Wetenschap voor Patiënten
(Science to patients)

Seminar 37: How is ME diagnosed?

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What diagnostic criteria are used?

There are a number of diagnostic criteria for both ME and chronic fatigue syndrome. For ME we have doctor Melvin Ramsay's original description of the illness. We have some criteria called the London criteria, we have International criteria, newly prepared criteria for ME. For CFS we have a range of criteria today. We have Fukuda criteria, we have Australian criteria, we have Oxford criteria here in the UK and we also have NICE criteria in the UK. And for both ME and CFS these criteria have similarities and differences and even within the criteria for ME and CFS there are similarities and differences. So this is a picture of great confusion for the average general physician who is presented with a patient in his consulting group who just wants to make a simple straightforward diagnosis of this illness. So I think most of my colleagues, just like the approach I would take, take a pragmatic view to diagnosing this illness. And we make use of these criteria which I have to say primarily are there for research purposes to identify people going into research rather than clinical purposes. So we make use of these criteria but we don't stick to them rigidly when we make a diagnosis of this illness.

To make a diagnosis of ME or CFS or ME/CFS it is the same process that you go through when you're making a diagnosis of any illness. You take a history, you examine the patient, you arrange some blood tests which we will come to shortly. As far as the initial part of the clinical consultation is concerned, it is extremely important to take a detailed history from patients with a possible diagnosis of ME. Because there are many other illnesses which can overlap with this illness and cause diagnostic confusion. So the history taking is extremely important and if there are other symptoms there in the history which are not typical of ME, they need to be pursued to make sure that you're not missing some other diagnosis. It's terribly important to examine the patients carefully, particularly their nervous system and muscle although on the whole you're not going to find any particular diagnostic examination abnormalities which are characteristic of this illness. You may find problems with balance, you may find problems with muscle weakness, you may find abnormalities in some parts of the nervous system examination but on the whole, examination doesn't add an awful lot to the diagnosis of this illness.

Which tests should be arranged when a diagnosis is considered?

When you're considering a diagnosis of ME, it's terribly important to check through a quite comprehensive range of blood tests and some urine tests. These tests are done not to diagnose ME, because we don't have a diagnostic blood test for ME, but they are there to make sure that you're not missing other conditions. So you want to check thyroid function,

you want to check liver function, kidney function, routine hematological checks, checks of inflammation or infection in the body, a very sort of wide-ranging test is what's called the ESR. And this list of tests is available, readily available, in all the sort of guidelines that are issued to doctors who are making a diagnosis of ME. They're comprehensively described in the MEA booklets on diagnosis. So those are tests which have to come back as normal before you should be making a diagnosis of ME.

Now there are also a range of what we will call second line tests, which range from brain scans to immune function tests on the blood, something like even muscle biopsies. Now you cannot arrange to do every single one of these tests in every patient who comes along for this possible diagnosis. It's not feasible, it's not workable, it's just not costable. So with these second line tests you have to reserve which ones you're going to do on the basis of clinical judgment. This will be based on whether or not there are symptoms which we might describe as red flag symptoms. So you got a patient who is losing weight, well that would immediately suggests that you need to be looking to do further investigations before making a diagnosis of ME. Or they have unusual symptoms, perhaps they have skin itch, skin irritation suggesting that they have a condition called primary biliary cirrhosis that can overlap with ME. Or they may have dry eyes, dry mouth, joint pains, suggesting they may have Sjogren's syndrome, in which you would want to go often do specific immunological tests, anti-auto antibody tests. They may have symptoms which are overlapping with multiple sclerosis, which can occur. And sometimes it is quite difficult to differentiate between ME and MS. And in that case you want to go off and do brain scans or whatever to look for a possible diagnosis for ME. So there are a lot of different tests which may be applicable but in certain circumstances. And using your clinical judgment as a doctor that's the situation when you go often do that sort of tests.

What other conditions should be considered before a diagnosis is confirmed?

Before a diagnosis of this illness is confirmed, as I was saying when we were talking about taking a very careful clinical history from patients, it is important to have at the back of your mind as a doctor that there are a large number of conditions - we list about fifty different conditions in the MEA booklet on this – that can be misdiagnosed as ME because the symptoms overlap. So when you're going through this history, you need to be aware and pick out symptoms which are not quite consistent with the diagnosis of ME and then start querying could that be another condition.

Let's take a couple of examples. You have a patient who comes along who has their fatigue, but also has a lot of bowel problems as well. Irritable bowel typed symptomatology. Now we know that irritable bowel typed symptomatology, bloating, alternating constipation and diarrhea, stomach pains is quite a common accompaniment to ME. A lot of patients with ME do have this. And it is quite tempting to just say well you got ME and you've got a bit irritable bowel syndrome. But when you have a patient like that who comes along what should be going through your mind as a doctor is, could this patient also have something like adult onset celiac disease? Which is not uncommon in the adult population, which is treatable to a large degree and can be misdiagnosed as ME. So you get a patient with fatigue, irritable bowel typed symptoms you should be doing a screening tests to rule out celiac disease at the same time. Another example might be, you get a patient with fatigue and joint pain. And we have a condition called joint hypermobility syndrome which can overlap with ME. And again there would be a different form of management if you had someone with joint hypermobility syndrome. Interesting about joint hypermobility

syndrome is that these patients often have bruising as well. So that will be another warning sign there. So there's a lot of different conditions which need to be seriously considered before you come to this diagnosis and say you've definitely got ME.

Who can make a diagnosis?

The diagnosis of ME in most cases, I stress most cases, is something that should be capable of being made by a good general practitioner, that's a doctor in primary care. Where a doctor in primary care is unable to make a diagnosis, then there should be facilities available at the local hospital. Either through an ME/CFS clinic or a specialist at the local hospital who has widespread experience in dealing with this illness, to whom a patient should be able to be referred for a confirmation of the diagnosis.

What about the International Consensus Criteria?

The International Criteria is the latest and most comprehensive criteria which aim is to be able to help doctors make a diagnosis of ME. It is a very detailed criteria and, as I've indicated earlier, I think most of my medical colleagues take a very pragmatic approach to making a diagnosis of this illness, and don't tend to sit there with a diagnostic criteria especially if it is long and complicated, sitting on their consulting room table. So I think as an aid to diagnosis this is a very helpful document. But I think to expect that every doctor is going to sit there with this criteria in his waiting room, consulting room and then using it to make a diagnosis of ME is probably unrealistic at this point.