable tendency for some children with ME and their families to be subject to a sort of persecution by child protection agencies and this is extremely unfortunate and painful. The most important way to prevent this is the child being under a paediatrician who has made a confident clear diagnosis of ME, and for him to make it clear to all the other agencies that he or she believes in ME as a physical illness. This is not a psychological illness, it is not due to the parents being overprotective. And if the paediatrician gets it right, the child is protected; when they don't get it right it is frightening to see the number of people who will then get it wrong from education to social work to psychiatry and I have personally been involved in 30 very, very distressing cases all due to this sort of failure to protect.

Seminar 34: Future and hope

Dr. Nigel Speight, consultant paediatrician. Broadcast 11th February 2014

What positive developments do you see related to ME in Great Britain?

Let's think of possible hopes for the future in this country. This has to include more biomedical research, which is going on now. And I think it would be very good to have more randomized control trials on both immunoglobulin and Rituximab which is going to happen in Norway and this country. To have further approaches to finding a cause which might lead to a treatment. So let's hope that is a way forward. At the moment I think the most urgent need is for someone, maybe parliament or the royal colleges, that actually gives more guidance to the medical profession to improve their management, diagnoses and protection of children with ME. At the moment this is not happening.

Are there any positive initiatives around the world?

Outside this country there are some other positive developments. I was delighted to hear, when I was in Norway a couple of years ago, that the Norwegian ministry of health apologized to the ME community in Norway for the failures of the medical profession in their management. And I think the more countries that can actually face up to the burden of ME in their own countries and stimulate the medical profession to manage it, the better. That can only be good. Obviously is a lot of biomedical research going on in America right now and there are further trials on Rituximab coming from Norway. I think finding a cure for ME is going to be the simplest way to cut through all the controverses and the abuse of ME patients, because the medical profession will then accept it as a medical illness. And hopefully this day will come in the next 5 to 10 years.

Do you estimate the actual cause of ME will be found, and if so, when?

I'm just a clinician, I'm not a great scientist, so I don't know. But hopefully we'll get big progress in the next five to ten years. It is possible that we won't find one single cause, that we actually will find several subgroups of ME. Some with auto-immune causes, some with more infectious causes, even ending into the same final common illness. But it really just does need a lot more research and resources, and much less emphasis on psychiatric research.