**Complementary and alternative medicines in MS**
**Dr Allen Bowling talking to Chris Jones of the MS Trust**

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**Christine Jones (CJ):** Welcome to this short video about complementary and alternative medicines in MS, or CAMS. We're very lucky to have with us today Dr Allen Bowling who is Director of the CAMS Program at the Rocky Mountain MS Center in Colorado. Dr Bowling is also Associate Professor of Clinical Neurology at the University of Colorado. He is the author of many books and articles on complementary therapies and MS. We're delighted he's agreed to join us.

I've tried to put together a list of questions that people with MS have asked the Information Team at the MS Trust and I'm going to be putting those questions to him today. So, hello Dr Bowling and welcome.

**Allen Bowling (AB):** Hi, great to be here.

**CJ:** Great to have you here and thank you for agreeing to talk to us today.

**AB:** My pleasure.

**CJ:** I suppose the obvious first question is why are complementary and alternative medicines so popular for people with MS. What it is that they address that conventional medicine doesn't?

**AB:** I think in the area of MS unfortunately with conventional medicine, as many people know, we don't have a cure for the disease process, and also in terms of the symptoms of MS we don't have perfectly effective treatments. Some of those symptomatic treatments can have side effects or they are not a hundred percent effective. So with the lack of fully effective conventional therapies, I think it is natural that people with MS wonder what other options they might have available.

I think some of the unconventional or CAM therapies may offer other treatment approaches for the disease process or for the symptoms. I think also some of these unconventional therapies can provide some self-choice in terms of what kind of therapy people want to pursue or can feel that is a more self chosen direction or individualised approach. I think it can provide hope for people, it can provide empowerment for people. So I think there are a whole collection of reasons that guide people, and it is probably a little different for each person who has MS, why they might think of some unconventional therapies.

**CJ:** So it's very much a control thing, isn't it?

**AB:** Right, right. MS is known as a disease that's very individualised and very different in each person who has the disease and I think, similar to that, many people with MS find comfort and, like I say, maybe some empowerment and hope in being able to personalise their treatment regimen and CAM therapies can be a way to do that. And provide control as you mentioned.

**CJ:** So in your experience, what are the common misconceptions about CAMs, both from the people with MS point of view but also from health professionals as well?

**AB:** I think that is a great question and I think often the perspective about CAM is very different whether it is someone who has MS or whether someone is a conventional health provider and I think you are kind of tapping into that with your question.

In terms of both sides I think there is sort this need jerk response that people often want to have when they hear about conventional and alternative therapies. They are often totally positive or totally negative and maybe people who have MS may be more on the positive side and conventional health providers may be more on the negative side. But I think there is this feeling out there of needing to be in the pro or con side of the this whole issue, and I think through our discussion and I think that as people become more informed in this area it becomes very clear that that's really a misconception that does not make any sense. What you really need to do is think about each particular therapy within the unique context of the disease like MS and then if you do that you start realising that there are some therapies where we have some evidence where it may make some sense; there are others that are just kind of ridiculous and expensive and should not be pursued. So I think you really need to have an evidenced based approach to have opinions in this area. So I think that kind of straddles both the professional and patient side of things.

**CJ:** I suppose the area that most people look at is diet - particularly vitamin supplements and the new research on deficiency in vitamin D being a possible trigger for MS.

**AB:** I think diet taps into two broad categories that I think are important to think about in terms of any kind of therapy, whether it is conventional or unconventional. The two categories are treating the underlying disease process - and those are known as disease modifying therapies, and on the conventional side those are things like the interferons and glatiramer acetate or Copaxone - and then there are symptomatic treatments to treat the very symptoms of the disease like weakness, walking difficulties, fatigue. I think it is very important for people to have in their mind whether they're pursuing something that is disease modifying or symptomatic, especially when we are talking about unconventional approaches.

So dietary approaches, as you mention, those fit on the disease modifying side of things. And the best evidence that I think we have for any unconventional therapy to have a disease modifying effect, affect the underlying disease process in MS, is with a dietary approach, where there is an increased consumption of polyunsaturated fatty acids, probably especially omega 3 fatty acids. There's quite a bit of scientific, epidemiologic, clinical trial evidence in that area. It is important to recognise that it is not perfect evidence. We still don’t have the definitive word but of all the therapies that are touted as being effective for disease modifying effect, I think we have the best evidence there. We also have studies, limited studies, of using those therapies in combination with some of the conventional medications. So there is no indication that those are harmful using this polyunsaturated fatty acid approach.

But I think that's important that people start thinking beyond polyunsaturated fatty acids to using other biologically based approaches like diet or dietary supplements. You need to be very cautious about experimenting in that area because we're talking about using biological approaches to alter the disease course. If we find out some of these biological approaches are not effective or may worsen the disease or may block the effects of conventional medication, that's a dangerous area to get into without any evidence.

You also mentioned vitamin D. I'd kind of put that number two after polyunsaturated fatty acids. We don't have quite the suggestive clinical trial evidence there but there certainly is some growing evidence scientifically in the animal model of MS; also in epidemiological studies, studies of large groups of people, so there is quite suggestive evidence there. Also, vitamin D has a preventive role in terms of osteoporosis - that's thinning of the bones - and people with MS appear prone to osteoporosis. So there may be both a symptomatic benefit and possibly a disease modifying effect with vitamin D.

But with any of these approaches that are being taken to have potential disease modifying effect, I think it is very important for people to talk to their conventional health care provider to get input because these are having drug like actions and they need to be sure there is not new evidence that it doesn't block the effect of some drug they are taking or maybe new evidence that it's really not something that people with MS should be taking.

**CJ:** You've just talked about two areas where CAMs can be helpful for people with MS, are there other areas that you would look at?

**AB:** I think certainly, as we talked about, the polyunsaturated fatty acid approach, especially omega 3 fatty acid - and there are studies being done in Scandinavia now that hopefully will give us a clearer answer, like I mentioned that's not definitive evidence at this point. There also is the interest in vitamin D and that's leading to some larger trials for treatment and also prevention of MS.

Then there is also a new drug which is quite interesting being tested on the conventional side known as FTY720 or Fingolimod which is actually in the final phases of clinical trial testing - so it is a big world wide phase III trial of this drug. It is quite interesting if you look back at the origin of this drug, it actually is derived from mushrooms used in traditional Chinese medicine. One of the chemicals from one of those mushrooms is chemically modified and now it's a very promising potential new disease modifying therapy for MS.

And I think the United Kingdom should be lauded for first of all gathering evidence for and against cannabis in MS and then taking a very objective, thoughtful approach to pursuing this area. There's been the CAMS study that produced some promising results that's lead into the CUPID study looking at effects of cannabis on people with progressive MS. I think cannabis has potential for both symptomatic and disease modifying effect. The problem with cannabis is currently it's smoked and it has all the dangers of cigarette smoking and we don’t have definitive evidence so it’s one of these areas where you really can't be totally pro or con. There is suggestive evidence and we need to get that evidence before we can make a final judgement on it.

**CJ:** So you've talked about those areas as being helpful for people with MS. Are there some complementary and alternative medicines that you would single out as being potentially dangerous?

**AB:** I think in that area it kind of goes back to what I mentioned earlier where people really need to think what they are using a CAM therapy for. They can be used for symptomatic treatment or for altering the disease process, that's called disease modifying therapies, and I think an area people need to be very cautious in is using a biological approach to treat the disease course. And by biological approach I typically mean using dietary approaches, using dietary supplements, therapies that are going to affect the underlying biology or biochemistry of the body. The area that people need to be cautious in is to use those therapies to alter the disease course. And the reason to be cautious is if we don't have evidence about safety and effectiveness for those therapies then it's possible they might have no effect, they might worsen MS, or they might block the effect of MS medication. So I think that is a very important area that people need to be careful about.

In that area there are some supplements which I know are recommended by some books on alternative medicine that actually recommend people take dietary supplements that activate the immune system. And, actually, as many people with MS know, that's not we want to be doing with MS, we want to be doing the total opposite, we want to be suppressing the immune system. So there are many errors in many books that we reviewed at our Center in terms of recommending immune stimulating supplements when we want to be doing the opposite.

**CJ:** A lot of people ask about echinacea and immune boosting supplements. What are your views on that?

**AB:** I think that's an area where there is never going to be a trial, for example, of echinacea. No-one is ever going to approve that a trial be done to see if you give 100 people echinacea do they get worse? So, it's really a theoretical risk that we know typically from test tube type experiments, that echinacea, for example, activates immune cells that are already too active with MS. So there's a theoretical risk with that but on the flip side in terms of the benefits, we do not know of any theoretical or proven beneficial effect of echinacea. So many of these immune activating supplements are in that category whether there is a theoretical risk and there is no known benefit.

Also we've been talking a lot about safety and effectiveness, a whole other category is the cost of some of these approaches, and certainly some of these supplements that often are marketed specifically to people with MS are claimed to be safe and very effective and they're also very, very expensive and many of those actually might be unsafe, there is no evidence that they are effective and, like I say, they've got a big cost associated with them.

Approaches where we have quite a bit of evidence at this point, the dietary approaches, vitamin D type approaches, those actually are kind of interesting. That's where we have the most evidence and those are actually are very reasonably priced approaches if people want to pursue those.

**CJ:** OK, Dr Bowling, so what should we look for, what should an individual look for, before embarking on a complementary therapy? And what should they look for in a practitioner?

**AB:** I think in terms of a general approach, it is quite similar to the approach with a conventional therapy. So I think first of all you want to know what options are available in terms of treating a symptom or in terms of treating the disease process. Then you need to get good objective information about those therapies. It is very important to have a discussion with your health care provider whether you are thinking of something conventional or unconventional. And then when you start a therapy have some plan to monitor for a response and if you don't get the response you are looking for then obviously you discontinue that therapy and then you embark on some other approach.

I think using unconventional therapies, it is important for people to be aware that the information on nearly all of them is limited so we don't have perfect evidence about safety and effectiveness so there some risk taking. I think it can be quite low in terms of the amount of risk that people take if they are thoughtful about how they choose therapies.

In terms of practitioners, that really depends on the particular CAM practitioner that you are talking about. There are, country by country, different guidelines in terms of licensing for practitioners, I don't know the specific United Kingdom guidelines but I know there are guide books for the United Kingdom and what kind of certification or licensing practitioners need to have.

**CJ:** You've talked a little bit about evidence. Is it reasonable to have different standards of evidence for CAMs as against normal, conventional medicines?

**AB:** That goes back to trying to figure out why we're using particular CAM therapies. I think if we're talking about CAM therapies to have a disease modifying effect then I think it is quite important to get some rigorous evidence. For example to make sure it's having a beneficial effect on MRIs, to make sure it's having clinical benefits for people, be absolutely certain it's not making people worse or not blocking the effects of some other drug they might be taking.

I think on the symptomatic side you can be a little more relaxed. I'm not advocating just experimenting with anything that is out there, but I think in terms of quality of clinical trial evidence, it doesn't need to be quite as high for people to do a little guess work or a little experimenting. For example, if someone has muscle stiffness and they want to try yoga for that, and they try it and some reason the yoga actually makes it worse, then they can just stop doing the yoga; that's not an irreversible process. But if they are doing some dietary supplement that makes the disease worse, people only have one brain and you can't be doing irreversible things. You don't want to be doing irreversible things with your brain.

But on the symptomatic side, especially milder symptoms, like I said, you can go with some milder or less rigorous evidence I think if you are just trying to come up with some approach that might just give you an extra benefit in that area.

I think it also touches on another area which goes back to the whole term CAM, which is the C is complementary, A is alternative and M is medicine. And where I think CAM can be especially helpful is in the C part, the Complementary part. Some of the unconventional therapies can potentially

be added into conventional therapies in a complementary way, especially on the symptomatic side. That can sometimes be done with the limited evidence we have at this point.

**CJ:** I've heard a lot of people say that the reason there's no research, or very little research, into CAMs is that it's difficulty to make money out of it as opposed to conventional medicines. Do you think that's the case?

**AB:** I think that certainly there is a lot of truth to that. Certainly in the United States most of the clinically relevant research in MS and most other diseases happens through pharmaceutical companies. That's just the way the system has evolved. In terms of our whole country the national budget for clinical research for pharmaceutical companies is huge compared to what the government sponsored research funding agencies have available. There has been a changing trend with that and so at least with the United States there's been increasing budgets for doing research in the area of complementary and alternative medicine.

Much of it ties into whether something is patentable and obviously a diet or some vitamin that is readily available cannot be patented and, therefore, there's not millions of dollars to be made if a clinical trial shows a beneficial effect and that's what the drug companies obviously what they want to develop scientifically and clinically.

**CJ:** That's great, Dr Bowling, thanks. Just before we close, are there any final thoughts that you could share with us?

**AB:** Yeah, I think that through this discussion, I hope it's become clear to people that there are all different types of CAMs therapies and you really cannot be totally pro or totally con in this area. You need to take the information about each specific therapy, interpret it within the unique context of the disease like MS, and if you do that some of these therapies look promising enough that I think they warrant future investigation. Some of them actually look totally ridiculous, they are expensive, they can actually hurt people with MS. So you really cannot be on the total positive or total negative side.

All the evidence related to these therapies is not complete, we really need to do more research and I think that's key for being more definitive in this area in the future. So therapies that are promising or therapies that are popular, we need to do research to look at how safe and effective they are, specifically in MS.

I think another point, and I've think we've touched on some these issues today also, is that even though the evidence is limited, I think there are some areas where CAM therapies, where people with MS can go into those areas and if they're wise about how they make decisions, I think it can be a nice complement, especially to conventional approaches for treating the disease.

**CJ:** Lovely, thank very much indeed for talking to us today.

**AB:** Thank you. Nice to be here. Thanks.